An Analysis of Community Based Health Approaches in the Delivery of Integrated Sexual, Reproductive Health and HIV Services for Adolescents with Disabilities in Siaya County, Kenya

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LIST OF ABBREVIATIONS

ACHO	Assistant Community Health officer
AIDS	Acquired Immunodeficiency Syndrome
APDK	Association for Physically Disabled in Kenya
ASRH	Adolescent Sexual and Reproductive Health
AWDs	Adolescent with Disabilities
CBO	Community Based Organization
CBHC	Community Based Health Care
CBHF	Community Based Heath Financing
CBR	Community Based Rehabilitation
CCSFP	County Community Strategy Focal Persons Community Health
CHA	Community Health Assistant
CHC	Community Health Committee
CHDU	Community Health and Development Unit
CHEW	Community Extension Worker
CHMT	County Health Management Team
CHO	Community Health Officer
CHS	Community Health Strategy
CHV	Community Health Volunteer
CHW	Community Health Worker
CORP	Community Own Resource Persons
CRC	Child Right Convention
DHIS	District Health Information System
DPO	Disability Persons Organization
FBO	Faith Based Organization

FGD	Focus Group Discussion
HBC	Home Based Care
HIV	Human Immuno Deficiency Virus
HRIO	Health Records and Information Officer
IGA	Income Generating Activities
KEPH	Kenya Essential Package for Health
MFK	Matibabu Foundation Kenya
MoH	Ministry of Health
NGO	Non-Governmental Organization
NHSSP	National Health Sector Strategic Plan
PHC	Primary Health Care
PSC	Peer Support Clinic
RMNCAH	Reproductive, Maternal, New-born and child and Adolescent Health
SCHMT	Sub-County Health Management Team
SRH	Sexual and Reproductive Health
VCT	Voluntary Counselling and Testing
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization
YFC	Youth Friendly Centre

ABSTRACT

There is evidence of widening health disparities among vulnerable groups and inadequacies in the public health care system in sub-Saharan Africa (SSA), including Kenya. In particular, adolescents with disabilities (AWDs) confront many challenges in accessing health services. Their increasing primary care needs and rights in terms of sexual and reproductive health (SRH) is beyond the capacity of the conventional health system. While the Community Based Health Care (CBHC) approach has improved basic health services for maternal and child health as well as HIV and AIDS interventions, its capacity and utility to address the SRH and HIV interventions required by AWDs is not adequately studied in Kenya. Furthermore, debates persist on the overall quality of services provided through such primary health care systems. This study therefore investigated the CBHC approach as an option for improving AWDs' access to and use of Kenya's state-run adolescent SRH and HIV services in Siaya County of rural Kenya. The descriptive qualitative case study design used systems theory that featured Urie Bronfenbrenner's bio-ecological (Person-Process-Contexts-Time) and the World Health Organisation's (WHO's) (building blocks) health systems assessment frameworks as the main models to conceptualize, design, collect, analyze and interpret the data. Qualitative methods of data collection were used to explore purposively selected CBHC programs, and included semi-structured interviews, focus group discussions, observations, case narrations and record reviews. The study exposed serious institutional level inadequacies of the existing CHBC approaches, which were largely mediated by the disabling operating environment in the county health system. These ranged from poor staffing, inadequate financing, inadequate family support and community care, and unresponsive policy and legislation frameworks that lack enforcement mechanisms. Furthermore, the study found challenges associated with personal attributes including age, gender, type of disability, schooling and awareness of risks and available community-based services. Sexual and

gender- based violence against the backdrop of an irresponsive justice system dominated the plight of AWDs in the county. As a result of analysing these factors, the evidence suggests a need to address the unique challenges surrounding the multi-dimensional issues that mediate access to and use of healthcare for adolescents living with disabilities to achieve equitable access to SRH & HIV services. In particular, the government should foster positive mechanisms of supporting community- based programs through co- financing with donors to expand the resource base for effective health services delivery, including SRH and HIV services for AWDs. Moreover, responsive policies and legal frameworks that were inclusive in approach to community care for AWDs would need to be clearly enunciated and enforced by the government and its stakeholders. Lack of data related to AWDs should be addressed to facilitate effective programming.

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DECLARATION

I declare that this work is original and has not been published anywhere to my knowledge. Every source has been duly referenced and credit given to the said sources.

STUDENT:

Name----------

Signature----------Date----------

SUPERVISOR:

Name----------

Signature----------Date----------

DEDICATION

Unto God Almighty,

To Adolescents with Disabilities

To Families Contending with disabilities

To my Mothers- Mary & Ruth Ogwayo, Grace Ouko and Esther Oduor

&

To Mbangas and Descendants into Godly Generations

CHAPTER ONE

INTRODUCTION

1.1 Introduction

Kenya, like many other African countries, is severely affected by the HIV epidemic, which continue to ravage all sectors of the population across demographic and socio-economic profiles of the country. For instance, Siaya County - the study area that is located in the western part of the country is a largely rural setting, characterized by subsistence farming, poor infrastructure and a few emerging urban centers that define low socio-economic context of the area. As is with the rest of Kenya, the county has a number of young people with various disabilities, ranging from physical to mental, many of whom have particular health issues including sexual, reproductive health (SRH) and HIV needs that require special attention of the public health system. These services however are often provided at locations and in ways that make it difficult for especially adolescents with disabilities (AWDs) to access as often as they may need them. Moreover, assistance to reach the facilities or communicate their needs to the health workers to access services is often hindered by physical, social, attitudinal and economic barriers beyond their abilities to surmount. Therefore, in the absence of alternative mechanisms of integrated SRH and HIV services, the AWDs often find it hard to be part of the health goal for health for all, now under the slogan 'no one should be left behind'. To this end, this study explores the potential that exits through community-based health approach to meet the SRH and HIV needs for AWDs.

This chapter thus describes the context of the study, including the key social determinants of health and development in the study area. It presents the problem statement, the objectives of the study, the rationale and structure of the overall report. It also presents preliminary findings on the capacity and suitability of community-based health care approaches to

provide acceptable quality ASRH and HIV services for AWDs in Siaya County, Kenya. The study had examined structures and functionality of community-based health systems, and explored the life experiences of AWDs, the state of the health systems building blocks; the ecological factors that underpinned ASRH and HIV services production, delivery, access, utilization and outcomes for the target group. This chapter therefore introduces the study by presenting its background, the research problem, the rationale of the study, the research objectives and questions. Furthermore, the chapter also provides the thesis outline.

1.2 Background

That Community Based Health Care (CBHC) is a comprehensive approach to the delivery of health for marginal communities in Africa remains dynamic and explorative is well documented. For instance, although the World Health Organization (WHO) at the Alma Ata conference of 1978 adopted comprehensive Primary Health Care (PHC) strategy to achieve the goal of Health for All (WHO, 1978), health inequities have persisted on. Moreover, the conference delegates resolution defines PHC as "the essential health care made universally accessible to individuals and acceptable to them, through their full participation and at a cost the community and country can afford" (WHO, 1978). The comprehensive PHC model therefore remains as the approach to service delivery and health promotion and is underpinned by a social view of health including community participation, empowerment, social justice, equity and action on the social determinants of health (Barton et al., 2019). Moreover, as also established in literature, the approach involves the active engagement of the community in planning, developing, implementing and maintaining the health services (Mayeden, 2016). Similarly, Kilewo and Frumence (2015) observe that CPHC too, aimed to increase community responsiveness, self-reliance, sustainability and efficiency. The foregoing thus implies that with adequate investment in and effective implementation of PHC, marginalised community groups, such as adolescents with disabilities, would be able to

access basic health care, like the rest of the population.

A study in Ethiopia by Woldemichael and colleagues shows that although remarkable success has been recorded in population health, especially in Sub-Saharan Africa (SSA), adequate investments has not been made to realize the full potential of primary healthcare for the most vulnerable groups in the region (Woldemichael et al., 2019). For example, the state of poor access to Sexual and Reproductive Health (SRH) services for groups such as AWDs in Kenya is a testament of gross inequity in healthcare (KNCHR, 2014). The available literature links the situation to weak and inequitable public healthcare systems in the region that are affected by inadequate resourcing, including poor governance (KPMG, 2013). While Kenya, like the rest of SSA, has attempted varying models of PHC that include selective services to its most vulnerable citizens, including AWDs, experiences on population health outcome too vary.

Revitalization of PHC through the community health strategy policy of 2006, which aimed to bring the Kenya's Essential Health Package (KEPH) to the community and the households (MOH, 2006), and devolution of health services to counties via the 2010 constitution inspires hope for universal access to health care. However, despite the resulting optimism from the anticipated devolved healthcare systems to the community level, the Kenyan Ministry of Health's Reproductive, Maternal, Newborn, Child and Adolescent Health (RMNCAH) Investment Framework of 2016 observes that there are still inherent gaps and challenges in the supply and demand components of the county health systems. The framework notes that:

> *"The key supply side challenges include suboptimal functioning of the health system with uneven distribution of the health workforce as well as constraints in competency and motivation of the health care providers to provide quality care; insufficient financing and weak supply chain management resulting in missing critical inputs*

> *required for service delivery, especially essential commodities; and poor quality and utilization of routine data for evidence-based decision making. Socio-cultural and economic barriers and constraints in physical access to health services continue to limit demand"* (KMNCAH-MOH, 2016, p. 8).

The situation has considerable implications for vulnerable groups, such as the AWDs, who are already limited by impairments, are to depend on the systems to access care. Moreover, although the 1994 International Conference on Population and Development (ICPD) held in Cairo, Egypt, recognized Sexual and Reproductive Health and rights (SRH & R) as human rights that are universal, indivisible, and undeniable, the systems for fulfilling such rights remains inadiqate for AWDs. In Kenya for example, while the SRHR of AWDs are unmet (KNCHR, 2014), the incidences and prevalence of HIV infection have remained high among young people, despite the region aiming to achieve 90-90-90 (90% of the population knowing their HIV status; 90% of those found to be HIV positive are started on antiretroviral treatment and 90% of those on ARVs treatment achieve viral load suppression to undetectable levels by 2020 (UNAIDS, 2012). The need for urgent evidence-based responses could no longer be delayed, hence the need for studies to gauge the nature and extent of the issues and to craft adequate responses. The foregoing motivated this study, as elaborated in the next sections of this chapter.

Siaya County is one of the 47 Counties of the Republic of Kenya, the county reporting among the highest HIV prevalence rates in Kenya at 17.8% (NACC, 2016). Furthermore, according to a local disability coordinating office in the county, the area is home to over 35,000 persons living with disabilities (PWDs) (7.7% of the county population), which was far beyond the national average of 4.6% (Government of Kenya, 2008). However, this does not include HIV-induced episodic and chronic conditions that the county might be experiencing. The

county is therefore among the worst affected regions in the country, with a pervasive high HIV prevalence (NACC, 2016), also being among the poorest, with government projecting that 40% of the population living below the poverty line (County Integrated Development Plan (CIDP), 2013-2017). The county has registered some of the worst child survival indicators in Kenya, with malnutrition, anemia and stunting being among the highest in the country (CIDP, 2013-2017). The quality of health care from the public health system is generally poor due to weaknesses at different levels including service delivery (ibid). Furthermore, according to the CIDP 2013-2017, the rate of contraceptives use in the county has remained low, at only 45%; the situation being attributed to myths and misconceptions on their use, socio-cultural practices and access to health facilities (CIDP, 2013-2017). Within this context, the implication is that there is lack of disability specific information on the prevalence of HIV/AIDS in Siaya County, which partly compounds the health situation and the ability to plan for responsive services targeting AWDs. Additionally, AWDs face greater challenges than their non-disabled counterparts in accessing SRH and HIV services due to stigma and discrimination associated with their condition (Carew et al., 2017).

Observable, progress in providing ASRH and HIV care for AWDs in SSA, Kenya included, remains slow (KNCHR, 2012). The problems include poor public financing, inadequate staffing, lack of commodities and inefficiencies, including poor governance continue to compound the fragile health system (KPMG, 2013). These are all against the backdrop of growing SRH and HIV care needs of AWD who face the risk of sexually transmitted infections (STIs) including HIV, unplanned pregnancies, and sexual and gender based violence (MOH, 2015). The available literature links the situation largely to weak and inequitable public healthcare systems in the entire region (Coovadia et al., 2009). Since the Alma Ata Declaration of Primary Healthcare in 1978 (WHO, 1978), community based approach to healthcare (CBHC) therefore remains complementary to conventional health

delivery systems in developing countries such as Kenya. This study therefore thus set out and assessed the capacity and appropriateness of CBHC systems in the delivery of SRH and HIV services for AWDs in Siaya County of Kenya.

1.3 Problem Statement

Kenya like the rest of the countries in sub-Saharan Africa region continues to experience slow progress towards universal access to essential healthcare including sexual, reproductive health (SRH) and HIV services, mainly due to poor public resourcing for health (KPMG, 2013). The situation has created inequity and inequality in access to care for the majority of the marginalised groups, especially adolescents with disabilities (AWDs) in Siaya County. For instance, access to and utilization of integrated SRH and HIV services by AWDs through the public healthcare systems has remained low (MOH, 2015). Although community-based health services (CBHC) have proved to be an important means to improve HIV/AIDS interventions (NACC, 2016) generally, as well as other community based initiatives such as community integrated management of childhood illnesses (C-IMCI), their utility for SRH and HIV interventions for AWDs is not adequately studied in Siaya. Moreover, in spite of the growing recognition of heightened risk of HIV, STI/ STDs and unintended pregnancies and their consequences among AWDs, little is known about the capacity and appropriateness of the CBHC Programmes in order to deliver integrated SRH and HIV services for the target group. Furthermore, in spite of the growing recognition of the impact of HIV and AIDS on AWDs (NACC, 2016;MOH, 2015), little is known about their perceptions, preventive behaviour and coping strategies. For instance there exists a dengerous assumption that individuals with, for example, physical, sensory (deafness, blindness) or intellectual disabilities are not at high risk of HIV infection (Aderemi, 2014)

1.4 Research Questions

The main research question this study sought to answer was: How adequate and appropriate were community-based healthcare (CBHC) programs as an option for improving persons with disabilities (PWDs') access to and use of Kenya's state- run Adolescent Sexual & Reproductive Health (ASRH) and HIV services? The following sub-questions guided the exploration of the phenomena in the context of the above propositions and ultimately answer the overall research question above included asking:

1. What was the current state of county health structure with respect to SRH delivery for adolescents with disabilities (AWDs)?
2. How functional were the existing community health structures in providing services to AWDs?
3. What were the experiences of AWDs in regard to individual, family, community; organizational and societal barriers to access to SRH &HIV services?
4. What were the existing opportunities for CBHC programs in regard to funding for comprehensive SRH and HIV services that would enable a sustainable scale-up of the programs to include more AWDs?

1.5 Aim and Objectives

This study aimed to understand the capacity and appropriateness of community- based health care initiatives in order to establish how AWDs were accessing sexual reproductive health and HIV services in Kenya.

The study had the following Objectives:

1. To describe the county health system contexts of SRH and HIV service delivery for AWDs.
2. To assess the functionality of selected community health models in SRH and HIV services.

3. To explore experiences of AWDs with regards to factors associated with their access to SRH and HIV services in the community.
4. To determine opportunities in CBHC programs for the sustainable delivery of SRH and HIV services for AWDs.

1.6 Significance of the Study

The rationale for this study was fivefold; the first being that adolescence is a very critical age in–the human life cycle (MOH, 2005). According to Kenya's National Sexual and Reproductive Health Policy (MOH, 2015), adolescence is a volatile stage in human growth and development for boys and girls with attendant vulnerabilities and risks. Adolescents are vulnerable to early and unintended pregnancy, unsafe abortion, female genital mutilation (FGM), child marriages, sexual violence, malnutrition and reproductive tract infections, including sexually transmitted infections (STIs) as well as HIV and AIDS (MOH, 2015), with AWD being at greater risk due to the vulnerability and fragility associated with such conditions.

Secondly, the access to healthcare in adolescents can be a real challenge, especially for AWD (MOH, 2015). In Kenya, the sexual and reproductive health rights of young people, especially adolescents with special needs such as disabilities, remain unmet (KNCHR, 2014). While adolescents in general are not accessing SRH information and services, the incidences and prevalence of HIV infection remains high among young people, including AWDs in Kenya (MOH, 2015).

Thirdly, the need to focus on this area of study emanated from the fact that many aspects of HIV/ AIDS were population-specific, requiring targeted strategies if the epidemic were to be contained and reversed. The UNAIDS global 90-90-90 race towards Zero was already a stage for unequal competition, pitting AWDs against able-bodied persons in a struggle for the

scarce healthcare resources in imperfect social markets. In this race, ironically, the mantra was “no one must be left behind”. This advocacy would imply that if nothing was urgently done, some critical participants like AWDs who are not of the same economic, social, physical, intellectual and technological capital, would not be able to equitably and practically engage with the rest.

Invariably for AWDs, SRH and HIV/ AIDS status has implications for almost every aspect of their lives, including their livelihoods, sexuality and reproductive health. For girls, it affected their family planning, experience of pregnancy, child bearing, family chores and care functions. The core argument of this study therefore posits that without adequate consideration of the location of adolescents with disabilities (AWDs) in the declared race towards significantly containing HIV spread and its health effects to zero levels, especially with respect to their access and utilization of SRH and HIV services, the world could as well be contending with HIV spreading through the marginalized and excluded groups, such as AWDs.

Fourthly, the fact that AWDs constitutes a critical proportion of the total population and are among the most at risk populations susceptible to HIV infection, made it essential to actively and systematically incorporate their knowledge and experiences in the SRH and HIV/ AIDS programme design, implementation and evaluation processes. It is on this basis that this study aimed to contribute towards the process of developing more inclusive, responsive and AWDs- sensitive policies and strategies, including their greater involvement in personal, family and community- based activities, to contain the spread of the epidemic among this often marginalized and socially excluded group in society.

Fifthly, in the context of programming, it was essential to obtain insight into the extent to which AWDs, felt susceptible to SRH, HIV and AIDS related risks (or currently believe they

have no problem), and whether they believed that the threat could be reduced by some action on their part. More so, the intervention planners needed to know the extent to which the targeted individual AWDs and community felt competent to get out and sustain the needed level of access and utilization of services for effective programming.

1.7. Disability, Adolescent Sexuality and Theoretical Framework

1.7.1 Conceptualization of disability

The concept of disability is subjective and of unending constructions, as detailed in the literature. For instance, the UN Convention on the Rights of Persons with Disabilities recognizes the concept of disability as an evolving one (UNCRPD, 2006). It further renders disability as a derivative of the interaction between persons with impairments as well as attitudinal and environmental obstacles that impede their equal and meaningful societal engagement with other people (UNCRPD, 2006). According to the WHO, disability has no clear definition, its conceptualization thus remaining contentious (WHO and World Bank, 2011). Generally, however, disability could be understood as the human condition that results from an impairment that may be developmental, emotional, sensory, mental, cognitive or physical, or a composite of these (GOK, 2010;WHO and World Bank, 2011). The most prevalent types of disabilities are however associated with chronic conditions, such as cancer, diabetes, HIV/ AIDS, other infectious diseases, as well as injuries due to road accidents and violence (Center for Disease Control, 2009;WHO and World Bank, 2011). The implication is that the lack of a clearly agreed-upon disability conceptualization portend ramifications for its accurate identification and distribution across ages and regions of the world with consequences for standardization of efficient responses.

1.7.2 Distribution of Disability

The distribution of disability is largely by estimations across many regions of the world. The WHO and World Bank observe lack of *"agreement on definitions and little internationally*

comparable information on the incidence, distribution and trends of disability" (WHO and World Bank, 2011, p. xxi). According to the World Report on Disability, it was estimated that disabled individuals constitute 15% of the world's population, with developing countries hosting 80% of PWDs (WHO and World Bank, 2011). It is noted, however, that true statistics of PWDs in different regions of the world, including Eastern and Southern Africa (ESA) region remain mere estimates due to the paucity of data. Consequently, in the region, disability prevalence remained high at between 14% - 35%, with Kenya, the study area, hosting 15.2% (WHO and World Bank, 2011; Hanass-Hancock et al., 2013). Moreover, it is expected that the prevalence of disability in the southern African region is likely to worsen due to improved life expectancy and an increase in life-long conditions, such as HIV and AIDS (Hanass-Hancock et al., 2013). In Kenya, glaring disparities in disability figures are noted, with the Kenya National Survey for Persons with Disabilities, 2008, indicating that 4.6% of Kenyans experienced some form of disability, and more disabled persons resided in rural areas, such as Siaya, than urban areas (KNACPD, 2008). Moreover, because AWDs are not a homogeneous group based on the disposition of their impairment and their social, physical, and mental necessities, the estimates by the WHO had indicate that there may be some 3.8 million disabled adolescents in Kenya (WHO and World Bank, 2011).

1.7.3 Challenges faced by adolescents with disabilities in Kenya

That adolescents with disabilities (AWDs) face a lot of barriers in their quest for equitable access to social services such as healthcare including sexual, reproductive health, HIV and education is established in literature. For example available evidence suggest that despite the presence of policies and laws adopted by the government of Kenya, AWDs have never fully enjoyed their constitutional rights (KNCHR, 2014). Chief barriers AWDs face include discrimination in terms of their access to facilities, stigma and lack of informed consent before procedures are carried out on them in health facilities (KNCHR, 2014). In some

communities, AWDs undergo forced sterilization, ostensibly to stem out a curse from the society (WHO and World Bank, 2011). Sadly, the sterilization is carried out without their's or their relatives' consent, in complete disregard of their right to autonomy (ibid).

Additionally, literature shows that transport and physical infrastructure were major barriers to accessing services for AWDs. For example, according to Maart and Jelsma (2014), public transport regulations do not facilitate modification of public vehicles, making them inaccessible for the disabled, while building planning laws have remained non-responsive to the requirements of PWDs in general. The implication is that the AWDs are excluded from care, including SRH and HIV information and services that they often need to access through referrals to far off health facilities, for which travel may be required. Moreover, evidence indicates that difficulties from some media that are inappropriate and inaccessible to adolescents with intellectual, hearing and visual disabilities may hinder them from benefiting from information through these avenues (Groce et al., 2011).

1.7.4 Disability Movements in Kenya

Although several institutions associated with disabilities in Kenya have emerged over time, each however is specialised in different disability type. For instance, the first disabled people's organization (DPO) to have been registered in the country is the Kenya Union of the Blind (KUB), established in 1959. The institution exclusively caters for the visually impaired individuals. The foregoing consequently necessitated the proliferation of other disability movements such as the Kenya Association for Intellectually Handicapped (KAIH), the Kenya Society for the Mentally Handicapped (KSMH), the Kenya Society of the Physically Handicapped (KSPH), and the Kenya National Association of the Deaf (KNAD) (Gebrekidan, 2012). The community and national based DPOs formed the United Disabled Persons of Kenya (UDPK) as the federal umbrella organization in 1989. To provide an

accountability mechanism, the Kenya National Commission on Human Rights (KNHCR) was appointed in April 2011 as the national agency to ensure AWDs enjoy their rights under the PWD Act 2003, the Constitution, and the UNCRPD, and to monitor any progress. Some of the international non-governmental organizations present in Kenya supplying services to PWDs and supporting projects include: Leonard Cheshire International, Mental Disabilities Advocacy Centre, Sight Savers International, and Handicap International (Mutua, 2009).

1.7.5 Intersection of Disability and Poverty

The linkage between poverty and disability is bi-directional, as disability often results in poverty and vice versa, with low access to education being a big challenge to AWDs in sub-Saharan Africa, Kenya included. For instance available evidence shows that disability has the potential to restrict school attendance of youth and children and limit human capital collection consequently driving the affected individuals into poverty (Filmer, 2008). For example, in Kenya, studies reveal that AWDs have lower educational achievement, whereby 59% of PWDs, including AWDs, had finished primary school compared to 74% of their non-disabled counterparts (Chataika et al., 2012). The implications are that the ability and self-efficacy of such AWDs who had failed to attain adequate basic education are thus most at risk of poor health, including HIV and unplanned pregnancies partly associated with violation of their rights including those related economic and SRH (MOH, 2015).

Despite Article 27 of the UNCRPD's emphasis on the right of AWDs to comprehensive employment and works through banning bias at all level of employment, hurdles still abound, especially for AWDs. In Kenya, for example, there is substantial variance in employment outcomes based on disability status, where only 34% of PWDs living in urban areas were employed compared to 66% of individuals without (Opini, 2010). Additionally, the type of employment differs with AWDs, depending substantially more on self-employment than

people without disability (Mizunoya and Mitra, 2012). While self-employment provides a good alternative, as job opportunities remain scarce in the formal sector, their establishment requires initial financing (Lindsay, 2011), and the implications therefore are that AWDs remain poor and inexperienced to engage in meaningful and dignifying work. Moreover, access to basic health care, including SRH and HIV services that require out- of- pocket financing, could be jeopardized at the risk of compounded by vicious cycles of ill-health and poverty common in such households hosting AWDs (CIDP 2013-2017). Furthermore, although some AWDs would require rehabilitation, training, social protection and assistive devices to cope with life and realize their full potential (Mizunoya and Mitra, 2012) such have remained untenable for their lot despite the available conventional frameworks.

For instance, while Article 25 of the UNCRPD underlines the right of AWDs to the greatest achievable standards of health, including SRH, without bias based on costs of investment, evidence suggests that inclusive interventions may require additional initial expenditures, minimized burden of illness and efficient health sector spending (McIntyre et al., 2006). These had the potential to generate savings that can offset the investment in the future (ibid). Moreover, although AWDs are at a heightened risk of getting HIV, often they are disregarded in pre-emptive procedures, their greater involvement in reproductive and sexual health programmes could produce substantial societal and individual level health and financial benefits (Munymana et al., 2014).

Reports from Asia and Africa demonstrate that both men and women with disabilities, who are presumed sexually inactive, experience sexual assault and rape by people without disabilities desperate to purge themselves of disease, this being based on the myth that having sex with a virgin would cure them of various ailments (Groce and Trasi, 2004). Although adolescents with disabilities reach puberty at the same age as their non-disabled peers,

contrary to common perceptions, they are likely to also be sexually active with attendant consequences (KNCHR, 2012). For instance, the 2014 HIV Estimates report shows that the AIDS pandemic was increasing among PWD including AWDs, yet they did not have access to specialized information to address the illness (NACC, 2016). Female AWDs were up to three times more likely to be raped than those without disabilities, with men and boys encountering similar risks of sexual abuse as the women (Nosek et al., 2016). Within the abuse context, children with disabilities were another group that requires specific consideration. Legal counsel has remained inaccessible to AWDs, with the courts, police station, and law offices frequently lacking assistive devices and personnel to facilitate communication (Mikton et al., 2014).

In summary, the research states that although the rights of AWDs are explicitly provided for in the constitution and other legislation, their implementing has been slow due to inadequate follow-up mechanisms to ensure accountability and fidelity to the laws. Some of the major challenges that impede the execution of legislation in Kenya include the lack of awareness of the rights and obligations provided for in law both by rights-holders and duty-bearers. Other hurdles relate to financial barriers that limit victims of rights abuses from seeking legal redress in court and getting adequate representation.

1.8 Structure of the Report

This thesis is structured into the following 9 chapters:

Chapter 1: Introduction: The chapter presents preliminary discussions surrounding disability, including the conceptualization, distribution of disability and challenges AWDs face in Kenya. It also presents disability movements in Kenya and the implications of intersection of disability and poverty and intersectionality of disability and HIV. Theoretical Framework: Here the Theoretical Lenses and Relevance, Systems

Theory-Origins, Development and Application in Health, Bronfenbrenner's Bio-ecological Model, Challenges in the application of systems theory, Relevance of Systems Theory to the Study and Propositions of the study that were explored.

Chapter 2: Literature Review: The chapter presents the literature review in relation to the theoretical frame for adolescents with disabilities. It presents reviews of primary health care models, CBHC configurations, experiences and dynamics, linkages, partnerships and networking, community participation, volunteerism and compensation as they relate to AWD. Moreover, the chapter reviews the sexual and reproductive health interventions for AWD. The concepts of adolescence, SRH and HIV were reviewed in context. The socio-economic dimensions of ASRH and HIV care and support needed by AWDs; Policy and legal contexts of ASRH and youth-friendly services.

Chapter 3: In this chapter, the methodology of the study, study design, study population, credibility, Data Processing and Analysis, Plan for Communicating Findings of the Study, Study Limitations and Risks, Management and Organization of the Study, Quality Control and Ethical consideration explored.

Chapter 4: Results on the State of health systems and SRH and HIV service delivery: The chapter presents findings for objective 1, which was to describe the county health system contexts of SRH and HIV service delivery for AWDs.

Chapter 5: Results on functionality of community based health programs: This chapter addressed objective 2, which aimed to assess the functionality of selected community health models in delivering SRH and HIV services. Community health services, physical access to the Health Facility; access to health information by AWDs; staffing and Health services linkage to poverty alleviation services for AWDs are also detailed. It contains finding and analysis on the state of CBHC programs in Siaya County; opportunities for SRH and HIV

service delivery for AWDs.

Chapter 6: Results on Barriers to access to sustainable services: This chapter addressed Objective 3 that sought to explore the experiences of AWDs with regard to access to SRH and HIV services in the community. Details the situation of access to justice for sexual and gender based Violence, Experiences of Justice Delayed and Denied, sub-counties Sexual Offences Cases for Alego Usonga, Bondo and Ugenya Law Courts Sexual Offences Cases. Furthermore, local cultural impediments to accessing justice regarding SGBV - Justice on Trial: Normative Culture on SGBV- _*Thuol Odonjo EiKo"* are advanced in this chapter.

Chapter 7: Furthermore, this chapter also addressed Objective 4, which set out to determine opportunities in CBHC programs for the sustainable delivery of SRH and HIV services for AWDs.

Chapter 8: Discussion: This chapter addresses the extent to which the problem identified in chapter 1 was addressed and the Aim achieved by reviewing the main findings of the four objectives. It demonstrates discussions on the all findings.

Chapter 9: Conclusion: This chapter provides conclusion on broad based issues that the study investigated. These include overall conclusion on the research question with respect to adequacy and appropriateness of CBHC approach to deliver SRH and HIV services to AWDs, access and utilization of services by the AWDs, inequities and inequality with respect to structural barriers that affect AWDs in their quest to enjoy sexual health and rights.

Chapter 10: Recommendations. The chapter identifies the study limitations, the significance of the findings, presents suggested recommendations with respect to advocacy, programming, policy and further research.

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CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

That the understanding of community based health care (CBHC) approach to the delivery of sexual, reproductive health (SRH) and HIV services to adolescents with disabilities (AWDs) in sub-Saharan Africa is critical remains undisputed. This chapter explores documented experiences of primary healthcare (PHC) strategy for community-based services to vulnerable groups, such as adolescents with disabilities (AWDs). More specifically it reviews the historical perspectives, varying models, successes and challenges regarding access to primary healthcare by AWDs. Therefore, concepts of adolescence, SRH and HIV, including socio-economic, political and gender dimensions of SRH and HIV with respect to AWDs are reviewed.

2.2 Primary Health Care Approaches in Africa

During the 1960s and the 1970s, services provided by modern health care became a lasting presence in the lives of many in addition to those offered by local traditional healers (Huillery, 2009). What had been accessible to some, mostly through the health activities of Christian missions, became a public good that was at least in theory meant to be accessible by all. However, for those residing in peripheral regions, the new developments in modern healthcare service provision remained limited, as personnel and material resources did not reach them. Furthermore, Streefland (2005) opine that the supply of pharmaceuticals in the public sector was largely insufficient in many areas, thus affecting access to health services through public healthcare facilities. The growing health inequality and inequities in access to health care between nations is evident and unsettling for those in need of specialised care (Magnussen et al., 2004).

The review notes that during these early times, the attention of the World Health Assembly (WHA) was drawn to the unequal distribution of the burden of disease and ill-health across the world, the Alma Ata Declaration giving rise to the primary health care (PHC) model of service provision (WHO, 1978).

Drawing from the WHO‘s definition of health as

> "*a state of complete physical, mental and social well-being and not merely the absence of disease*" and the declaration "*that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition*" (WHO, 1946; preamble),

the PHC model is an all-inclusive approach to health system organization that protect and promote societal health (Hone et al., 2018; WHO, 1978). This has remained so albeit with some adaptive efforts to make the model more relevant to the emerging times and health needs and transitions. For instance recently, PHC is reaffirmed in the 2018 Astana Declaration and regarded as a driving force for achieving the SDGs development agendas and global health for all (WHO, 2018;The, 2018;Walraven, 2019a). As was then two models for implementing PHC (comprehensive and selective) exist for varying reasons. The 1978 Alma-Ata Declaration advanced the comprehensive model of PHC as the most appropriate to combat ill health by also addressing the social determinants of health. However, one year later, the selective approach that is more disease and condition specific was introduced. This has elicited unending debate as to which approach between the two is more effective, comprehensive or selective PHC (Magnussen et al., 2004; Baum et al., 2017).

It is however noted that, each of the two approaches has its merits and demerits. For instance, the CPHC model as then remains an approach to service delivery and health promotion that

was underpinned by a social view of health, community participation, empowerment, social justice, equity and action on the social determinants of health (Barton et al., 2019). Proponents of a comprehensive approach have argued that the model is most effective in addressing the underlying causes of ill health and improving health outcomes sustainably, with the action steps being promotive, preventative, rehabilitative, curative and palliative care (Baum et al., 2017; Walraven, 2019a). Such care would include sexual and reproductive health services targeting the most vulnerable groups, such as adolescents with disabilities (AWDs) who could not easily find an effective alternative to care.

Moreover, CPHC is recorded to have taken a horizontal model (where all services were provided together and were given equal value) of service delivery (Msuya, 2004; Baum et al., 2016), often financed through public health systems with the long-term aim being to address all health problems (De Maeseneer et al., 2008; Pyrek, 2019). Furthermore, it is collaborative and inter-professional in nature so that an all-inclusive care is provided to patients, their families, caregivers and communities in a wholistic sense (Tamayo et al., 2017). Inherent in the approach is the active involvement of the community in planning, developing, implementing and maintaining health services (Mayeden, 2016), with the intention of increasing their responsiveness, self-reliance, sustainability and efficiency (Kilewo and Frumence, 2015). Comprehensive approach to care though appealing to community needs, is however affected by health resource limitation, meaning that services have to be targeted (Baum et al., 2017). For instance, financing for CPHC programs in low- and middle- income countries has continued to be a challenge, compared to the high-income countries, the former invariably failing to allocate as much funding for health as the latter (Rifkin, 2018;Obimbo, 2003).

The viability of the CPHC model has therefore continued to attract criticism, as was then a year after Alma-Ata declaration. Critics have doubted the practicability of CPHC, and are advocating for a less expensive and more easily attainable approach; having succeeded in offering the selective PHC (SPHC) model as an interim alternative in many developing countries (Obimbo, 2003; Patchala et al., 2016). Moreover, the proponents of selective approach have hailed interim gains with the focus moving to hybridized rehabilitative and curative measures with very little of everything else (Baum et al., 2017). Furthermore, SPHC known for vertical mode of service delivery that fully addresses a single health problem and developing strategies to reduce or eradicate it. For example, as Walraven observes, interventions in the areas of maternal and child health, immunization, family planning and micro-nutrients are delivered through vertical programs that were deemed to rapidly reach high coverage for the selected priorities (Walraven, 2019b). This approach is criticized for paying very little attention to individual and community empowerment, consultation and responding to community needs, which affected self-reliance and sustainability.

Moreover, evidence suggests that vertical programs were very appealing to donors and political establishments arguably for being specific and measurable; with assurance of quick results and less effort to manage relative to horizontal model (Msuya, 2016). The researcher notes that when PHC was conceptualized at the 1978 Alma-Ata Declaration, countries debated its application in different contexts. For instance, in many middle- and low-income countries, such as Kenya, financing an all-inclusive CPHC was considered complex and expensive. A case is thus made by proponents of selective approach with a view that, the limited government resources are rather better spent targeted at specific problems (Baum et al., 2017;Rifkin, 2018). While supporters of the SPHC model argue that this approach enable quick interim gains, those of the alternative view maintain that CPHC approach is long-term and the gains are sustainable (Barber et al., 2018; Baum et al., 2017). There is often a reliance

on non-governmental organizations, missionary hospitals and donors who run vertical PHC programs (Organization, 2016;Mash et al., 2018). The consequences of over- dependance on foreign funding in many African countries are that PHC has been reduced to selective vertical programs, such as malaria or HIV, rather than a CPHC approach that included disease prevention and health promotion (Bresick et al., 2019). The implications are that efforts towards universal access to basic health care that would include the most vulnerable like the AWDs got derailed.

For instance, a study in five sub-Saharan African countries (Mali, Sudan, Uganda, Botswana and South Africa) shows that due to the lack of funding, providing comprehensive primary healthcare is hindered by staff shortages in their poorest areas (Willcox et al., 2015). Furthermore, the same study observes that Sudan, Mali and Uganda (the poorest countries of the five) all fall short of meeting the WHO‘s recommended target of 2.28 health workers per 1000 population; whereas Botswana and South Africa are both reported to exceed it (Willcox et al., 2015). The complexities associated with the staff shortages imply poor or inadequate services for the most vulnerable groups, such as adolescents with disabilities (AWDs), whose only avenue for care would be at the primary care levels.

As Bloom and Canning (2000) rightly opine, the PHC strategy had aimed to extend curative and preventive care to communities by engaging village health workers and emphasizing the principle of self-reliance. Nevertheless, in the course of the 1980s, any advancement undertaken in public health care provision and health development in post-colonial SSA stalled in a background of political instability, structural adjustment measures, financial indebtedness and economic recession (Nsutebu et al., 2001).

In regard to the economic problem, Coovadia et al., (2009) demonstrates that while limited resources were accessible for the daily administration of government health care, the World

Bank and IMF imposed austerity measures that unfavourably affected household sustenance, including the possibilities to pursue treatment when health issues arose. The implication is that the individuals and the most vulnerable groups like AWDs would have to pay for services they receive hence stagnating public investment in PHC. Konadu-Agyemang (2000) describes this phenomenon as a 'process of contraction', that involves a declining quality of care due to the low motivation of personnel occasioned by factors such as poor staff salaries that often delay or are decrease; and limited supply of drugs.

In addition, the process includes the unpredictable coverage of basic health services with reduced accessibility due to the introduction of user fees and the disintegration of CBHC initiative as external support to village health workers faded (ibid). On the same Wouters et al., (2012) observe that since the early 1980s, the provision of government PHC in SSA is characterized by rising resource scarcity that in many instances lead to a process of contraction.

In Nigeria, literature suggests that the federal, state and local governments play critical role in implementing health services in the country. Policies such as 1987's National Health Policy and the proposed National Health Act 2014 aimed to provide effective comprehensive PHC services. Another plan by the Nigerian government was incorporating PHC into the curriculum of medical schools and the Community Health Officers training program, which was an investment in training PHC workforce in teaching hospitals countrywide (Uzochukwu et al., 2015;Gyuse et al., 2018). However, the healthcare system in Nigeria is often characterized by mismanagement and poor inter-government funding, which in effect thwarts the investment in the critical health system building blocks including staffing, supply chain and equipment; thereby compromising the coverage and quality of PHC services in Nigeria (Oyekale, 2017; Abimbola et al., 2015; Olatubi et al., 2018). In contrast however, the failures

of the public health system have given significant rise to the private sector as well as traditional and spiritual healers (Gyuse et al., 2018; James et al., 2018).

Since independence in 1963, the Kenyan government has developed various policy reforms for better health care. These include: Kenya Health Policy Framework (KHPF 1994– 2010), National Health Sector Strategic Plan I & II, the Constitution 2010, and finally, the Health Bill of 2015 (Okech and Lelegwe, 2016; Kibui et al., 2015). As a result, health indicators, such as life expectancy, and infant and child mortality, showed some improvement (Odwe et al., 2015; Okech and Lelegwe, 2016). The PHC approach started in Kenya in the 1960s; the first community-based model being applied in Kakamega District from 1974 to 1982 with the support of the Ministry of Health (Labonté et al., 2017).

From the perspective of the World Health Organization (WHO) PHC arose due to an awareness of the inability of the bio-medical model to take care of the main health needs of its populations; it could treat diseases for some but it could not provide health for all (WHO, 1978). Thus, a CPHC approach remains an attempt to move health beyond the boundaries of a narrow bio-medical framework and address environmental, social and economic contexts of people‘s lives regarding disease and health (Buong et al., 2013) as was then envisaged.

Although the Government of Kenya approved the PHC approach in 1982, there were no clear policy guidelines for its application on a large scale. Health indicators in the country stagnated or declined, which required the Ministry of Health undertake reorganization (Labonté et al., 2017). As an effort to revitalize comprehensive PHC in 2006, the Government introduced the Community Health Strategy as the approach to health care service delivery. Community Health Strategy is an initiative aimed at improving health indicators by actively engaging communities in managing their own health, being primarily organized at individual, family and community levels. This was conceptualised in the

National Health Sector Strategic Plan II and services enunciated in the Kenya essential health package (KEPH). Notable, the Government has since established and operationalized at least 2944 Community Health Units in support of the initiative (Muendo, 2017;Labonté et al., 2017). A community health unit is the lowest health delivery point in the county health system, which covers a population of 5000 people and works directly with houses in the community. The main providers here are the community health volunteers. The establishment of community health systems therefore could be viewed in the light of different formations and practicalities. As Magnussen et.al aptly capture that,

> "…*By the mid-1970s international health agencies and experts began to examine alternative approaches to health improvement in developing countries. The impressive health gains in China as a result of its community- based health programs and similar approaches elsewhere stood in contrast to the poor results of disease-focused programs. Soon this bottom-up approach that emphasized prevention and managed health problems in their social contexts emerged as an attractive alternative to the top- down, high-tech approach and raised optimism about the feasibility of tackling inequity to improve global health*." (Magnussen et al., 2004).

The following section explores the community home-based health care (CHBC) model typologies and their relevance to this study.

2.3 Community home-based health care

The community-based health care approach has diverse typologies, each constituting of a distinct mix of services, reach, staff and delivery scheme. The most recognized types include integrated, community home-based care (CHBC) and facility-based, the focus of each program varying. For instance, studies show that CHBC programs focus on psychosocial support to patients and their families, and deliver their services principally through volunteer

networks in the society (Nsutebu et al., 2001). Facility-based programs focus on medical aspects of care engaging teams, such as health professionals who can offer higher levels of care. CHBC is defined as the care provided to people in their environment by their families, supported by communities and skilled welfare officers to fulfill not only the health and physical needs, but also the psychosocial, material and spiritual (Mohammad and Gikonyo, 2005). Such CHBC care, which largely targets marginalised and vulnerable people, including those living with disabilities, also emphasize affordability as a key principle for access, another variant being reliance on volunteer caregivers, all of which stem from the Alma Ata conference in 1978 (WHO, 1978).

The prevailing studies indicate that CHBC expenses differ by program expansion and maturity, service package and location (urban and rural). In Rwanda for example, Chandler, Decker, and Nziyig observe that in HBC, a CHBC approach has lower approximated costs per client than the facility-based method (Chandler et al., 2004). Wouters et al. (2012) suggest that in developing countries, where resources are limited, CHBC for HIV is increasingly considered as more affordable and accessible than inpatient care, both for governments that must finance inpatient facilities as well as for patients who were incapable of travel to or paying for inpatient care. Notably, evidence shows, that these expenditures are costly in rural areas as equipment is often needed for referrals or staff transportation (ibid). Furthermore, scope and program maturity also affect the costs of CHBC, with the expense per home care visit in Botswana being reduced from $10 to $1 as the program enlarged and expenditures increased by 31%, which resulted in more patients, thereby making the program more efficient (Ama and Seloilwe, 2010).

Kenya‘s health care delivery system is also faced with a shortage of human resources (MOH, 2012), which limits the effectiveness and efficiency of CBHC delivery system, particularly

the community midwifery programme, as the concentration of medical practitioners in urban settings was higher than in the rural areas (Mannah et al., 2014). Moreover, inadequate supplies of equipment as well as the unavailability of medicines and vaccines has rendered community-based midwifery programme in Kenya ineffective, thus increasing child and maternal mortality (ibid). Additionally, limited funding, including inadequate remuneration of medical staff, has also impeded the effectiveness and efficiency of community based health care services, while long distances between the health centers and households, compounded by poor road conditions, has made it difficult for the expectant adolescents with disabilities (AWDs) mothers to access maternal services (Mannah et al., 2014).

In Western Kenya, lack of proper linkages and coordination between community and health facilities, as well as the limited training received by community health workers, impede the effectiveness of community-based health deliver information systems (Flora et al., 2017). Most community workers lack the ability to quantify as well as analyze health situations using reliable data to plan and manage health care service delivery (Flora et al., 2017). These challenges result in community members resorting to traditional and outdated practices to treat medical conditions and illnesses (Kirigia and Barry, 2008). The implication is that the challenges from time to time force the government to respond through policy development and reviews for a health system hoped to deliver equitable healthcare to the citizens, including AWDs.

2.4 Policy Contexts of Primary Health Care in Kenya

In an effort to respond to the health challenges that faced a majority of its citizens, Kenya became a signatory to the International Declaration for attaining "*health for all by the year 2000*" through the 1977 Alma-Ata Conference. The declaration aimed to establish the accountability of health ministries and personnel, with guarantees to fulfil the basic health

needs at low cost. Kenya thus launched PHC in 1977 as a pilot programme and later initiated the CBHC programme to 14 districts in 1986 (Opiyo and Njoroge, 2009). The PHC interventions were improved by the Bamako Initiative of 1987 that endeavoured to enhance access to primary healthcare by increasing the equity, financial viability, efficiency and effectiveness of health services (MOH, 2006). Nevertheless, due to shrinking health budgets and a global recession, this all-inclusive broad-based PHC approach was discarded. The setting was further aggravated by the Structural Adjustment Programmes (SAPs) introduced by IMF and World Bank in the 1980s, with the IMF observing:

> *"Generally, the programs focused on the reduction of government expenditures as a baseline policy approach, with currency devaluation also being employed to encourage exports and rectify trade deficits. Importantly, and in terms of health and NHS, SAPs often insisted on the implementation of fee-for-service regimes in education and healthcare; and, more widely, on the promotion of free market principles to stimulate efficient allocation of resources. These state-restrictive measures (or 'rolling back' policies) were further supported by the privatization of state-owned enterprises and general reduction of government interference in the national economy."* (Buckley and Baker, 2009)

Implementing community health services has remains unending journey and a priority of the Ministry of Public Health and Sanitation (MoPHS) and its associates in Kenya (MoH, 2005). In 2006, the MoPHS assumed the Community Health Strategy to actively involve societies in managing their health (MOH, 2006). Moreover, Opiyo and Njoroge (2009) agree that the comprehensive objective of the community strategy was suited to improve community access to healthcare in an attempt to enhance productivity and thus decrease hunger, poverty and maternal and child mortality, as well as refine education performance across all the phases of

the lifecycle.

The Second National Health Sector Strategic Plan of 2005-2010 introduces another procedure to deliver healthcare services to Kenyans, known as the Kenya Essential Package for Health (KEPH) (MOH, 2005). The community-based element of the KEPH acknowledges and enunciates Level 1 services aimed to empower communities and households to take charge of their own health. Level 1 is the community- based component that provides the basic community health services, including promotive, preventive and basic curative care. In addition, it had introduced five life cycle categories and six service delivery levels as seen in table 2.1 below.

Table 2.1: Lifecycle Cohort

Cohort	Health Services
Pregnancy and the newborn (up to 28 days):	The health services specific to this age-cohort across all the Policy Objectives
Childhood (29 days – 59 months):	The health services specific to the early childhood period
Youth and adolescents (5 – 19 years):	The time of life between childhood, and maturity.
Adulthood (20 – 59 years):	The economically productive period of life
Elderly (60 years and above):	The post – economically productive period of life

Source: KHSSPI (2013-2017)

Consequently, as per the above table, SRH and HIV care and services for AWDs are envisaged largely within the first three cohorts. The community health strategy describes the

best approach as one through which communities and households take an active role in their health and other development issues. Moreover, it envisages that communities would be effectively engaged in their health issues and demand for service from all providers in order to better their health status. In this regard, one of the major purposes of this approach was to build the capacity of households to evaluate, plan, execute and manage health issues so as to allow them to contribute actively to the nation's socio-economic development. Another proposed impact is to empower households to demand their rights and seek liability from the formal system for the effectiveness of health services. Moreover, the shift in strategy that now puts the community at the core of services delivery envisages synergistic arrangements of inclusive care in a devolved fashion to achieve effectiveness and efficiency in healthcare.

2.5 Linkages, partnerships and networking

Albeit with recognizable challenges to referral mechanisms for the patients or clients seeking care, Kenya's health system had attempted to foster synergistic arrangements for healthcare in a devolved model from the community level to the highest possible level of care. The lowest level of care was the community health unit (CHU) which was a health service delivery structure in a defined geographic catchment serving a population of approximately 5,000 people. Every unit was assigned 2 Community Health Extension Workers (CHEWs) and community health volunteers who offer provide preventative and basic curative services. This being the level at which the basic in every CHU, including a Community Health Committee (CHC) as the governing body, have been established to serve as a link between the health facility and the community, their training taking 10 days. The chairman of the CHC was a community member, the treasury was a Community Health Volunteer (CHV), and the secretary was a Community Health Extension Worker (CHEW), these were professionally trained health and development workers that support community health volunteers, community health committees by providing supervision and bridging community

health units and the higher health system (MOH, 2006). The CHC's role was to manage the operations of Level 1 health services in the community by actively engaging in the hiring and supervision of CHVs, as well as examining with them the community data and actions plan to address their communities' health problems (MOH, 2006). Cases of diseases at the community level is referred to the health facility, whereby CHEWs compiled and forwarded the information to the district health records and information officers (DHRIO). Figure 2.1 below provides the six levels structural arrangement of healthcare service delivery in Kenya from the household to the national referral levels. Community based health care programs largely operated at primary care levels in particular, community unit (level 1).

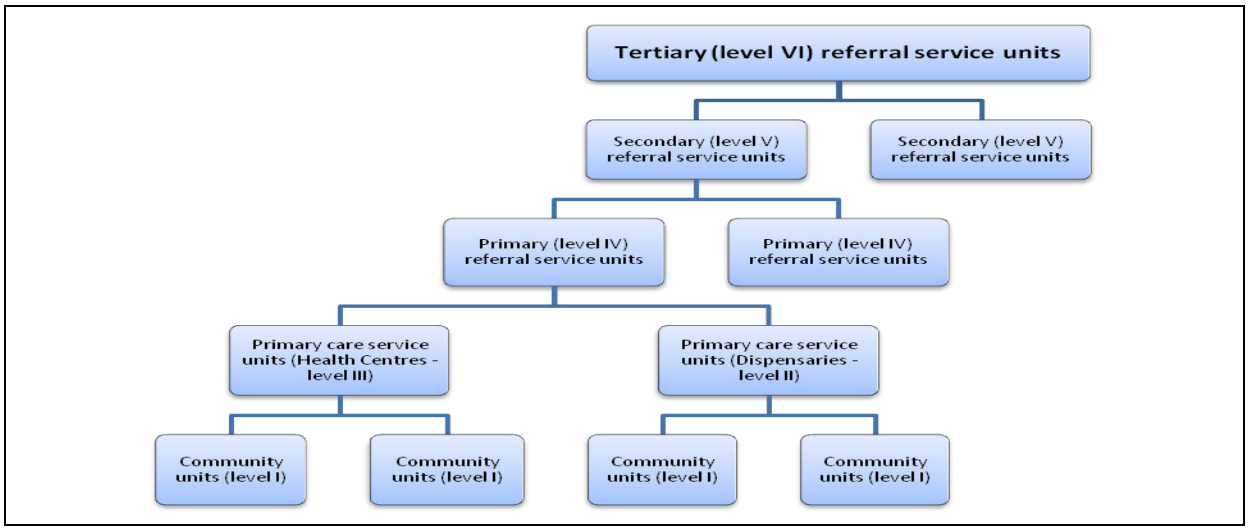


Figure 2.1: Levels of service delivery

Source: KHSSPI (2013-2017)

For cases that could not be addressed at the health facility, the patient is referred to the next appropriate level. The community strategy document had stipulated that each trained CHEW is required to supervise 25 CHVs. It also identified CHVs as gate keepers of health in society, who had been observed to be effective in discussing actions for health with household members as they shared common experiences and situations (Health, 2007). In all counties, the CHVs were selected by the community through a traditional leader (e.g. a chief or

baraza), after which they undergo training by CHEWs. The two- level training; consist of an initial 10 days of compulsory instruction, followed by optional technical training, which takes 10-15 days, depending on the module being taken. Additionally, from time to time, refresher training is conducted based on the necessity, but occurs at least quarterly. CHVs were encouraged to pursue other opportunities that may emerge and after five years of service, they may attain a certificate of recognition (MOH, 2006). The implication is that less attention is provided for issues related to adolescents with disabilities and how they should be facilitated to access care within the health system and its structures.

2.6 Community Participation, Volunteerism and Compensation

Ensuring sustainable community engagement is core to community health service. The World Health Organization (WHO) asserts that community participation is fundamental to the effective delivery of affordable, accessible, acceptable and technologically appropriate community-based healthcare programs in poor contexts of the world (WHO, 1978).

By definition, a Community Health volunteer (CHV or CHW) is not considered a full-time salaried worker of the MOH or other institutions. The main reason is that the MOH cannot afford to compensate CHVs over the long-term. The health cadre frequently work full-time, even longer hours, alongside salaried personnel, which results in them demanding regular remuneration for services provided.

Volunteerism had been the foundation of CBHC programs in Africa, and while full-time salaried CHWs were scarce in Africa, many had received some form of cash incentive since 2013 when governments began to incorporate the community volunteers into formal MoH cadres (lowest rank of paid health workers e.g. SA, Ethiopia, Zambia, Malawi). For instance, in Malawi, Health Surveillance Assistants were the equivalent of CHWs, having been in service as paid health staff (Celletti et al., 2010). In Kenya, the MOH (2006) indicates that

CHVs work as volunteer, part-time employees, being compensated for direct expenses incurred in community health service provision. Although the Kenya government opted for part payment of CHVs, this cadre of community resource persons largely still worked as volunteers with no pay. Additionally, to motivate the volunteers, they were allocated an essential care package that was provided and replenished by trained community health assistants; they also had bags to carry work materials and protective clothing. The kits were delivered to CHEWs quarterly, with each containing basic equipment, renewable supplies and drugs, and were expected to cater for 5,000 individuals over three months.

In a study reviewing the impact of health outcomes using CHWs, Lehmann and Sanders (2007) indicated that many CHWs programmes reported high attrition rates, with greater values being associated with volunteers, although a number of churches and NGOs in eastern and southern Africa have run effective CHBC programmes using volunteers for many years. In Kenya, material and financial incentives were linked to CHW retention, with many respondents in a past study indicating that working materials (75%) and compensation (65%) would stimulate them to continue working as CHWs (Takasugi and Lee, 2012). Furthermore, the evidence suggested varying reasons for high dropout rates among CHWs. These included poor relationships that sometimes occur between CHVs and NGO officials as a result of mistrust especially in the ways elections of CHVs were conducted as well as insufficient support from the community where they serve (Olang'o et al., 2010).

2.6. 1 Community Health Services

Community Health Services referred to a wide range of health services in community-based settings as part of comprehensive primary healthcare strategy (MOH, 2006; MOH, 2012). Primarily, community health services focus on behaviour change, disease prevention, health promotion and life prolonging services that make the most significant contribution to the

improvement of health, wellbeing and quality of life of the population (ibid). The Kenya Essential Package for Health (KEPH) in the Health Sector Strategic and Investment Plan 2013-2017/18 defined health services and interventions to be provided at various levels.

Although the services were envisioned to be provided through KEPH's age specific six life cycle cohorts including: Pregnancy and the newborn (first 2 weeks of life); Early childhood (2 weeks to 5 years); Late childhood (5 to 12 years); Adolescence (13-24 years); Adult (25-59 years) and Elderly (over 60 years), for AWDs all the six lifecycle cohorts were found to be linked to their needs. For instance the study found pregnancy and the newborn (first 2 weeks of life) touches on AWDs that were prone to unplanned pregnancies that resulted from sexual and gender based violence meted against them Early childhood (2 weeks to 5 years) ¨ Late childhood (5 to 12 years) ¨ Adolescence (13-24 years) ¨ Adult (25-59 years) ¨ Elderly (over 60 years).

The study established that community health services constitute all the community- based aspects of the KEPH that were provided at level 1. Level one was found to provide the basic community health services that include promotive, preventive and basic curative care. The level 1/Tier essential package of services as prescribed by KEPH includes services outlined in the table below (MOH, 2005; 2013). The community-based element of KEPH acknowledged and initiated level 1 service, which intended to empower the community and households to take charge of their own health. Table 2.2 provides the essential package of health the county is committed to deliver to all its citizens through community strategy.

Table 2.2: KEPH Services

Services	Interventions
Disease prevention and control to reduce morbidity, disability and mortality	i. Practicing good personal hygiene in terms of washing hands, using latrines, etc. ii. Using safe/treated drinking water iii. Ensuring adequate shelter, and protection against vectors of disease iv. Preventing accidents and abuse, and taking appropriate action when they occur. v. Ensuring appropriate sexual behaviour to prevent transmission of sexually transmitted diseases vi. Communicable disease control: HIV/AIDS, STI, TB, malaria, epidemics vii. First aid and emergency preparedness/treatment of injuries/trauma viii. IEC for community health promotion and disease prevention
Family health services to expand family planning, maternal, child and youth services:	1. MCH/FP, maternal care/obstetric care, immunization, nutrition, 2. Community-Integrated Management of Childhood Illness (C- IMCI) 3. Adolescent reproductive health 4. Non-communicable disease control: 5. Cardiovascular diseases, diabetes, neoplasms,

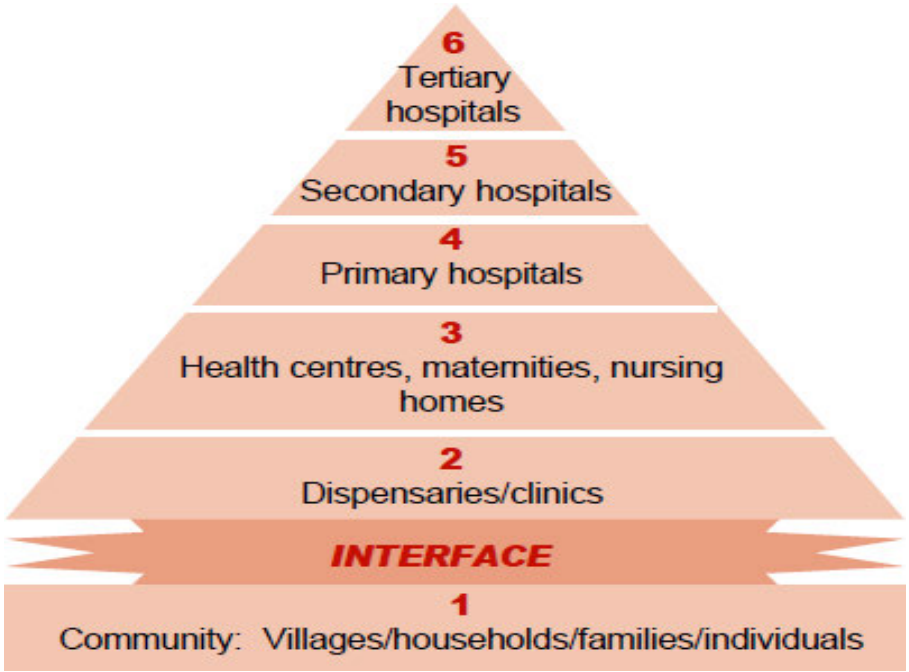
	anaemia, nutritional deficiencies, mental health 6. Other common diseases of local priorities within the district, e.g., eye disease, oral health, etc. 7. Community-based day-care centres 8. Community-based referral system, particularly in emergencies 9. Paying for first-contact health services provided by CORPs
Hygiene and environmental sanitation:	a) IEC for water, hygiene, sanitation and school health b) Excreta/solid waste disposal c) Water supply and safety, including protection of springs d) Food hygiene e) Control of insects and rodents f) Personal hygiene g) Healthy home environment: environmental sanitation, develop kitchen gardens h) Organizing community health days
Health promotion	Ensuring a healthy diet for people at all stages in life in order to meet nutritional needs. Building healthy social capital to ensure mutual support in meeting daily needs as well as coping with shocks in life. Demanding health and social entitlements as citizens. Monitoring health status to promote early detection of problems for timely action. Taking regular exercise.

	gender equity. Using available services to monitor nutrition, chronic conditions and other causes of disability.
Care, seeking compliance and treatment and advice	Giving sick household members appropriate home care for illness. Taking children as scheduled to complete a full course of immunizations. Recognizing and acting on the need for referral or seeking care outside the home. Following recommendations given by health workers in relation to treatment, follow up and referral. Ensuring that every pregnant woman receives antenatal and maternity care services
Governance and Management of health services:	The activities include attending and taking an active part in meetings to discuss trends in coverage, morbidity, resources and client satisfaction, and giving feedback to the service system either directly or through representation.
Claiming Right	These activities include: Knowing what rights communities have in health Building capacity to claim these rights progressively Ensuring that health providers in the community are accountable for

Community Health Strategy

The Community Health Service is functionally linked to other services of the health system.

Each CHU has a Link Health facility which it interacts directly with, while it is in turn linked to facilities at higher levels/ tiers of the health system through referral. The community health strategy describes the best approach as one through which communities and households take an active role in health and other development issues. The strategy envisions that communities should be effectively engaged in their health issues and demand service from all providers in order to better their health status. In this regard, one of the major purposes of this approach is to build the capacity of households to evaluate, plan, execute, and manage health issues, so as to allow them to contribute actively to the nation's socio economic development. Another proposed impact is to empower households to request their rights and seek liability from the formal system for the effectiveness of health services. The shift in strategy now puts the community at the core of service delivery envisaging synergistic arrangements of care in a devolved fashion to achieve effectiveness and efficiency in healthcare.



***F*igure 2.2: Interface between community level and healthcare system under KEPH**

Source: Ministry of Health (2006)

The six levels consist of:

1. **Community level (level 1) -**was the foundation of the health service system, with a focus on health promotion and disease prevention as well as specified services that were most effectively delivered at this level through community units (CHUs). In the essential package, all non-facility- based health and related services were classified as community health services. Key providers here were the community volunteers with support from trained professional health workers as link to higher levels of care.

2. **Primary care (level 2)** were health facilities, including dispensaries and clinics

3. Primary care (level 3) health centres and maternity/ nursing homes. All these levels were provided preventive services e.g. immunization and also curative services.

4. **County level (4 and 5)** consisted of first level hospitals and county referral hospitals whose services complement the primary care facilities through referral in order to provide enhanced health services.

5. **National level (6)** consisted of tertiary level hospitals with highly specialized services that complete the set of healthcare services available to persons in Kenya.

2.7 The Adolescence, Sexual and Reproductive Health and HIV

According to the WHO and World Bank (2011), an adolescent is any individual aged between 10 and 19 years of age. Adolescence is a phase characterized by significant development, remarkable growth, and changes in the life course or girls and boys, associated with potential and opportunities as well as risks and vulnerabilities (MOH, 2015). Adverse sexual and reproductive health consequences among youth include sexually transmitted

infections like HIV, early marriage, abortion, early childbirth, and unintended pregnancy (Mensch et al., 2003). These outcomes were generated by risky behavior, such as insufficient access and utilization of contraceptives, including condoms for dual protection, multiple sexual partners, gender and sexual violence, substance abuse and early sexual debut (Ozer et al., 2005). These unfavourable outcomes inhibit young individuals' capacity to attain their social and economic objectives, which in turn affects their nation's long-term development (Kirby et al., 2007).

A lack of effective reproductive healthcare services for youths, exacerbated by lack of available and affordable contraceptive education and commodities, means contraceptive utilization among single and married youths is low in developing regions. Moreover, among married adolescent girls in Kenya, only 40% used a method of contraception, with one in three adolescent girls having an unmet need for family planning (Ikamari and Towett, 2008). Furthermore, the available evidence also suggested that while some youths may choose to bear a child, many pregnancies happen in the context of human rights infringements, including sexual abuse, coerced sex or child marriages (Baumgartner et al., 2009).

2.8 HIV and Adolescents in Sub-Saharan Africa

Since the first case in the 1980s, there has been a rapid spread of HIV in the sub-Saharan region of Africa despite the limited transmission routes. Moreover, although the HIV pandemic was initially restricted to key populations like sex workers, people who inject drugs, and gay men, later however, it also spread to the rest of the population through the bridge population like clients of sex workers and bisexual males. A recent report by UNAIDS indicates that as at 2018, the global distribution of new HIV infections in the general population is at 46%, clients of sex workers and other sexual partners of key population at 18%, gay men and other men who have sex with men at 17%, people who inject drugs at

12%, sex workers at 6%, and transgender women at 1%. This translates into nearly about 1.7 million people newly diagnosed with HIV in 2018, or 5,000 new cases a day (Shete, 2013; UNAIDS, 2019).

According to the incidence-prevalence metrics, the number of people living with HIV in a given region increased over time if the number of new infections per 100 people is greater than 3.0%. While important progress has been made in the war against HIV/AIDS, much work remains to be done since the global incidence-prevalence ratio is 4.6%. Western and Central Europe and North America, which were high-income regions, have an incidence-prevalence ratio of 3.1% - already meeting the benchmark of 3.0%. Other regions in the world were still struggling to get there, with 3.9% in Eastern and Southern Africa, 4.6% in the Caribbean, 5.4% in both Latin America and Asia and the Pacific, 5.5% in western and central Africa, 8.0% in the Middle East and North Africa, and 9.0% in Eastern Europe and Central Asia (UNAIDS, 2019).

In 2018, the majority of global infections (54%) was among the key populations and their sexual partners (infections in the general population was 46%), in Eastern and Southern Africa new HIV infections were predominantly transmitted within the general population (75%) than was within the key population (25%). This translated to about 2,000 new infections a day in Eastern and Southern Africa region. Eastern and southern Africa remains the region most affected by the HIV epidemic, accounting for 47% of the global HIV new infections (up from 45% in 2017) and 53% of people living with HIV globally (UNAIDS, 2019; UNAIDS, 2018).

It is important to note that, according to the UNAIDS 2017 report on disability and HIV, people with disabilities were present in all the key and vulnerable populations including people who inject drugs, sex workers, lesbian, gay, bisexual and transgender people, men

who have sex with men, children out of school, people who experience violence, women and girls, adolescents, and migrants.

The report also notes that although more than one billion people worldwide were living with a disability, data on HIV prevalence among people with disabilities were scarce. The little data from sub-Saharan Africa imply a 1.48 fold increase in the risk of HIV infection in men with disabilities compared to 2.21 fold in women with disabilities compared to people without disabilities (UNAIDS, 2017). These sentiments were shared with the UNAIDS 2019 report which mentions that people with disabilities were often left behind by HIV responses although the prevalence of HIV among people with disabilities were on average three times higher among people with disabilities than it is among the general population(UNAIDS, 2019).

According to the 2019 UNAIDs report, young women between the ages of 15-24 accounted for 26% of new HIV infections in the Southern and Eastern Africa region, however, it is not known how many disabled young women were in this number. The 2017 report notes that many people with disabilities did not have access to HIV services because of barriers such as stigma and prejudice, exclusion from sexual education, and lacked of funding for alternative forms of communication, such as sign language and braille (UNAIDS, 2017; UNAIDS, 2019). The implication is that there was lack of evidence to determine trends in HIV among people with disabilities in Southern and Eastern Africa, a region that accounts for 47% of the global HIV new infections and 53% of people living with HIV worldwide.

Although the HIV situation in sub-Saharan Africa (SSA) continue to improve, the available literature suggest that Africa's youth, aged between 15 and 24, are still disproportionately affected and infected by HIV. For instance, in 2010 UNAIDS had observed that across the continent, HIV prevalence among adolescents differs exponentially, from more than 25% in

Zimbabwe to less than 0.1% in Egypt, with South Africa and Nigeria having the highest number of youths living with HIV at 1.9 million and 1.3 million respectively (UNAIDS 2010). Although the rate of infections has shown decline, the pace has remained slow. Hervish and Clifton (2012) observed that diverse nations were achieving noteworthy declines in HIV prevalence, mostly due to changes in sexual behavior patterns among young people, including increasing condom use, having fewer partners, and waiting longer to become sexually active. However, the dearth of data regarding disabilities and HIV across the region continued to blur the picture of HIV situation among adolescents with disabilities (AWDs).

Yet, ironically, the level of knowledge among adolescents and young adults on the causes of HIV is lowest in countries where the prevalence is high (Idele et al., 2014). A survey conducted in countries with generalized epidemics found that less than half the adolescents (aged 15-19) in most of the countries had a basic understanding of HIV. For instance, in SSA, it was found that only 26% of adolescent girls and 36% of adolescent boys of the same age had sufficient knowledge of HIV, with disparities being linked to gender, place of residence, education and household wealth (Idele et al., 2014). To make matters worse, as observed in Kenya, there is insufficient information on effective reach out to adolescents in particular, adolescents with disabilities (MOH, 2015).

Similar to other developing countries, youths including AWDs in Kenya experience numerous health, economic and social challenges. Yet, at this stage in their lives, they need to develop life skills, as they are exploring and establishing their identity in society to enable them to become socially fit and responsible adults in their communities (Biddlecom et al., 2009). Moreover, Hindin and Fatusi (2009) observe that due to a large populace, inadequate access to healthcare and poverty, some adolescents (including AWDs) do not have an opportunity to acquire life skills, and therefore involved themselves in risky sexual behaviors.

For instance, as literature shows, adolescent boys and girls are found to have engaged in sex by the age of 15 (Kabiru et al., 2010).

The challenges of HIV care and support needs of adolescents could be daunting, with UNAIDS contending that between 2001 and 2012, the only group that had realized increased mortality as a result of AIDS were adolescents between 10 and 19 years. This was attributed to the lack of prioritization of strategic plans for young people to scale-up HIV treatment, as well as a lack of testing and counseling (WHO, 2013).

Despite the knowledge that adolescence is a delicate period in which sexual and reproductive needs required urgent attention, the situation has generally remained unsatisfactorily attended. In particular, AWDs faced greater challenges than their non-disabled counterparts in accessing SRH & HIV services due to the stigma and discrimination associated with their condition (Burke et al., 2017). Some countries in SSA, such as Senegal, challenge the necessity of SRH services for adolescents due to legal and religious justifications. Many teens cite this as the reason they do not seek SRH, including HIV services (Burke, et al., 2017). However, legal barriers were not the main impediment to access SRH & HIV services for adolescents, including the AWDs.

Studies show that many countries, Kenya included, which are experiencing a generalized HIV epidemic, are finding it more effective to assign the task of HIV treatment to Primary Health Care (PHC) centres (Diese, et al., 2010). In Kenya, these include dispensaries and health centres (level 2 and 3 facilities) where community strategy actors, namely CHVs, CHCs and CHAs, are based (MOH, 2006). While treatment was expected to be far easier to access at PHC level for most patients, including HIV+ AWDs seeking ARVs, barriers still remained. According to available evidence, barriers such as poor staffing, inadequate commodities and financing, congested facilities and negative community perceptions of the

systems persist (KPMG, 2013) such could exclude vulnerable groups like AWDs from accessing care. Optimists, however, believe that this could be reversed. For instance, in their technical brief on decentralizing HIV treatment and care, Diese et al. (2010) contended that promoting care at the PHC level should be implemented by supporting continuous quality improvements, removing barriers to quality service delivery, and dealing with the scourge of stigmatization and discriminatory practices. These should have extended to community-based initiatives that were largely taken care of by community health volunteers who werethe main link between those needing care and the PHC facilities (MOH, 2006).

2.9 The Socio-economic and Gender Dimensions of SRH and HIV

The socio-economic and gender dimensions of SRH and HIV are skewed against young women especially those living with disabilities. For instance, studies in SSA showing that adolescent girls in developing countries are particularly vulnerable, as many have little education and live in poor contexts (KNCHR, 2012). Wider socio-economic factors, such as limited economic opportunities, lack of education and poverty among girls largely therefore contribute to high adolescent pregnancy rates including risks to HIV infections (MOH, 2015;Were, 2007). Furthermore, adolescent pregnancy, whether unintended or deliberate, heightens the risk of maternal mortality and morbidities, arising from such causes as prolonged labor and delivery, and unsafe abortion (MOH, 2015).

Evidence suggest that young women, AWDs included, represent a substantial percentage of the number of unsafe abortions. For instance, the WHO (2011) demonstrate that adolescents girls residing in low-income countries account for nearly 2.24 million unsafe abortions, while those below the age of 25 years were severely affected by the consequences and constitute almost half of all abortion deaths. A study undertaken in Kenya on the magnitude and prevalence of abortions indicated that young women below 19 years accounted for 45%

of all critical abortion-related admissions and 17% of all females seeking post-abortion care services in Kenyan hospitals in 2012.

Preventing unintended pregnancies would enhance the ability of young people including AWDs to access educational and employment opportunities, which in turn would contributes to reducing poverty, improving household savings and the overall status of women, as well as enabling an increase in economic development (Kirby, 2002). Other negative cultural practices were still a factor against AWDs progress. For instance young women in SSA are affected by harmful traditional practices, such as sexual initiation and inheritance rights, widow cleansing and especially, child marriages (Myers and Harvey, 2011). Furthermore, Myers and Harvey (2011) suggest that forced, early and child marriages contribute to driving young women into a cycle of powerlessness and poverty. Under such circumstances, adolescents, in particular those with disabilities, are likely to experience illiteracy, poor reproductive and sexual health, forced sexual relations, abuse, violence and a lack of education, and therefore bear the worst form of infringement of individual autonomy in decision making (KNCHR, 2012;KNCHR, 2014). While the international Convention on the Right of the Child (CRC) regards marriage under 18 years of age as an infringement of rights, and should thus be outlawed (Assembly, 1989), the phenomenon remains common in Africa.

Moreover, it is observed that in nations where the legal age of marriage varies by gender, the age of females is often lower than that of men. For instance, in Benin, which has among the highest prevalence of child marriages, the legal age of marriage is 15 years for women and 18 years for men (Walker, 2012). This variability in jurisprudence of age of marriage complicates the reinforcement of CRC that defines a child as any person below the age of 18 years. The conceptualization of forced and early marriage is thus complex, and reliant on individual contexts. Although Article 3 (h) of the United Nations Convention on the Rights of

Persons with Disabilities (UNCRPD) advocates and compels State Parties to observe "*respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities*" (UNCRPD, 2006), very little is known regarding children living with disabilities, where societies often view them as being a curse or a bad omen.

Furthermore, the fact that gender is a key driver to vulnerability to HIV infections is well established in literature. In its preamble (item b), the UNCRPD flags the vulnerabilities and risks that women and girls face both within and outside their homes, and may include gender-based-violence, sexual abuses and exploitation (UNCRPD, 2006). Young girls are particularly at risk, as the available statistics single them out as the ones who were most vulnerable to new HIV infection. For instance, according to UNAIDS globally, 62% of all new HIV infections among adolescents involve girls (UNAIDS, 2016), this number being higher for SSA, where the figure stands at 71%. This could be attributed to the disproportionately higher number of girls in the region (80%) who do not complete secondary education, hence affecting their ability to acquire information to protect themselves and to ensure they access treatment (UNAIDS, 2016). The implication is that, where HIV, disability and poverty existed in the life of an adolescent in particular the female, access to HIV information and services from the formal health system could be limited. Moreover, an episodic (on and off) occurrences of disability that arise from the HIV and the associated anti-retroviral therapy (ART) regimes could open frontiers of new demands to overstretch health care and support systems at the community level.

2.10 Legal and Policy Contexts of SRH and Adolescents with Disabilities

For effective and equitable enjoyment of rights including sexual and reproductive rights by adolescents with disabilities, the country was enjoined into international and regional legal

instruments. The ratification of regional instruments or international treaties has a domestic effect on Kenya's legal system. Section 2 (6) of the Constitution of Kenya states that ―any convention or treaty formalized by Kenya shall constitute section of the legislation of Kenya in that respect therefore, the African Charter on the Rights and Welfare of the Child and the Convention on the Rights of the Child have been completely domesticated in the state through the institution of the Children's Act. The challenge however, remained in the will and effort by the State to faithfully implement and enforce the provisions of the laws to protect all children, including AWDs. Kenya endorsed and ratified the UN Convection on the Rights of PWDs in 2007 and 2008. Additionally, it is a signatory to The Convention on the Rights of the Child (UNCRPD, 2006; Unicef, 1989), and is fully bound to observe the rights of children with disabilities. Regionally, Kenya is a signatory to the African Charter on Human and People's Rights. All these instruments bind Kenya to ensure that the needs and the rights of all children, including AWDs, were met and protected.

Despite SRH being a human rights and development issue, comprehending this for AWDs remained a challenge. Observably, SRH is an essential and among the most contentious and sensitive human rights, as it concerns the wellbeing and health of people, families and society (KNCHR, 2012), including AWDs. Moreover, evidence from Merrick (2007) suggests that approximately a third of the global burden of early mortality and morbidity among females of reproductive age is caused by poor SRH. Consequently, it is important for countries to have sufficient and quality SRH information and services for all people, including AWDs, to have an improved quality of life. SRH rights contain various human rights that were included in international and regional documents and national laws. These include the Convention on the Rights of Persons with Disabilities (2006); the Convention on the Rights of the Child (1989); the Convention on the Elimination of all forms of Discrimination against Women (1979); the Convention on the Elimination of all forms of Racial Discrimination (1966); the International

Covenant on Economic, Social and Cultural Rights (1966); and the Covenant on Civil and Political Rights (1966) among others (Oronje et al., 2011). In most cases however, the challenge lies in enforcing the rights and not so much in the availability of requisite policy or legal instruments.

Kenya is a signatory to several commitments and declarations that assure the right to SRH, including the Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases (2001); the Sustainable Development Goals (SDGs); the Maputo Protocol (2003); the African Charter on the Welfare of the Child (1990) and that of the Human and People's Rights (1981) (Crichton et al., 2008). At the national level, the Kenyan Constitution assures healthcare rights, and emphasizes the significance of prioritizing the needs of marginalized and vulnerable groups in the allocation of healthcare (NCLR, 2010). In addition to the Constitution, Kenya has multiple parliamentary legislations that aim to safeguard and advocate SRH rights for all including AWDs, - Prohibition of Female Genital Mutilation Act 2011, the Children's Act 2001, and the Sexual Offences Act 2003 (Crichton et al., 2008). Despite all the policies and legal instruments, adolescents, especially those with disabilities, remained excluded from actual access to essential services, such as SRH and HIV (KNCHR, 2014; KNCHR, 2012).

Unreinforced Provisions for AWDs

The constitution of Kenya (2010) has several provisions that underpin the fundamental rights and freedoms of AWDs. More specifically, in Part 3, AWDs have a specific application of rights under Article 54 of the constitution of Kenya (CoK, 2010) that were both practical and strategic to their access to basic services such as SRH and HIV. These rights include and not limited to the following:

a) To be treated with dignity and respect and to be addressed and referred to in a manner

that is not demeaning;

b) To access educational institutions and facilities for persons with disabilities that were integrated into society to the extent compatible with the interests of the person;

c) To reasonable access to all places, public transport and information;

d) To use sign language, braille or other appropriate means of communication; and

e) To access materials and devices to overcome constraints arising from the person's disability

The Persons with Disabilities Act, 2003, covers equal opportunities, rehabilitation and rights for AWDs, and mandates the establishment of the National Council for Persons with Disabilities (UNCRPD, 2006;KNCHR, 2014). It is envisaged that such a body would advocate the rights of AWDs to access essential services including SRH and HIV care and treatment. The Social Assistance Act 24 of 2013 provided that AWDs were eligible for social assistance if the disability leaves them incapable of providing for their own basic needs. The Free Primary Education Act, 2003, eliminates all barriers that denied children from accessing education especially those with disabilities and from poor economic backgrounds. This Act was supplemented by The Basic Education Act 14 of 2013, which focuses on the promotion of special needs education. Under this Act, children with special needs were distinguished as including special talented and gifted learners, pupils with multiple disabilities and hearing impaired, as well as emotionally, visually, physically, mentally or intellectually challenged pupils (Bines and Lei, 2011).

Moreover the constitution of Kenya, under the social and economic rights section, guarantees access to the highest standard of health, which includes reproductive healthcare (Article 43.a), and guarantees the right to access emergency medical care, and that the state was to

provide social security for persons who were not able to take care of themselves, or their dependents . With regard to legal representation on any matter including sexual violation, the PWD Act (2003) requires that the Attorney General provided mechanisms for free legal representation of such persons, however, this was not enough to ensure effective legal representation. Individuals with limited financial ability tended to focus more on basic survival, and therefore tend to have limited time and resources to afford lengthy and costly legal proceedings. Although the basic functions were now devolved, there was also a lack of goodwill among public bureaucrats to enforce the mandated legal protection (Khaunya, et al., 2015).

Unsupportive Policy Environment on SRH for Adolescents

Despite the effort by the government of Kenya to create policy environment for SRH and HIV needed for adolescents to access quality services and information, the attempts have remained inadequate especially for AWDs. For instance, in the initial, Kenya adopted the 2005 National Guidelines for the pprovision of youth- friendly services, which highlight critical RH services package for youths (MOH, 2005). The package includes: voluntary counseling and testing and comprehensive post-rape care; screening and treatment of HIV/AIDS and STIs; providing contraceptives; training in life skills and livelihood expertise; counseling as well as providing education and information on SRH. The guideline however, does not expressly prioritize the need for disability friendly services. According to Shaw (2009) an effective policy should address SRH challenges including those of adolescents and disabled youths; socio-economic factors; substance and drug abuse; gender-based violence and female genital mutilation (FGM) and early marriage. Observable, the forgoing is against the backdrop of a similar call by the 2007 RH policy that requires the adolescents to have complete access to youth-friendly SRH services and information; and multi-sectoral approach to address SRH needs for young people (MOH, 2007).

Moreover, the Ministry of Education and Ministry of Public Health and Sanitation (MOPHS) jointly developed the National School Health Policy. Notable, although the policy acknowledges the need to advise students about SRH, and furnish them with suitable skill to avoid sexual violence, disease or unwanted pregnancies (MOE and MOPHS, 2009), it does not clearly address SRH needs of school-going AWDs. Hervish and Clifton (2012) argue that such a policy should approach adolescent pregnancy from a human-rights perspective that recognize young women's right to education during and after pregnancy; and stipulates the allocation of counseling to a pregnant girl and her family to ensure her wellbeing (ibid). Additionally, the government developed the 2010-2012 Reproductive Health Communication Strategy, which recognizes the allocation of universal access to RH services and the provision of sufficient information on SRH as a priority for adolescents to enhance their reproductive health (Beguy and Mberu, 2015).

The Constitution (2010), article 43, prescribes that young people including AWDs should enjoy the right to healthcare, including RH services. Furthermore, various laws, including the Counter Trafficking Persons Act and the 2006 Sexual Offences Act, seek to guard adolescents from sexual abuses, such as rape, defilement and incest, and stipulates tough penalties for offenders (Hindin and Fatusi, 2009).

Policy Environment on SRH for AWDs

Although the government recognizes disability as a significant consideration in national planning, this has not translated much for AWDs. The 2003 Persons with Disabilities Act advocates for representation of AWDs, through the National Council for Persons with Disabilities (NCPWDs), in the execution of health programs under the MOH. Not only does the 2010 Kenyan Constitution (GOK, 2010) provide for rights to health and life for AWDs, but the government also implemented a national policy to eliminate inequality in the

provision of services, and guaranteed that all AWDs should access them (GOK, 2010). The implications never-the-less, in real sense, is that the services are only accessible to a section of individuals with disabilities that are disproportionately distributed among the diverse disabilities groups. Furthermore, there is no evidence that it is available to the effect that the latest ASRH policy framework promulgated in 2015 is meeting the needs of AWDs. This implies that the aambiguities in the policy provisions regarding access to SRH services to children below 18 years remain as bottle-necks to their effective implementation.

2.11 Institutional Arrangements for SRH and AWDs

Statutory Bodies and Agencies

The existence of an agency for disability issues in Kenya - The National Council for Persons with Disabilities (NCPWD) continues to attract its fair share of deficiencies. The government organization was established in 2004 following the passing of the PWD Act 2003, has the responsibility to champion the rights of AWDs and mainstream disability issues in all features of political, economic and socio- cultural development. The Council oversees the implementation of the action plan of the African Decade of PWDs, as well as engaging in awareness raising, administering cash transfer schemes and educational grants, and monitoring and evaluation (KNACPD, 2008). The Ministry of Health is accountable for the allocation of health services and provided specialized services for AWDs, including physiotherapy, occupational therapy and assistive devices through the Division of Rehabilitative Health Services. Nevertheless, access to these services is restricted for poor children with disabilities and those with severe disabilities. Devolved structures from the national to the county levels had an adverse effect with respect to services for AWDs. For instance, disability issues were largely a national government function and not a concurrent one to be shared with county government (GOK, 2010). Therefore, at the county disability was not a priority and disability organizations were inadequately prepared for advocacy and

monitoring (Mwamuye and Nyamu, 2014);

Integrated SRH and HIV Services

In 2009, the Kenyan government implemented the National Reproductive Health and HIV and AIDS Integration Strategy, which aimed at integrating HIV and RH services (Sweeney et al., 2011). The goal of integration was to offer more sustainable, affordable, acceptable, convenient and comprehensive HIV and RH programs at all service-delivery centers. In the same year, the National Condom Policy and Strategy (2009-2014) was implemented, which intended to guarantee that every Kenyan is able to receive correct information on condoms and a consistent supply, irrespective of their social, economic or geographical status (Godia et al., 2014). Furthermore, Kenya adopted the Population Policy for National Development, a new populace and development policy in 2012, in response to the rapid populace increase, which could decrease the momentum of achieving the nation's Vision 2030, as well as present a challenge to economic development (Izugbara and Egesa, 2013). The policy aims to attain a high quality of life for citizens by using the available resources to address population growth in a sustainable manner.

Although the MOH has the responsibility of coordinating and managing adolescent sexual and reproductive health (ASRH), gaps still abound in service provision courtesy of existing national strategies and policies. Moreover, the policy environment for the provision of SRH information and services to AWDs in Kenya is still limited, thereby working against the overall population health gains being sought (KMNCAH-MOH, 2016;MOH, 2013). Despite efforts to ensure collaboration is achieved among stakeholders, the process is further complicated since ASRH is provided through a devolved health system across various tiers: Community Health Services (tier 1), Primary Care Services (tier 2) and County Referral Services (tier 3) (MOH, 2015).

Inadequate AWDs-friendly Services

Despite its commitment to the Cairo Programme of Action, the Kenyan government policy to enhance adolescents' access to information and SRH services for all is yet to be fully implemented for the benefit of AWDs (KMNCAH-MOH, 2016; KNCHR, 2012; KNCHR, 2014). Furthermore, the government has not incorporated young people as a special category in service delivery which would in essence lead to the establishment of reproductive health facilities for them (Speizer et al., 2003). The government response, programmes and interventions were therefore perceived to be precipitated by emerging public health issues, such as HIV, and not solely due to the need to address the SRH needs of adolescents (Dick et al., 2006). To strongly demonstrate this would require evidence on unmet SRH and HIV needs for all adolescents, including AWDs. Apart from the support groups for adolescents, other actors, such as government and NGOs, need to participate in interventions that relate to issuing condoms, providing antiretroviral drugs to prevent perinatal HIV infection, providing antiretroviral therapy (ART) and undertaking voluntary medical male circumcision in areas of high HIV prevalence and low circumcision settings (Idele et al., 2014) that target AWDs.

Lack of Baseline Data on ASRH

The unavailability of baseline data on the ASRH status of adolescents with disabilities, and the extent of their health needs, requires an effective legal and policy framework (Pfeiffer et al., 2010). The existing evidence on the factors and outcomes of adolescent pregnancies is not comprehensive, making it strenuous to design and adapt programs for diverse youths (Idele et al., 2014). Therefore, the utility of current evidence, including systematic reviews that endorse interventions for enhancing ASRH results, has been limited (KNCHR, 2012;KNCHR, 2014). Similarly, the implication is that the development of programs and formulation of policies on adolescents SRH requires up-to-date information concerning situation of adolescent sexual behaviors and activity to be availed, especially information

regarding AWDs.

Poor Access to HIV testing and treatment

Despite evidence that effective treatment of HIV started with knowing that one was positive, followed by counselling, majority of adolescents in many countries did not know their HIV status (Idele et al., 2014). For instance, in Kenya There was overwhelming evidence that testing is the gateway to accessing treatment and care, yet this opportunity has been missed by many young people oblivious of the need to test, therefore posing a potent threat of new infections and negative outcomes among adolescents with disabilities (NACC, 2016).

There is no age-disaggregated data on the availability and uptake of ART among adolescents, especially those with disabilities (NACC, 2016). Over the years, increased HIV-related deaths among adolescents has raised the alarm over the low coverage of ART, while at a secondary level, adherence to treatment and retention remains poor (Idele et al., 2014). The latest HIV treatment guidelines now require that those diagnosed with HIV infection adhere to treatment (MOH, 2016). Under the new guidelines, anybody testing positive is immediately started on ART, although this would still require effective psychosocial support, including AWD to adhere to the treatment.

Lack of Psycho-social Support

Among the challenges that adolescents faced during transition phase of their life into adulthood were psychosocial changes. Reactions could be positive or negative, depending on the support structures available and whether or not they belonged to support groups that helped them navigate through the challenges. Studies had shown that the biological and psychosocial changes they experienced make adolescents, especially girls, vulnerable to HIV infection, and that early sex debut multiplies the risk of new infection (Idele et al., 2014). The implications of poor conceptualization of sexuality and SRH for young people, especially

AWDs, that lead to serious health consequences. Furthermore, adolescence was a period in which a transition took place from childhood to adulthood, and involved various transformations, such as physical, cognitive, emotional and social changes. Healthy adolescents need SRH services, especially when they were living with HIV/AIDS.

CHAPTER THREE

METHODOLOGY OF THE STUDY

3.1 Introduction

This chapter outlines the research approach and process, which adopted a descriptive qualitative design. The design involved an embedded single case approach in collecting, analysing and triangulating descriptive qualitative data from varying sources relevant to the study objectives. The approach to this study is influenced by the conceptualization of the phenomena from literature review and the professional background of this researcher in community health and development in the context of systems theory as applied in the health systems building blocks and bio-socio-ecological models. For instance, data collection was done by reviewing patient records (soft and physical sources); conducting focus group discussions with community health volunteers, community members living with disabilities and Sub-County Health Management Teams (SCHMTs); in-depth interviews with adolescents with disabilities (AWDs), their guardians/parents; observations and case narrations from critical cases with unique experiences. Siaya County was selected due to the poor health indicators, including HIV/AIDS, compared to other regions in Kenya (NACC, 2016). To ensure robustness and an adequate level of rigor, the study included a number of embedded sub-county-based units of analysis: Alego Usonga, Bondo and Ugenya subsystems, which host varied community-based health organizations, the community based health care programs (CBHC), Community Health Units (CHUs) and individual AWDs. Moreover, the study included collecting and analysing data from the 3 courts of law in the county on SGBV against children especially AWDs. This chapter outlines the methods used to address the study objectives, as indicated in Table 3.1 below.

Table 3.1 Objectives, methods and data sources

Objectives		Methods	Data source
1	To describe the county health system contexts of SRH and HIV service delivery for AWDs.	a. in-depth interviews c. document review e. Checklist	i. Health records, policy, plans ii. Health facility master list, iii. SCHMTs, iv. Health providers v. CHVs, caregivers, CHC CHAs vi. Disabled Persons organizations (DPOs) vii. county officials viii. Facility service area PWDs
2	To assess the functionality of selected community health models in SRH and HIV services	a.in-depth interviews c. document reviews d. observation	i. Project reports/records/plans iv. CBHC providers iii. SCHMT, County health, planning/finance officers vi. DPOs officials AWDs/parents/guardians PWDs
3	To explore experiences of AWDs with respect to their access to SRH and HIV services in the community.	a.in-depth interviews, b. FGD	i. AWDs, (18 and 19 years) ii. parents/guardians of (AWDs 10-17years), CHVs,
4	To determine opportunities in	a.in-depth interviews b. FGD	i. Senior staff of CBHC providers ii. Project documents

CBHC programs for the sustainable delivery of SRH and HIV services for AWDs	f. field notes

3.2 Study Design

Qualitative research is inquiry aimed at describing and clarifying human experience as it appears in people's lives. Researchers using qualitative methods gather data that serve as evidence for their distilled descriptions. Qualitative data were gathered primarily in the form of spoken or written language rather than in the form of numbers. Possible data sources were interviews with participants, observations, documents, and artifacts. The data were usually transformed into written text for analytic use. Selection of interview participants required purposive and iterative strategies. Production of interview data requires awareness of the complexity of self-reports and the relation between experience and language expression (Polkinghorne, 2005).

The above extract from Polkinghorne aptly summarizes the qualitative research paradigm upon which this study is premised. The descriptive qualitative design used embedded single case methodology that employed multiple methods to collect and analyse qualitative data towards the objective of this study. A qualitative case study research is an investigation and analysis of a single or collective case in order to capture the complexity of a phenomenon (Stake, 1995; Stake et al., 1998; Polkinghorne, 2005). The phenomenon under study involves people and social behaviours that were complex and unpredictable, which therefore requires subjective understanding rather than objective explanations, as in the natural sciences (Green and Thorogood, 2013). This study took a descriptive approach (Green and

Thorogood, 2013) and a qualitative single case-study design (Yin, 2014) with embedded units of analysis to assess the capacity and appropriateness of CBHC programmes in Siaya County, Kenya. The assessment is with respect to access to comprehensive community-based sexual, reproductive health and HIV care by adolescents with disabilities. The descriptive qualitative approach therefore provided the best paradigm for this study. Case-study research was merited with a degree of flexibility that is not common to other qualitative approaches, such as grounded theory or phenomenology (Hyett et al., 2014; Merriam, 2009; Stake, 1995).

Yin recommends embedded single-case study designs for researches such as this, the design being a bridge between less robust holistic single-case designs and the more rigorous, but resource demanding, multiple-case design (Yin, 2014). The embedded case design benefits from multiple units of analysis within a case to compensate for the lack of stability and slippage-from-course that characterize a holistic single-case design (Yin, 2014). The researcher is however aware of the pitfalls inherent in the embedded design. As Yin noted, there is a propensity to fail to return to the larger unit of analysis after focussing on the sub-unit (Yin, 2014).

Although in Kenya healthcare service delivery is devolved to the 47 counties, there is paucity of data on how the services were currently reaching vulnerable groups like the adolescents with disabilities (AWDs). According to the Fourth Schedule Part II of the constitution of Kenya 2010, county governments were charged with the responsibility of providing health services, including ASRH and HIV/AIDS services in their jurisdictions to all citizens in need (CoK, 2010). Meanwhile, the national government retained the responsibility for policy development, training, capacity building, and monitoring and evaluation (CoK, 2010). In the wake of this new constitutional arrangement, the country was formerly aligning public, private and community health systems under one system, but with jurisdiction at different

levels and packages of service delivery. These systems have in the past operated separately with less impact at the community level since each was thinly spread across expansive areas with fewer resources for adequate health services reach or coverage putting primary health care dream in jeopardy (MOH, 2007).

Moreover the effort towards the revitalization of primary health care (PHC) that adopted a new approach to comprehensive PHC delivery in Kenya, known as community health strategy (CS) aimed to achieve universal access to healthcare, remains for exploration. The strategy defines the structure and expected functions of the community-based health services in a given county that is further divided to function within sub-county systems.

For this study therefore, Siaya County health system was purposively selected, as the study largely focused on the embedded units of analysis that emanate from sub-county (Alego Usonga, Bondo, Gem, Rarieda, Ugenya and Ugunja) levels, where CBHC programs were supposed to operate via a community health strategy approach (as a sub-systems) to level one health service delivery. In this study that delves in an understudied phenomenon, therefore, the exploration access and utilization of ASRH and HIV services by adolescents with disabilities formed the basis for the assessment (output and outcome side of the systems equation).

3.3 Study Area

Siaya County, the study area, is along the equator in Western Kenya, and lies in the basin of Lake Victoria, approximately 400 km west of Nairobi. As indicated in the County Integrated Development Plan (CIDP), the framework for development in Siaya County for the period 2013-2017, the county is bordered by Busia County to the North, Vihiga and Kakamega Counties to the North-East, Kisumu County to the South-East and Homabay County across the Winam Gulf to the South. It lies between Latitude O026‘South to O018’ North and from

Longitude 33058'East to 34033'East' (County Government of Siaya, 2013). The land is mainly grassland with good rainfall and is of medium agricultural potential.

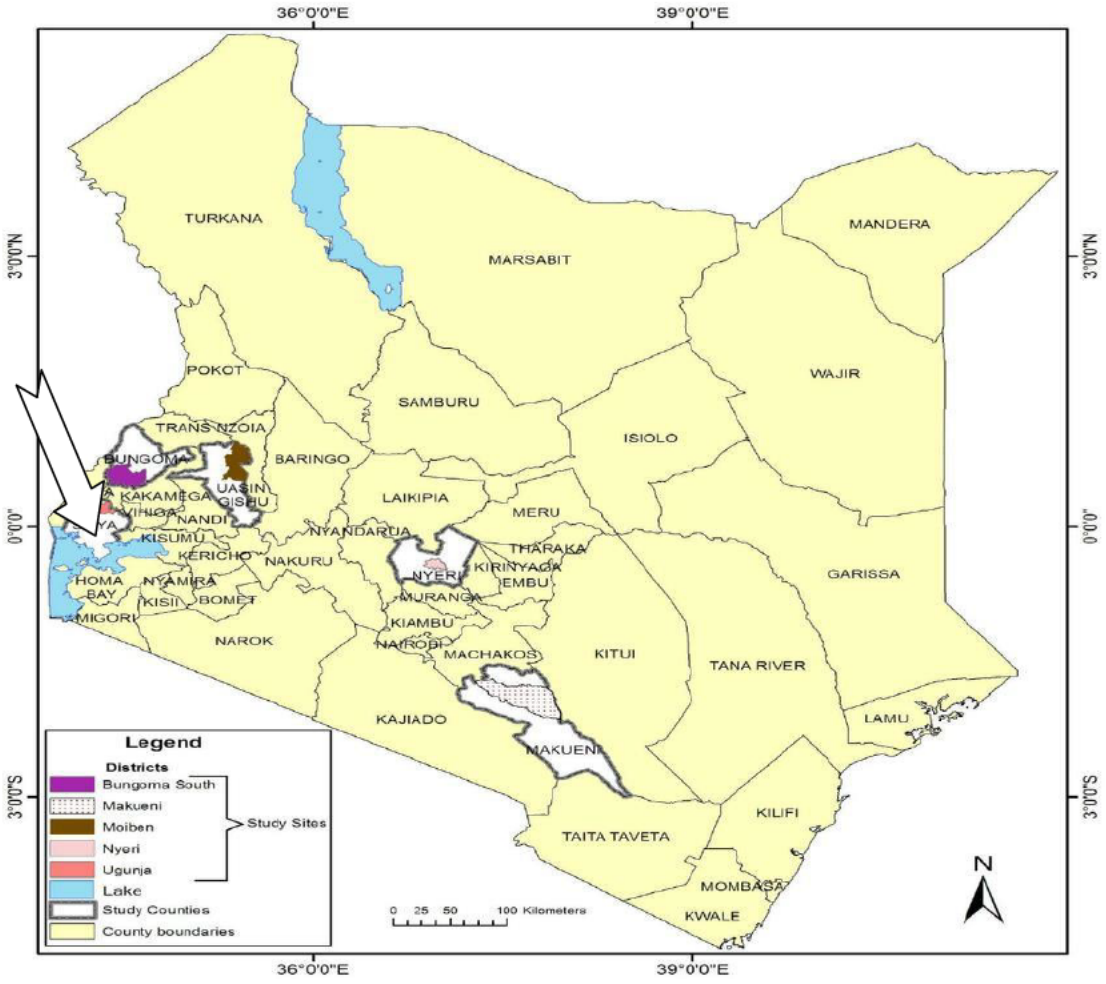


Figure 3.1: Location of the study area

The socio-economic activities of the county comprise mainly of subsistence agriculture or petty trading, which occupy 80% of the population. Many people depend on fishing, rice farming, small-scale trading and engage in subsistence farming, according to Kenya Demographic and Health Survey KDHS 2008-2009 (Demographic, 2010), many of these activities not being suitable for persons with disabilities. Furthermore, according to Siaya County Integrated Development Plan CIDP-2013-2017 (GOK, 2013), due to persistent development challenges, close to 40% of the total population live below the poverty line.

The county faces numerous development challenges that include inadequate infrastructure, water shortages, erratic electricity supply, high prevalence of HIV/ AIDS and high unemployment rates (CIDP 2013-2017). In such a context, marginalised groups, such as AWD, were likely to be disadvantaged due to the intersectionality of these challenges with their already vulnerable situation of being disabled and adolescents at the same time.

According to the Kenya National Bureau of statistics (KNBS) (2013), only 16% of Siaya County residents have a secondary level of education or above, with 64% having a primary school level of education, and 20% with no formal education. The county education department is implementing integrated or inclusive school programs that bring together non-disabled children and those with special needs to learn under the same setting. However, there were a number of special schools in the county offering institutional care, especially for extreme cases of disabilities. These include St. Ordour-Aluor Mission School for the Blind in Gem sub-county, Nyamira and Nyangoma Schools for the Deaf in Bondo Sub-county.

Development and prosperity for Siaya County is contingent upon the health of its population, with the county having set to achieve "the highest possible health standards in a manner responsive to the population needs" (CIDP, 2013-2017). According to the county government, the approach is not only to expand existing curative services, but also to reorient the health system from curative health care to preventive and promotive health care (CIDP, 2013-2017). It is also encouraging that the county's health infrastructure was rapidly growing, courtesy of the increasing devolved funds from the Constituency Development Fund (CDF), Local Authority Trust Fund (LATF) as well as other funds, such as the from Economic Stimulus Program (ESP). Despite these efforts, however, there is a gap in health infrastructure development specifically associated with young people, in particular those with disabilities, in the design and approach to health care access and utilization. Incentives to

invest in expensive curative health infrastructure and services remains more attractive to both national and county decision makers at the expense of affordable, acceptable and appropriate packages of care, as prescribed in the KEPH (2006).

According to the CIDP 2013-2017, there were 149 health facilities in Siaya County including 120 that were public facilities (80 % of total facilities), the rest belonged to private providers (for profit and non-profit). The public health facilities consisted of one county referral hospital, six sub-county hospitals and 113 primary care facilities (levels 2 & 3). At the lowest level there were some 187 Community Health Units (CHUs) were also reported to provide community health services in the county, although in the overall, the county health system faces various challenges in delivering and promoting its services, ranging from identifying, linkages to care, retention and HIV viral suppression.

3.4 Theoretical Framework: Systems Theory

While a number of theoretical models existed that could be used to direct the study, two complimentary systems theory models were used in this study. The World health Organization's health systems building block and socio-bio-ecological model for human development (Bronfenbrenner and Morris, 2007) were found to be most relevant to frame the data collection, analysis and interpretation. The study had aimed to generate evidence to inform policy, programming and further research agendas towards improved systems of delivery and utilization of SRH services for adolescents with disabilities (AWDs) in Kenya. This sub-section therefore details systems theory: origins, development and application in health; Bronfenbrenner's bio-ecological model, challenges in the application of systems theory, and propositions of the study.

(i) Systems Theory: Origins, Development and Application in Health

This study related to health systems and their efficacy to deliver healthcare to the most

vulnerable sections of the population in particular, adolescents with disabilities. This section therefore reviewed the origin and evolution of systems theory in its varying models and contexts, to inform the rationale of choosing it in this study. In this study the concept of systems thinking and systems theory were used interchangeably. The concept originated in the early 20th century in the fields of engineering, ecology and economics. Ludwig von Bertalanffy, a biologist by profession, was one of the early scholars to delve into the subject of systems thinking. He devised the concept of *open systems theory* in order to explain the organismic conception of biology: an organism was a system made up of different parts and processes that were organized to form a whole (Drack, 2015). However, Bertalanffy's greatest contribution came towards the end of the 1930s with ideas initiated on *General Systems Theory,* which reinforced the fact that systems thinking could not be confined to one field, but was rather open to application in many disciplines, including health (Flood, 2002). Systems theory enables connections to be made between functionally differentiated parts to bring about integration at a higher level of functionality. General systems theory therefore tried to provide a framework that united the various disciplinary applications under a set of universal principles, models and laws that could be applied to all systems in general (Lv, 1968). This implied that ssystems thinking was to be applied to a system that was goal-oriented and with means of verification that ensured fidelity. Moreover, it also meant that unless there was a clear purpose for the system, systems thinking would be ineffective in achieving a predicted result.

Consequently, a system test was a prerequisite to a 'systems thinking' definition (Arnold and Wade, 2015). Accordingly, the test needed to determine the existence of three components, namely: a purpose, elements (these entail characteristics of systems thinking) and interconnections (Arnold and Wade, 2015). Moreover, systems thinking must contain a consideration for long-term planning, feedback loops, non-linear relationships between

variables, and collaborative planning across areas of an organization (Kopainsky, et al., 2011). Therefore, a system took different forms, depending on a number of factors including being either open or closed, simple or complex (Cordon, 2013).

Noteworthy, every organization including the health system was faced with problems that arise from an environment that constantly bred threats as well as opportunities (Ackoff, 2001). Health systems were not insulated from the environment in which they operate, their adaptive capacity being constantly tested, with the pressures which in the case of this study would include dominant cultural beliefs about access to sexual and reproductive health services by adolescents with disabilities (AWDs). According to Meadows, a system is largely responsible for its own behaviours, independent of external conditions. She notes that an outside event might provoke the behavior of a system, but that the same outside influence applied to a different system produced entirely different behavior patterns (Meadows and Wright, 2008). This has the implication that systems were themselves responsible and capable of responding to external influences in a manner that either promotes the integrity of the system or diminishes it. For instance, community- based healthcare systems may be affected by resistance from the policy, cultural or even economic dimension of provision of care to adolescents with disabilities (AWDs). Moreover, the varying components of the community health system, which include subsystems such as: human resources for health, financing and leadership, delivery mechanisms, including health information management, remain relevant to this study.

The study entailed interrogating each subsystem and their impact on the whole system in the delivery of SRH for AWD. Furthermore, in the study the AWDs is equally viewed as system with its components, including belief systems, age group and gender considerations, which were of interest to this study. Each system was unique in their own way and had the option to

either cope with or ignore situational changes and live with the consequences including extinction. Moreover, from Bronfenbrenner's model that the study has adapted, varying contexts of the AWDs environment constitute sub-systems (family, community, institutions and the society) with which the AWDs interacts directly or indirectly to access care needs for growth and development (Bronfenbrenner, 2005; Bronfenbrenner and Morris, 2007). For this study the care needs for the AWDs included access to basic healthcare in particular, sexual and reproductive health; and HIV services through community-based systems.

However, systems thinking is not without criticisms. One of the biggest critics of Systems Thinking, Jay Forrester, argue that 'systems thinking' had no clear definition or usage, and that where it was used, it merely implies system dynamics. Furthermore, he argues that the term had evolved to only refer to a superficial understanding of what a system was, and that perhaps it was used only in acknowledging the importance of a system (Forrester, 1994). He further argued that system dynamic was more appropriate for understanding situations in the real world and how to deal with them. Despite the fact that Forrester was using the term differently than it was intended by scholars such as Senge and others, he raised a crucial argument in terms of prompting the need for a clearer understanding of systems thinking as a concept (Arnold and Wade, 2015).

(ii) WHO Health System's Building blocks model

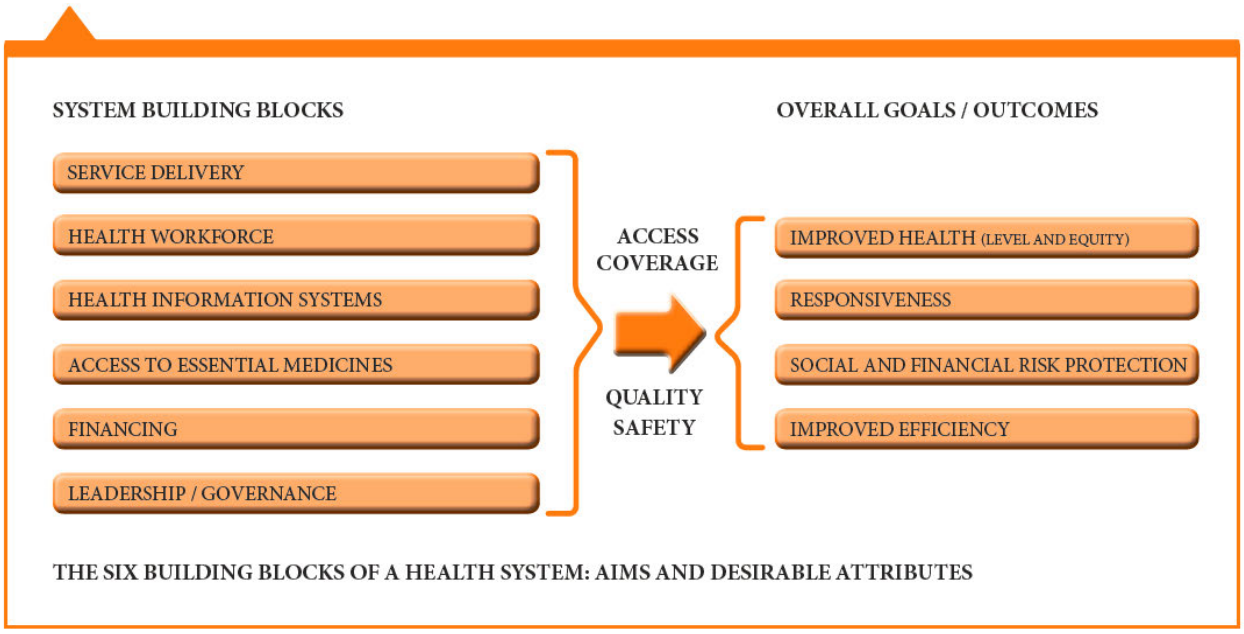
Despite the improvements in medical technology and the advancement in healthcare across the globe, access to health services that were responsive to the needs of marginalised communities like adolescents with disabilities (AWDs) had remained elusive. Available literature suggested that such services were often inaccessible, unaffordable, and unavailable; or where they were found, they are of poor quality (WHO, n.d.). In the year 2007, the World Health Organization published a health system building block framework with the aim of promoting a common understanding of what a health system is and what constitute health

systems strengthening (Department of Global Health, London School of Hygiene, 2014). A health system is conceptualised as consisting of six blocks: service delivery, health workforce, information, medical products, vaccines and technologies, financing, leadership and governance, as well as process elements (access, coverage, quality and safety) and outcomes (WHO, 2007).

Although the six building blocks that stand out as the pillars required in meeting the health care needs of the people being served, experiences with the building blocks seem to vary. Research suggested that Health systems around the world differ because of the different contexts in which they find themselves, therefore the amount of resources they were able to deploy towards projects and programmes and the values and principles that underlie the systems also vary (Sida, 2016).

In the 1978 Declaration of Alma Ata[i], countries of the world acknowledged that the primary healthcare approach was the most appropriate for the prevailing world order since it would ensure that services were taken as close to the people who need them as possible by ensuring proximity to people's residences and places of work (WHO, 1978). A properly functioning health system had good indicators for maternal mortality (low maternal mortality being the ideal) while a weak system were characterized by poor indicators maternal mortality (high maternal mortality) as well as high dependence on humanitarian support to deal with health-related issues (Sida, 2016). According to USAID, (2015), a well-performing health system should achieve lasting population health improvement through synergistic health system functions of human resources for health; health finance; health governance; health information; medical products, vaccines, and technologies; and service delivery (USAID, 2015).

Figure 3.2: Health Systems building blocks



Source: Monitoring the building blocks of health systems: : A handbook of indicators and their measurement strategies.

Ultimately, the implication is that the goal of strengthening the health systems building blocks was to ensure that no one is left behind in terms of their expectation from the healthcare industry; and this resulted in a universal healthcare coverage. A robust health system also provided functional linkages with the communities which it served and learned from the past, adapted to the present and changed for the better (MSH, 2015). Moreover, according to the WHO (2010), weak health systems bred chaos that led to further weakening of the system. In Africa for example, outbreaks such as Ebola and other infectious diseases; and Malaria, HIV/ AIDS and Tuberculosis occurred and were difficult to tackle due to weak health systems (WHO, 2010), that got overwhelmed by the demand from the outbreaks..

(ii) Bronfenbrenner's Bio-ecological Model

While this study focuses more on the recent version of Bronfenbrenner Urie's bio-ecological models, a little background of the model is essential to appreciate the development of the

theory. The model had stated that a child, the environment in which they exist and the relationship between the two can be understood in a broad sense as systems and sub-systems within systems (Bronfenbrenner, 1975). Moreover, according to the ecological model, children developed in a constantly evolving environment which begins with the most intimate relationships that extend outwards into other dimensions of the wider world. It therefore emphasized a multi-dimensional study of a child‘s environment in order to understand their growth and development process (Bronfenbrenner, 1975).

Bronfenbrenner observed that while there were obvious differences between the well-being of children based on the economic status of their families, the social conditions that prevailed in the face of urbanization also played a key role when their well-being is considered over a long period of time (Bronfenbrenner, 1975), which also applies to children in a rural context. Having realized that aspect of human development had been ignored, Bronfenbrenner further emphasized the aspect of context. He theorized that the environment is made up of multiple layers, and in the prevailing societal contextual circumstances, each layer plays a part in the growth and development of a child. It is at this point that the ecological model changed to the bio-ecological model (Tudge et al., 2009). He went on to define the ecology of human development as:

> "*The ecology of human development involves the scientific study of the progressive, mutual accommodation between an active growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these setting, and by the larger contexts in which the settings are embedded*" (Bronfenbrenner, 1979)

Bronfenbrenner's embedded contexts include five layers that contribute to AWDs' growth and development process, as outlined in his theory:

1) Microsystems (Individual) level: is made up of the immediate environment in which a child lives and interacts with, such as home, school, church, care givers or peer groups. The interaction between the AWDs and the elements in this environment therefore make a contribution either positively or negatively to their growth and development process as well as to their access to health services, including sexual and reproductive health services;
2) Mesosystems (relationships) level: this involved the interaction of elements in the microsystem. For instance, the interaction between the AWDs' parents and teachers in schools also contributed to the process of growth and development of a child. These also involved factors related to family ability to sustain the AWDs in school, peer discrimination and social stigma from neighbours;
3) Exosystems (Community) level: involves factors that affect the performance or functionality of the microsystem elements, which in turn affect AWDs growth and development process indirectly. When a parent has a promotion at work or loses their jobs, the child would either join a good school or drop out of school. The factors that this study considered here included parental social networks including participation in disability welfare groups, nature of employment or business interactions in the marketplaces and how these could affect care.
4) Macrosystems (Societal) level: this involves factors outside the microsystem, such as polices, political stability or economic performance, which affects the growth and development process of a child. In this study, factors such as the community concepts and beliefs about disability, religious foundation of the family and the caregivers, adolescent sexuality and reproduction; health system, institutional arrangements including justice systems; health policies, education, social protection policies with respect to access to sexual and reproductive health services by AWDs were analysed.

5) Chronosystems (Times/maturation) level: this involved the changes of the child's characteristics and their environment over time (Bronfenbrenner, 1979). Bronfenbrenner acknowledged that development was an on-going process that takes a lifetime, and its relevance therefore extended beyond infants and youth

This ecological theory was later demystified by explaining the processes of human development within it. Apart from the aspect highlighting the context, Bronfenbrenner clarified that individual characteristics and time had to be considered in describing human behavior under the ecological model (Tudge, 2016). Moreover, while making the change, the most significant addition was the inclusion of the proximal processes (including parenting practices) and how different personality types influenced them (Tudge, 2016). Proximal (support from the parents on sexuality issues) and distant (policies regarding access to SRH services by AWDs) in this study refers to influences on AWDs' behaviour and barriers to health services (Bronfenbrenner, 1998; (Ashiabi and O'Neal, 2015). Thus, it became clearer as the model envisioned proximal and distal processes that affect AWDs in the form of historical, organizational, political, and relational and policy contexts.

Furthermore, a review of the model noted that culture should not be treated as separate from the individual, as it was part of human activity (Vélez-Agosto et al., 2017), and suggested that culture must be considered in the individual level and not at the societal level (ibid). The view of this researcher from experience however was that, cculture fitted at different levels, including societal level where it exerted considerable influence on other systems beyond the individual domain, hence its macro-ness. Such influence therefore determined, for example, how sensitive services such as adolescent sexual and reproductive health, were delivered to AWDs, irrespective of their own views.

Conversely, Velez-Agosto et.al (2017) could be relevant, particularly with respect to sub-cultures, such as the consideration of youth culture that could only be contextualized to given peer groups. The individual in the target group, or in this study of AWDs, could espouse own culture that was dominant among peers about sexuality, irrespective of obtaining societal cultural imperatives. This implies that the location of culture in the model would depend on axiological orientation of individual researchers, particularly in respect of emotive phenomenon such as SRH and AWDs. Their ways of thinking and reasoning could have been shaped by experiences they had accumulated from learning and understanding varying moral concepts.

Thus, Bronfenbrenner's bio-ecological theory remains relevant to this study, which sought to analyze the multi-dimensionality of access to and utilization of SRH and HIV services by AWDs for their balanced growth and development. The interaction of AWD with the environment, and the quality of those interactions, would presumably determine whether or not they would access essential elements of life, including health services such as SRH and HIV care. As there were other dynamics that were considered to affected access to SRH and HIV services that emanated as related to the demand side of the health system (the person side), a second model was needed to bring out the perspective of patients and communities that were targeted by healthcare systems. For this reason, this review also considered the bio-ecological model and used it to explain the individual linked interactions at various systems levels.

(iii) Challenges in the Application of Systems Theory

In applying systems theory, several challenges arise, the main one being the difficulty that arises from aligning policies and priorities among stakeholders. According to De Savigny and Adam (2009), health system stewards in developing countries want primarily to strengthen

health system, while donors bring in money and want their interventions to achieve quick and measurable results. An effective health system is one that takes cognizance of both the demand and supply side when designing interventions (Bartlett, et al., 2016). Moreover, systems do not operate in a vacuum; this was especially so since politics, culture, socio-economic and technological influences abound in the environment in which the systems have to operate.

(iv) Relevance of Systems Theory to the Study

This study was about health systems and their efficacy to deliver healthcare to the most vulnerable sections of the population particularly, adolescents with disabilities. Systems theory in the context of healthcare is used to understand complex problems in the course of delivering these health services. Engaging with systems theory has formed the basis for reviewing service delivery for health as one of the frameworks applicable for this study. In addition, the theory is used to guide how to frame the issues affecting adolescents with disabilities, based on their experiences of health services, especially sexual and reproductive health and HIV/ AIDS services.

(v) Propositions of the Study

To keep the study focused on the researcher's propositions with regard to this study, the following were considered:

1. The current state of community-based healthcare in Siaya County with respect to structures, functionality, social determinants of health, level one service delivery and acceptability. These aspects have the potential to greatly influence SRH and HIV care delivery for AWDs;
2. Community Health Services in the county were not adapted to the minimum package for SRH and HIV integrated services to take care of the needs of AWDs;

3. The state of financing, socio-economic status, cultural norms and service delivery mechanisms were the main barriers to access and utilization of care services by AWDs at the community level; and

4. Although currently there were many gaps and challenges facing CBHC systems, there were opportunities to enable them to deliver ASRH and HIV integrated services that were more adolescent and disability-friendly, as well as adequate, reliable and acceptable.

(vi) Conclusion

Objective		**Component of systems model the objective relates to**
1	To describe the county health system contexts of SRH and HIV service delivery for AWDs.	Macro-system upwards
2	To assess the functionality of selected community health models in SRH and HIV services.	Meso to Macro-system
3	To explore experiences of AWDs with respect to access to SRH and HIV services in the community	All 5 levels
4	To determine opportunities in CBHC programs for the sustainable delivery of SRH and HIV services for AWDs.	Chronosystem

***The adapted conceptual Framework*:**

The research situated in ecological systems theory (Figure 1.2) and health systems model elucidates insights on how adolescents with disabilities interact with SRH and HIV services in different settings of community-based approaches. It also deals with how the approaches were influenced by general disposition of the county health system or other contextual

systems. In addition, it also investigates how socio- economic and political factors such as SRH and HIV policies, legislation on disabilities, children's rights, SRHR and funding affect the overall experience that AWDs in the study area have in relation to having their needs met.

SOCIO- ECOLOGICAL MODEL (SEM)

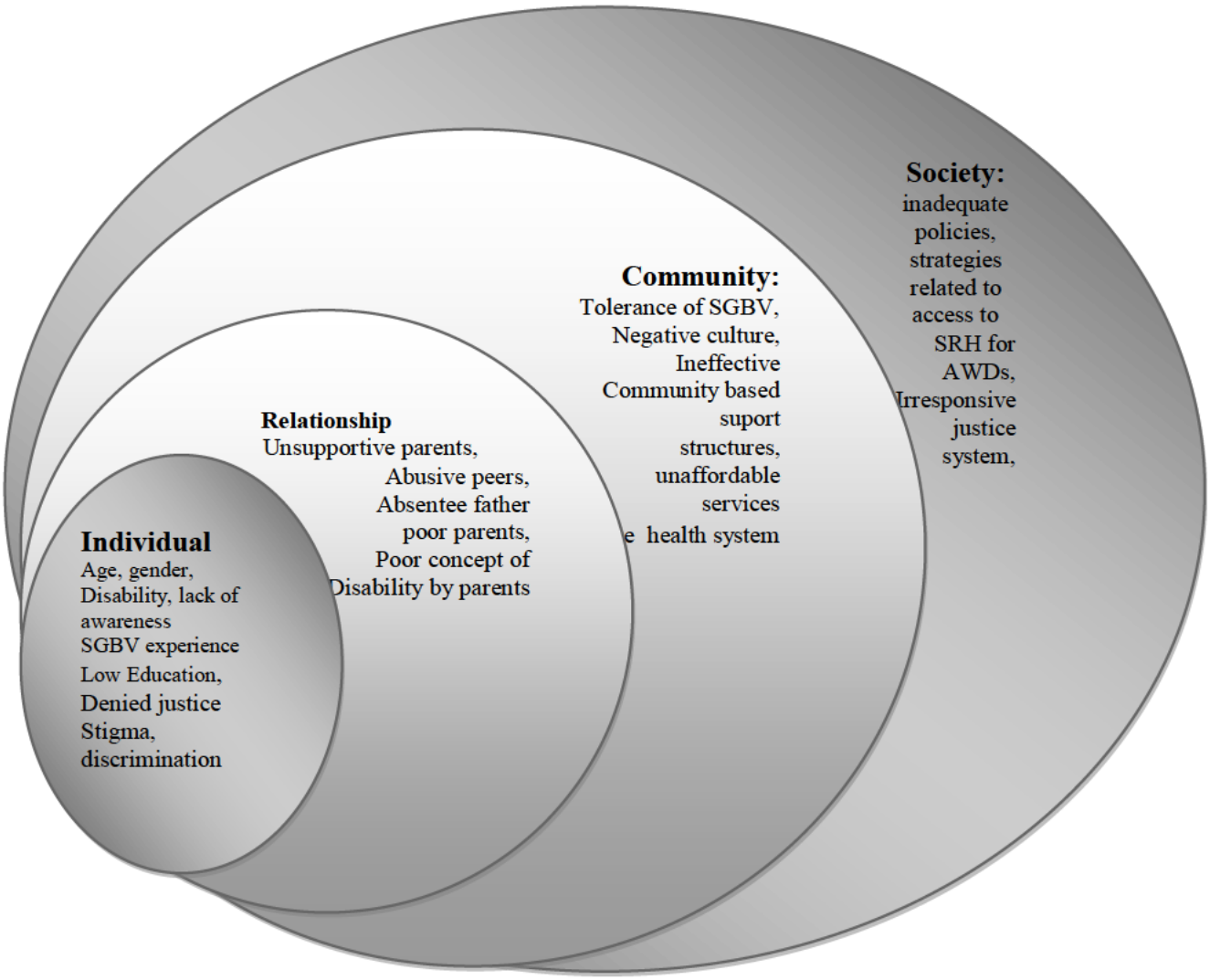


Figure 3.3: Socio-bio-ecological model

Adapted SEM by the researcher from Bronfenbrenner's (2006)

Furthermore, the realization was that adolescents with disabilities were in constant interaction with their specific settings, whether negative or positive. Such settings and the influences

they have may sometimes be induced by self or by others whether deliberately or not, given the nature of disability, age, education level, parenting experience and disability onset. For instance, lack of access to SRH services by young adolescents was likely to be as a result of delayed milestone in development with attendant delayed SRH experiences. Others would however be hypersexual in orientation as was observed with the mentally handicapped adolescents. Others still, would be introduced to SRH need through coercion/ defilement (SGBV) that then makes interaction with the health system inevitable. The services thus sought were those that were triggered by need for addressing a risk situation that has already occurred. Given the foregoing, three main situations were identified:

1. Forced interaction (SGBV) whereby the AWDs were sexually violated against their will and consent;
2. Agency pragmatism (precaution) where the AWDs were protected against imagined and real consequences of violation and shame associated with disability. Parents or guardians negotiate on behalf of the AWDs on matters sex and reproductive health; and
3. Consensual autonomy: The AWDs can make their own decisions without interference from anyone.

These settings depict the unique nature of interactions that determine access and utilization of SRH and HIV services by adolescents with disabilities in Siaya County. Further, the study aligns with Bronfenbrenner's theoretical perspective of the ecological system theory that showed concentric ecological layout of the various domains that come into force in conceptualizing the ASRH issues being discussed. The contention against Bronfenbrenner's model in this case is analyzed using networked view offered by Nancy Darling (2007). Her perspective provided a distinction of sub systems or other systems in the wide environment (ecology) to render for interaction. In this case the research revealed that although aspects

such as legal systems, defilement of children and health systems appeared within the ecological domain of the adolescents with disabilities this layout could not place them concentrically as nested in the ecology. Their autonomy (constituting AWDs as systems) influences the nature of their interactions with other systems, thereby warranting separate consideration. The nested or networked debate moreover revealed potential weaknesses in Bronfenbrenner's (1979) original work which had not considered the role of the individual child. Nonetheless, Bronfenbrenner's (2006) subsequent theory update, now christened "bio-ecological systems theory" actively centralizes the child themselves as an influence as much as he or she is influenced by the environment (active interaction). The latest version that emphasizes Person-Process-Context-Time (PPCT) Model is thus applied to help understand the interactions and their implications for access to care by AWDs.

To put PPCT model into context, the argument is that personal attributes greatly mediated proximal processes that included family care and parental monitoring of AWDs. The age, gender of the child, their disability, their growth and development and personality were found to influence their parental relationship and vice versa. The interaction of mothers and their adolescent sons was found to be driven by shamed and restricted outflow of affection and disclosures. This was mainly with respect to sexual overtures that drive the larger part of adolescent development. Understandably the mental age and physical milestones become a difficult balance for mothers hence were torn in between overreacting and giving up altogether (either of which may not solve the problem they face). Bronfenbrenner's time value for optimal child development cannot be underrated. Under chronosystem, time sequences were critical for our appreciation of the historical development of adolescent outcomes with respect to access or utilization of SRH & HIV services. Here the historicity of events in the life of adolescents with disabilities constitutes the bulk of life experiences some of which determine the individual's propensity to engage or not to. Longitudinally, as the

adolescent grows his/ her needs also become more complex. This should include the onsets of disability and adolescent outcomes in terms of dealing with stigma and poor self-image that may affect self-esteem to cause formidable barriers to reasonable social participation. For instance, it would be noticed that those who were born with disabilities faced more rejection from the communities than those who acquired the condition after birth. Somehow the onset of impairment could be explained in the latter group as opposed to the former whose plight was left for speculations and misconceptions.

For children acquiring disabilities after they were born, there seems to be general societal grace and sympathy to the affected family. Somehow, this was perceived to ameliorate care for such AWDs as everyone, beyond their immediate family, would want to help towards a restored status. Conversely, individuals whose disabilities predated birth, together with their families faced isolation and victimization. As this study revealed, such children were immediately rejected by their own parents especially the fathers who then chose either to abandon the family or eject the mother and the child away from their home. The belief is that the child would bring bad omen to his family arguing that in the lineage of the child's mother, an abominable act might have occurred between close relatives.

Siaya County has several young people of diverse disabilities across varied age groups and unique experiences. Individuals and groups living with disability were selected to share their experiences and to contribute information regarding the situation of disability generally and with respect to access to social services such as education, health care and participation in daily life activities including community meetings and general events. The respondents would share on when and how their disability come about, their lived life experiences including interactions with family members, friends, school mates, community members and different institutions of relevance to their plight.

3.5 Study Population

The study included three sub-counties health systems (Alego Usonga, Bondo and Ugenya) and carefully selected individual adolescents with disabilities, as earlier defined, as well as subcounty health management teams (SCHMTs), Community volunteers (CHV), Community Health committees (CHCs), caregivers, and health staff from referral link facilities, government officials (National council of Persons with disabilities, and county). In addition, interviews were held with the officials of organizations of persons with disabilities (DPOs). The study participants were identified through purposively selected CBHC catchment areas zoned by sub-county administrative and health officials. CHV/CHC and CHS Focal persons who were identified through the county/sub-county health departments helped in identifying the persons for inclusion.

3.6 Sample size

Researchers agree that qualitative research require only a sample enough to describe the phenomena and meet the goal of the study. Creswell (1998) and Morse (1994) proposed a sample size of between five to 25 participants for descriptive studies. Determining the sample size in this study is therefore guided by the aforementioned perspectives, with the main principle governing sample size in qualitative study being data saturation (Morse, 1995). Although the numbers sampled can be increased or decreased depending on the flow of new information, this study depended on well-chosen sources and techniques of data collection to increase robustness of the study. The main consideration is the richness of the information that the study gleans with respect to in-depth understanding of the phenomena rather than the spread.

3.6.1 Sampling Design

A 5-step process was used to identify all the study participants (Figure 3.2), which consisted of A. the sub-county and CBHC programme participants, and B, the adolescents with disabilities and their families especially the parents or the guardians. See the figure 3.2 below:

A. Sampling of sub-counties and CBHC Programs

Sample Profile

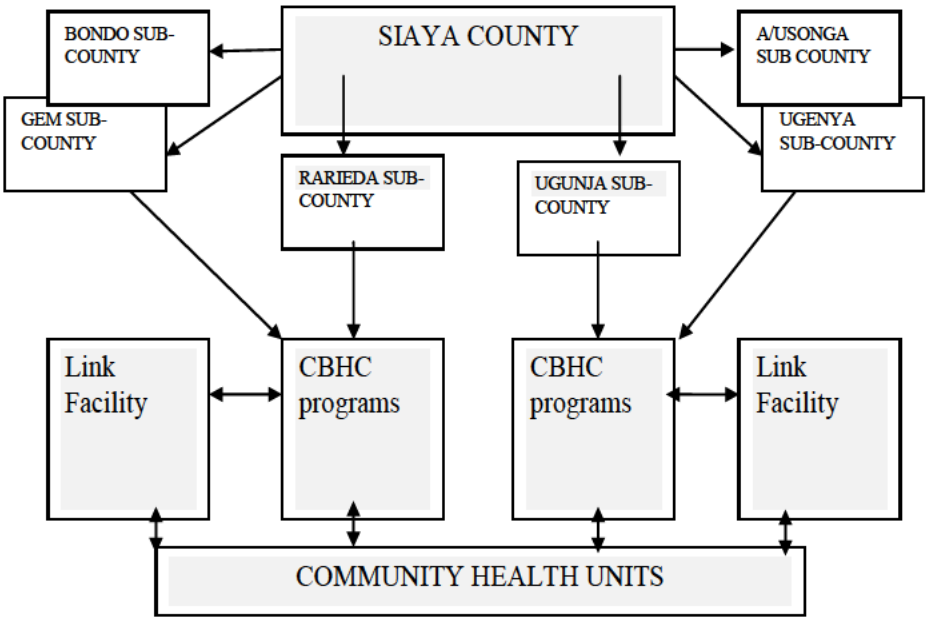


Figure 3.4: County Structure Sampling Profile

Selection of the sub-counties and Providers

Step 1: Select 3 out of 6 sub-counties in Siaya (Gem; Alego/Usonga; Ugenya; Ugunja; and Bondo). Out of the above enunciated 6 sub-counties, 3 sub-counties Alego Usonga, Bondo and Ugenya) were selected as the embedded/sub- units of analysis. The main criteria used to select the three sub-counties include: The 3 sub-counties provide critical variations in contexts that enriched the study perspectives. For instance, Alego Usonga is the County headquarter that hosts all the decision-makers including the health leadership; it has the foremost referral health facility among all the sub-counties. Bondo is both an urban and rural

sub-county with fairly established health system that cascades into the community. The region presents robust economic base with elaborate fish landing beaches hence un-comparable business hub among the sub-counties. The last sub-county purposively selected is Ugenya. This was an emerging deep rural sub-county with yet-to-develop infrastructure ranging from poor roads, ill distributed social facilities including underdeveloped transport systems as compared to the rest of the sub-counties. All the foregoing characteristics and researcher's personal knowledge of the areas formed the consideration for their selection for the study.

Step 2: Community based health programs were identified through the health officials at the sub-counties that had been purposively selected. The sub-county officials helped in the identification of the community based health programs that were already collaborating with the county health system in the delivery of community health services.

Step 3: The compiled CBHC was assessed against pre-determined inclusion-exclusion criteria below to identify those suitable for participation.

Inclusion criteria:

The criteria included entities that were duly registered by the relevant government authority (for instance registrar of societies for faith-based organizations, gender and social services for community-based organizations, at least 1 year prior to the study/collection of data for track record in terms of legitimacy and resilience. Also considered was the consistent involvement in community health services from registration to the time of this study (establish from reports) and had to be community driven in approach (CHVs, CBOs and FBOs). Moreover, they had be linked to community unit/local health facility/Persons with Disability Organizations (PDOs)

Exclusion Criteria

Those excluded were organizations that had rregistered in less than 1 year from research data And had no critical link to community health unit, referral facility or PDOs. Also, those that were not active on the ground as per SCHMTs assessment were excluded.

Step 4: The shortlisted CBHC programs in each of the three sampled sub-counties were reviewed and then categorised as:

a) Programs for only PWDs (community-based rehabilitation);
b) Vertical health services targeting only young people, including those with disabilities (e.g. HIV testing and counselling, awareness creation, condom distribution etc.); SRH,

c) Comprehensive level 1 healthcare services (curative, preventive, promotive and rehabilitative) targeting everyone in the community (AWD included).

Step 5: Based on program area coverage, one typical CBHC program was purposively sampled from each of the three categories in Step 4, as indicated in Table 3.2 below**.**

Sub-county: Alego Usonga	**Sub-county: Bondo**	**Sub-county:Ugenya/Ugunja**
CBHF STIPA (NGO)	Nyangoma Mission Category (FBO)	MFK CPHC (NGO)
K-MET YFC only SRH	FHOPK: YFC only SRH	DOHO-CBO (CPHC)
Only disability SIDIPEG-(DPO)	Only disability (DPO)	Only disability (DPO)
Total:3 Programs sampled	Total:3 Programs sampled	Total:3 Programs sampled

Table 3.2: CBHC Sample Categories

Selection/sampling of AWDs Participants

The selection of participants to this study was systematic but also purposive in approach. Various institutions including organizations dealing with disabilities, ministry of health, local administration including personal intuition assisted in the identification, selection and access to critical sources of information required. For the AWDs and their families this entailed five steps to identify suitable ones for interviews as outlined below:

Step 1: The researcher identified and compiled a list of AWDs through local disability organisation and community health units (CHUs) in the sampled sub-counties (Persons with Disabilities Organizations' membership and Community health volunteers). Others not in the registers were identified through snowballing or referral by community organization/members, including health facilities that work with them.

Step 2: Participants were enlisted through the following inclusion and exclusion criteria:

Inclusion criteria:

This included those aged 10-19 years old that were either living in or out of institution of care within the study area; accepted to participate voluntarily through self-consent or by assent to own trusted guardian; those who had any form of disability including blind, deaf/dumb or wheelchair confined; those that had lived continuously in the area for at least six months preceding the study for purpose of sharing their rich lived experience with respect to access to care in the study area.

Exclusion criteria:

This included AWDs below age 10 and above age 19 years; Short-term visitors who have not lived continuously in the area in the six months preceding the study; those not ready to participate in the study even with authority consent from parents/guardian; those insisting on being paid to participate in the study including those who were mentally unable to participate.

Step 3: The identified and selected persons were divided into three main disabilities/impairments categories from critical case perspective (reliance on assistive devices or were aided): Visual impairment included only those who were totally blind to find how far the health systems could stretch to provide care to most vulnerable. Physical disabilities included those confined to wheelchair; hearing/speech impairments included those with total deafness and inability to talk and others (albinism and mental challenges). The critical case approach to case selection the research opined that by choosing extreme cases for examination, by extension the mild or moderate cases were covered. For instance, in this study it would be expected that the services were enjoyed to the extent possible by everyone including those with severe disabilities.

Step 4: Sampling: The identified disability cases were then purposively selected from and for each category of impairment in the sampled sub-counties as seen in table 3.3 above

Step 5: Informed consent and assent for the interviews were sought before engaging the participants for interviews, with the parents and guardians of the underage or severely impaired adolescents consenting and participating in the interviews on behalf of their children. The table 3.3 below constitutes the summary of the sampling process of the adolescents.

Table 3.3: Impairment sample categories

Sub-county Alego Usonga	Sub-county Bondo	Sub-county Ugenya/Ugunja
Mental: 1 Female Physical: 1 Male	Deaf = Female 5: 1 Male Physical: 1 Male Mental: 1 Male	Deaf 6: 4 Female 2 Males Physical: 2 Males Mental 2: 1 Female, 1 Male
Total: 2 Disability Cases identified and interviewed	Total: 8 Disability Cases identified and interviewed	Total:10 Disability Cases identified and interviewed
*Some 6 AWDs declined to participate which was readily accepted as had been explained that participation was at free will.		

3.7 Overall outlook of sample categories

The table 3.4 below is a summary of the samples categories and sizes that the study consulted to answer the research question.

Table 3.4: Study population and sample size

Participant categories	**Number interviewed**
a. AWDs segregated by gender and impairment type	20 people
b. CBHC programs segregated by type	9 cases
c. Community health volunteers/CHC/PWDs	6 FGD
d. Community leaders	6 KII – 2 per sub –county
e. Health providers from typical CBHC case facilities/program (Professionals)	6 KII -2 per sub-county)
f. Caregivers	2 x 3 community units coverage area
g. National/County /sub-county/ officials	2 FGDs;4 Key informant interviews (KII)

3.8 Instrumentation, training and piloting

The study used qualitative methods including focus group discussions (FGDs), in-depth interviews, observations and case narrations to collect data as guided by the two models - Health Building Block model and Bio-socio-ecological under the following themes as in the table 3.5 below:

Table 3.5 Assessment Themes

Health Systems Building Blocks (SUPPLY SIDE) Themes for assessing health system-based issues that affect the function of CBHC programs to deliver SRH & HIV for AWDs	Bio-socio-ecological model (DEMAND SIDE) Themes for assessing experiences and interactions of AWDs with the environment that affect access and use of SRH & HIV services in the community
Leadership/Governance Human resources for Health Financing Commodities and Technology Health information system Services Delivery	(1) The microsystems (individual) (2) The Mesosystem- (interpersonal) (3) The Exosystem (community) (4) The macrosystem (organizational/structural) (5) Chronosystem (Time element)

Furthermore whereas the above components defined the context of analysis, the character of the processes, the person affected. The study thus developed and used qualitative data collection methods that require observation, interviewing and discussion guides with open-ended questions for individual variation (different attributes) to saturation whereby less and less new information could be gleaned (Schwartz et al., 2011; Chenail, 2011). Moreover, the process was guided by the two conceptual frameworks that were chosen for this study as in (Figures 1 and 2) and also as aligned with the objectives of the study. Further, the researcher incorporated feedbacks from the supervisors in refining the tools, conducting training for the data collectors on how to use them and pre-testing of the same.

To ensure the appropriateness and consistency of the study instruments, the researcher piloted them in a location with participants of similar characteristics to those of the study area especially the non-sampled sub-county of Gem (for language consistency). However, the

researcher was flexible on the dynamics of the pilot since this qualitative study did not require rigidity in the instrumentation in the scale of quantitative research designs (Chenail, 2011). After pilot testing the study tools were thus finalized in eEnglish and Swahili, being part of the most commonly spoken languages in the county of study. Timing of the application of the guides was also adjusted to ensure that the interviews only last 45-60 minutes per session to avoid bias from instrumentation fatigue that result from long interviews. To maintain the constructivist's approach to the study therefore, this researcher envisaged a key role as part of the research instrument albeit guarded to minimize bias that were inherent in such research designs (Chenail, 2011). The researcher then reviewed the data collection tools and adjusted them where necessary, the language and terminologies to achieve standardization of the specific data collection tools for all the data collectors as well as the respondents. Moreover, all research team members were trained on the conduct of the study, including handling interview participants, how to use the research instruments, conducting interviews; note taking and tape recording of sessions and observation skills. Above all, ethical conduct was emphasised and observed by every research team participant (Nachmias and Nachmias, 1976).

3.9 Team Members and Data Collection

The team members in this study included the principal investigator (PI) who took overall responsibility for the ethical conduct and processes of the research, from beginning to the end. The PI also provided oversight and logistical support to team members and addressed any conflict or concerns from the team, the public or any authority that might have adversely affected the study and its participants. Other team members included two co-investigators with expertise in social, reproductive health and health systems research. The roles of the co-investigators included providing support to the PI in managing data collection processes at sampled and designated sub-counties (3 out 6), data management and quality assurance at all

levels. The co-investigators addressed any issues that arose from the field in close consultation with the PI. They made sure that ethical considerations of the research was adhered to, which included proper management of consents; confidential and respectful handling of participants and information collected that might cause any form of harm to those interviewed or affected by the information.

The team leaders were answerable to the PI on all matters related to the research, and ensured security of all research materials and equipment accessed before, during and after the field. Such materials and equipment were all handed over to the PI for safe keeping and their disposal, as applicable. No team member except the PI (ethically) was allowed to share or disseminate any material gathered in relation to the study. Other team members recruited at the field level included research assistants, including data collectors, community guides/recruiters, AWDs' minders, and sign language interpreters. This researcher supervised all the team members, although the team leaders supervised their terms, which were very small, as the method of data collection required only a few people. Moreover, the researcher engaged the expertise of two psychological counsellors (male and female) who were on standby to respond to any psychosocial stresses that might have affected the respondents during and immediately after the interviews. Given the sensitivity of the phenomena under study, the foregoing consideration could not be avoided. Arrangements had also been made with Matibabu Foundation Kenya (health providers) to be on standby for referral cases that would be sent to them from this researcher's team as a result of psychological or even physical discomfort.

At the office level, two data entry clerks managed the data alongside the researcher. The role of the data clerks included organising data per source, questions and objectives of the study; they also cleaned the data, develop entry fields, enter and analyse the data. They assisted in

generating frequency tables and graphs from the basic descriptive data. Office space and computers with relevant data management software (Microsoft Excel) were be availed for the critical study team members during the process.

Informed consent for the interviews was sought before engaging the participants for interviews, with the parents and guardians of the underage or severely impaired adolescents consenting and participating in the interviews on behalf of their children. Adolescents with disabilities who were below (18 years) age of giving consent or those who were of age but could not able to give consent were asked to provide assent to a caregiver or guardian after careful explanation. The cases that were sampled duly provided consent or assent that were witnessed by a community research guide that lead the team into the interview venues (See consent and assent forms samples in appendix 3).

Every research team member ensured close monitoring, supervision and accountability at all levels to ensured maximum quality control. Physical and psychological comfort of participants was adhered to by the research team. For instance, the interviews were held in conducive - safe environment with minimum disruptions and that ensured adequate confidentiality for the participants. Given the vulnerable state of the participants, particularly the AWD, the researcher constantly monitored them for any adverse psychological and physical discomfort during the interviews. The interviewers ensured that the interviews took between 45 minutes to one hour. Occasionally, questions to the participants were reframed to make communication easy for the AWDs that had serious communication problems but had consented to participate. Those with speech and or hearing impairments were supported with sign language translation from trained interpreters.

By consent from the participants some of the interviews and discussions were tape- recorded- and later transcribed for analysis (Merriam, 2009).

Moreover, the process (things that go on in the life of AWDs that affect their growth and development), person (personal attributes including age, gender and disability) the five levels contexts (micro, meso, exo and macro systems) including time (chronosystem) element (PPC-T) of Bronfenbrenner's ecological systems theory were further described:

a. Individual level (Process, Person and microsystem):

In-depth interviews were conducted with individual AWDs (pre-existing and/or HIV induced) to elicit their perceptions and capture their individual opinions regarding their conditions, health and SRH needs and experiences with regard to CBHC services; how they coped over the time without the services they need. For ethical consideration, where the individual could not respond competently due to impairment or age (below 18 years) barriers, an adult agent, mainly the parents or guardians, were involved in the in-depth discussions with assent from the child where practicable.

b. CBHC/CBR facility levels: **(Mesosystem to Chronosystem).**

In-depth interviews were held with identified CBHC staff to obtain their understanding of the needs of the index participants, their experiences with financing, staffing, providing SRH/HIV services, challenges and their coping mechanisms. A semi-structured guide was used to direct the responses to obtain in-depth information from individual staff members and allow for variations for enrichment of the study. Key informant in-depth interviews with staff that were in-charges of the nearest public health facility to explore existing and potential service pathways for AWDs at various times and family/community support. At these levels, health facility/programme capacity assessment tools were used, including observation checklists, and financial records and reports were reviewed for trends, allocations, sources and utilization.

c. Community Level: (Mesosystem, Exosystem and Macrosystem).

Focus group discussions were held with community members (CHVs and CHCs) grouped by gender to elicit information on community factors that may influence access to SRH care by AWDs. Moreover, focus group discussions were held with CHVs to elicit their views, experiences and challenges with respect to volunteerism, and their current and possible future roles in SRH for AWDs. Key informant interviews were held with opinion leaders (religious and traditional) to understand cultural dynamics and their implications for access to SRH & HIV services by AWDs.

d. Policy and Health Systems Level: (Macrosystem and Chronosystem).

Both primary and secondary data was obtained at this level. The study reviewed relevant documents, including health policy, legal and strategic frameworks, reports, annual plans; budgets; patient records/service registers obtain secondary information with respect to adolescent SRH. The effort was to obtain contextual understanding of why AWDs were not accessing SRH and HIV services. Observations were done using a checklist to assess the state of equipment, staffing, commodities and appropriateness of the health facilities infrastructure. Issues related to the six building blocks were considered and examined as here as well

e. National and County levels: (Macrosystem and Chronosystem).

The institutional arrangements, legal and policy environments for SRH for AWDs were interrogated through document reviews on disabilities, adolescents and SRH & HIV. At the county level, that was also cascaded into sub-counties, services delivery, staffing and health financing especially for SRH for AWD in the context of CBHC programming, management and funding. (Currently counties were the sole points of healthcare services delivery (GOK, 2010). Here, the six health systems building blocks were assessed as key anchorage for the overall health system. The six building blocks, and the SEM guided the collection of data,

analysis and presentation the study also constructed a stair case model for understanding the sequence of events that characterize the journey AWDs who are survivors of SGBV would go through as they seek for justice.

The Tilted Justice Process- Staircase Model of SGBV Recourse for AWDs

The journey to justice for adolescent with disabilities for sexual violation is truly an uphill battle. To understand the experience and the pitfalls that confront the victim, the researcher constructed a stair-cased model to analyse thematic issues that emerged from the individual, family, community, police, courts and the glory accorded to the violated to deny the affected AWDs justice. The model provided a lens through which, in an ecological perspective, the factors within the individual victim and those outside her conspire to defeat justice and perpetuate sexual and gender based violence (SGBV) against AWDs in Siaya County. Below is a graphic presentation of the process analysis that depicts the experiences of AWDs seeking justice for SGBV meted against them. The Figure 3.5 below shows how the AWD has to endure painful physical and psychological pains as they experience negative sexual life. The staircase depicted unearths the underline obstacles to justice for SGBV against AWDs in Siaya County of rural Kenya. The information was gathered through the court records, KII with leaders, FGD sessions with segments of health volunteers and related institutions like the ODP, children's department adolescents themselves.

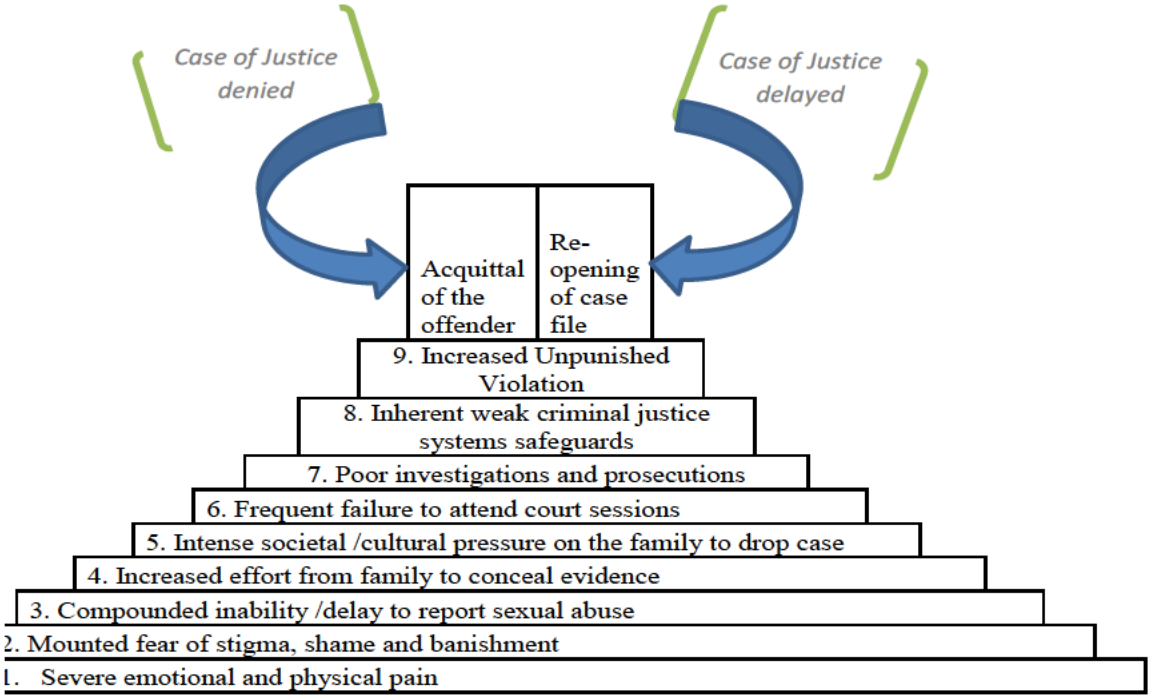


Figure 3.5: Justice Process staircases

Throughout the data collection process, the researcher made field notes of any interesting observations for the study. Moreover, the field notes constituted a first-hand source of reflexive data that enriched the study.

3.10 Credibility, dependability and trustworthiness

To attain credibility, trustworthiness and dependability, the researchers deployed inclusive processes in the design of the study through to its completion ((Nachmias and Nachmias, 1976; Stake, 1995 and Yin 2014). Data was collected from different sources to ensure that there was adequate consensus on the final constructs of the study (triangulation) (ibid). The study ensured that the instruments yielded accurate data through self- checking/triangulation of questions, using more than one question to address concepts that were explored. Triangulation of data sources and a variety methods of data collection would ensure internal validity in case of quantitative study, moreover, this being a case study approach, the findings are context specific, hence are not to yield to rigor of external validity (Fisher et al., 2002).

Since this research involves adolescents with varying disabilities (AWDs), the services of experts in specific areas of communication were used, especially in cases of hearing and speech impairment, which helped to reduce chances of misinterpretations and inaccuracies in data gathering. The specialized assistants were trained on the study instruments to ensure clear understanding and minimize errors. Furthermore, given the sensitivity of the topic under investigation, sexuality and contraception, gender considerations were observed. Both female and male interviewers were appropriately deployed for each of the gender category of research participants to ensure free discussion of sensitive issues of exploration.

3.11 Data Processing and Analysis

Data processing ensured that right from the field data collection, transcribing; analysis, interpretation and presentation quality was maintained. The events recorded in this process were transcribed and transferred to thematic matrix for analysis and reporting. The data was then analysed as per sources, for instance basic quantitative data from the health facility checklist was then analysed using Excel software and descriptive statistics generated according to the constructs the study set to explore. The secondary and transcribed primary data was analysed using manual content and thematic analyses techniques. (See thematic matrix under appendix four). Furthermore, the data from tape-recording was equally transcribed and analysed.

At the analysis and interpretation stage, both primary data (including field notes) and secondary information was triangulated to create the reality and ensure credibility and trustworthiness of the study (Schwartz et al., 2011). This study used both inductive and deductive approaches in the analysis. Inductive approach was applied to the data as aligned to already existing rubrics in the models used that include the WHO's six health building blocks and the Bronfenbrenner's five bio-socio-ecological systems level. The deductive approach

entailed the gleaning of the codes and themes as they emerged from the data. The iterative process continued to a saturation point whereby no new relevant codes could be found from the data. The codes were grouped and summarised into themes and sub-themes. For instance the sexual and gender-based violence against AWDs and the justice recourse elicited quite significant interesting findings that were not in the purview of the study. The findings were presented in the form of tables, narratives and direct quotes. All the subunit analysis and findings was congregated at the larger case unit level for consolidated view and understanding of the phenomenon studied (Yin, 2017)

3.12 Plan for Communicating Findings of the Study

The research report was disseminated to key stakeholders at the county level. This includes Siaya County officials, CBHC providers, and organizations dealing with persons with disabilities. For the national and wider audiences, the report was shared through the relevant commission for research, science, technology and innovations (NACORSTI) for open public access.

3.13 Study Limitations and Risks

The main limitations of the case-study design and its methods of data collection includes that it becomes context specific and uses a small sample size (Stake, 1995; Yin 2014). Furthermore, the methods of data collection were prone to a biasing of results, as the researcher's subjective views were present in the interview processes. However, the researcher was conscious of these limitations and used triangulation for data collection and analysis. Furthermore, in this single case study, embedded units of analysis were used to enhance the in-depth understanding of the phenomena, with improved levels of rigor (Merriam, 2009;Stake et al., 1998;Yin, 2006;Yin, 2015). Another limitation is that some of the adolescents with disabilities could not answer questions for themselves hence had to rely on agents who may not have adequately explained the life experiences of these children with

regard to sexuality and reproduction issues.

3.14 Management and Organization of the Study

3.15 Quality Control and Ethical Considerations

Relevant gatekeeper permission was obtained before the study began, while others were obtained during the study as the need arose. The emergent nature of the study required consultation with other relevant sources of information that were not envisaged at the start of the study. Ethical clearances were provided by the African Medical Research Foundation **(AMREF- ESRC P358/2017)** in Kenya where the study was conducted, and from the University of KwaZulu-Natal (UKZN) Biomedical Research Ethics Committee **(HSS/1183/017D).** At the onset of field work, relevant authority remained engaged. For instance, at the structural and facility levels, official applications were made to appropriate government levels and offices to avail relevant officials for the purpose of the study. This ensured co-operation, support and transparency in accessing the necessary participants for the interviews and documents for reviews. Furthermore, the study participants at all levels of the health and administrative structures of the county felt unfettered and therefore provided the relevant information within the ethical conduct of the study.

More specifically therefore, the following ethical considerations were adhered to:

1) Ethical approval was obtained from UKZN BREC (HSS/1183/017D) and in Kenya (AMREF-ESRC P358/2017)

2) Prior to the field engagement, the researcher ensured all necessary clearances and authorizations were obtained from relevant authorities (The Government of Kenya, County Government of Siaya, disability organizations and local organizations). This included Parental/Guardian consent was sought for adolescents under age 18 years and those who had mental impairments, hence were not able express themselves.

3) All research team members were strictly instructed to comply at all times with the prohibition rules of unethical behaviour in research.

4) Voluntary informed consent principle was observed to ensure respondents willingly participate in the research process without coercion or undue influence through inducement. All research team members were bound to respect all views expressed by respondents even if at variance with their own views. Verbal assent from adolescents with disabilities who could not speak for themselves either as a result of being underage (below 18 years) or due to severe disability, was sort to the extent that was practical and ethical before anyone in their interest would speak on their behalf. Again sensitivity and respect for the right of the child was maintained for the comfort of the child.

5) To protect the identity of participants on personal and sensitive matters shared during the study, pseudonyms or codes were used to refer to specific persons.

6) The findings and views gathered were handled in a manner that was accurate and harmless to the respondents with sources, role and intellectual contributions appropriately acknowledged.

CHAPTER FOUR

STATE OF SIAYA COUNTY HEALTH SYSTEM

4.1 Introduction

The backdrop of health services delivery was characterized by the state of health systems building blocks in the country. The chapter therefore opens with the overview of key findings of this study, Structure and State of County Health System Functionality of Community health service, Link Health Facility Characteristics, Administrative and management practices; The results were reported using the six health system's building blocks that include leadership and governance, health financing, human resources, commodities & technology, health information system (HIS) and service delivery. The implications for the functionality of other linked systems from the community level with respect to the delivery of sexual and reproductive health SRH and HIV for adolescents with disabilities (AWDs) were covered.

4.1.1 Overview of key findings

This study observed that the current state of Siaya County health system across its building blocks was inadequate to support effective function of the community-based health program in delivering sexual, reproductive health and HIV services for adolescents with disabilities (AWDs). Many factors determined health and access to healthcare, including SRH and HIV services for AWDs in Alegao Usonga, Bondo and Ugenya Sub-counties of Siaya County. According to the District Health Information System (DHIS) and the CHVs, who often engaged with daily household healthcare at the community levels, the common health problems in the study area were malaria, HIV, diarrhoea, coughs and ulcers; non-communicable conditions such as high blood pressure, diabetes, cancers and now severe injuries from motorbike (*boda boda*) accidents. The most common disabilities were: physical, visual, hearing and mental disabilities which imposed limitations to the extent to which those affected could enjoy good health. Poor socio-economic status of the households hosting

AWDs was found to affect health. Moreover, the way communities and the service providers conceptualized disability and adolescent sexuality determined the extent to which AWDs would receive support to access care.

Other common social determinants that affect health and the health behaviour of AWDs in the county included high poverty levels; discrimination by the family members and caregivers; low educational level, and lack of proper infrastructure to accommodate those with disabilities, such as poor roads and inaccessible buildings (lack of ramps). However, community-based healthcare (CBHC) programs through CHVs were found to play an important role in addressing these social determinants. For instance, the focus group discussions with CHVs and in-depth interviews with the community health assistants indicated that the main roles of the CHVs included sensitizing community members and caregivers on the needs of AWDs. They also referred the AWDs and do follow up to ensure that they received the necessary healthcare services at the facility, and engaging them in income generation activities (IGA) to ensure that they generated some income.

The study found from interviews with national and county health officials concerned with SRH and HIV service delivery as one officer expressed,

> *"…Existing policy and legal provisions with regards to essential healthcare services in Siaya County are inadequate and skewed against AWDs. More particularly, frameworks needed to support community initiatives are non-explicit on how to include AWDs in SRH and HIV care and support."*(KII Participant 6)

This study observed that access and utilization of such services by vulnerable groups, such as AWDs, urgently required explicit and affirmative legal and policy environment. Health providers in a FGD agreed as expressed by one of the participant that,

"…there appears to be a generally slow- paced approach to drafting and enacting comprehensive laws and policies to provide the necessary frameworks for inclusion of AWDs in the production, delivery and consumption of social services, in particular SRH and HIV services.it is six years into the devolved healthcare dispensation in Kenya, no sexual and reproductive health services specifically target AWDs in Siaya County. Ironically, even in circumstances where laws and policies were in place, albeit at national, regional or at international levels (including universal human rights), their implementation and enforcement remain problematic (FGD Participant 4)

4.2 Structure and State of Siaya County Health System

4.2.1 Leadership and Governance: County level

Regarding Leadership and Governance, the Department of Health and Sanitation was responsible for all the counties heath functions. The County Health Management team (CHMT) stewards all the health programs within the county. The CHMT was composed of all departmental heads at the county level and supervises health programs at county level including community health services for vulnerable groups like adolescents with disabilities. Below that was the county health management team was the Sub County Health Management team (SCHMT).

The structure of Siaya County health system derives from the Kenyan constitution that was promulgated on the 28th August 2010. A key shift in health care delivery arrangement, as per the fourth schedule of the constitution, was the devolution of the health service delivery function to the Counties, with the view of enhancing equitable access to healthcare (GOK, 2010). Under the healthcare system structure, the national government was responsible for policy formulation (sexual and reproductive health policies, HIV control and management guidelines), setting standards and providing technical supports to the counties. Moreover, the

national government was also in charge of the national referral health facilities and policy development; capacity building (training of various cadres of human resources for health) and resource mobilization.

The health management structure in Siaya County was therefore devolved to the lowest units of care to provide basic health services, such as SRH and HIV care to all including the AWDs. This study observed that effective and appropriate healthcare for marginalised and vulnerable groups requires a functional and responsive management system. Regarding leadership and governance, the Department of Health and Sanitation was responsible for all county heath functions. The County Health Management Team (CHMT) stewarded all the health programs within the county, being composed of all departmental heads at the county level, and supervising health programs at county level. Below the County Health Management Team was the sub- County Health Management Team (SCHMT). Before devolution, the SCHMTs were known as district health management team (DHMT), which covered the whole of the former larger Siaya District that included Gem, Ugenya, Alego-Usonga, Bondo and Rarieda. After devolution, Siaya District became a County with six sub-counties, namely: Gem, Ugenya, Ugunja, Alego–Usonga, Rarieda, Bondo, each with their own SCHMT. Moreover, each SCHMT has a total of 15 members (although sometimes not guaranteed due to shortages) who were Program Managers in charge of AIDS coordination, reproductive health, malaria, community health services, pharmacy, DHIS, public health, nursing, clinical services, including the Medical Officer of Health. The SCHMTs report directly to the CHMT, which has a similar composition as the SCHMTs.

Across the sub-counties, the SCHMT members interviewed identified their roles to include but not be limited to the following: Overseeing delivery of health services in the sub-county; ensuring adequate and competent human resource management, staffing for health facilities

(they recommend to the CHMT; staff required for the different health facilities and the CHMT posts directly); ensuring harmony among staff through building teams and resolving conflicts; financial management (although such funds were not available); resource mobilization (especially from partners working at the sub-counties levels) and commodity management role, as explained below:

> *"…for example, the sub-county public health nurse (SCPHN) does orders for levels 2 and 3 health facilities, i.e., dispensaries and health facilities. Sub-county hospitals do their own forecasting and ordering based on their consumption needs. Allocation for commodities is done according to workload. The SCPHN uploads requests to KEMSA portal, which thereafter sends commodities to health facilities directly using the master facility list (MFL) codes. The health facilities share their delivery notes with the SCPHN who compiles a report to the county. Commodity consumption is checked during supervision (although supervision has not been consistent since devolution)".* (FGD participant 2*)*

4.2.2 Leadership and Governance: Community Health Unit level

Health governance structure at the community level remained weak and sub-optimal in function across the study area. The Community Health Committees (CHCs) constitutes the governing arm of the Community Health Unit and provide leadership to the CHUs and oversight in the implementation of health and related matters in community health services at Tier 1. The CHC that composed three members that the study observed to be mainly men: secretary, chairman and a patron. These were elected by the community members gathered in local community fora called Chief's *barazas*. The convener of the forum was usually the local Ward administrator who in this case moderates and supervises the election of

The study established that the roles and function of the CHC include supervision and

monitoring the CHVs, advocating for community health needs and related issues, mobilization and coordination during community dialogue days and action days. It was also established that CHC meets once a month to review the CHVs reports before submission to the CHA. In addition, they meet quarterly with the CHVs to organize dialogue days, based on the indicators in the chalk boards and have quarterly carry out action days. Generally, it was reported that the CHCs have a structured plan of their meeting dates. However, policy stipulates that there should be monthly dialogue days in every Community Health Unit.

The study also established that leadership qualities of the CHC members and their roles were not well entrenched among a good number of the CHCs interviewed. Some struggled to explain what their actual role was as CHC member. Moreover, although they were clear that their position was on a voluntary basis, they looked disenchanted. Moreover, the study further established that CHCs have various challenges that were mostly related to lack of compensation and motivation. As much as the CHVs were given a stipend, the CHC had no form of recognition or compensation from the county government or from the partners as CHVs did. This has become a challenge due to the fact that they were the community health unit (CHU) managers and in-charge of CHVs, yet they receive no form of stipend. From the discussion it was indicated that the CHCs support and supervise the work of the CHVs; together they agree on issues of interests to inform the dialogue days; together they also organize community action days. It was however noted that this relationship was not very useful due to lack of motivation or compensation of the CHC, as their counterpart volunteers (CHVs) who are on monthly stipend of $20-30, while CHC did not receive any but were expected to continue working.

The CHCs interviewed explained their frustrations with the way they were discriminated against and isolated, especially by non-state actors involved in vertical healthcare programs.

These groups choose only to work with CHVs in the projects but ignored the governance structure of community health services that comprise the CHCs. This process would appear distal to the plight of AWDs, with very real consequences, especially where the quality of community healthcare service delivery, including SRH and HIV, are compromised due to poor leadership or even lack of it thereof.

Occasionally however, they had resorted to task shifting with CHVs in order to receive some compensation. Those who were not taking double roles as CHC as well as being CHV were unhappy and expressed dissatisfaction with way the community strategy was being implemented. In addition, CHC are rarely capacity built to increase their effectiveness in discharging their duties. The study found that for CHC to be effective in discharging their duties, they need to be facilitated, trained and given tokens of appreciation or a stipend.

4.2.3 Health Financing

Financing for health care services in the county was generally inadequate. The study interrogated the sources and process of health financing in the study area Health care in Siaya County was financed through multiple sources. Key among these was the public financing, private financing mainly the out-of-pocket and the development partners budget support. From the public sources, the economic department finance and budgets issues sectorial ceilings to the other county departments which have to work around this. According to a key informant interviewed,

> *"Health department like all departments are responsible for both the recurrent and development expenditure. However, budgets for development are made together with the input of the public, through public participation. Apart from that, during the budget making process unforeseen circumstances may necessitate the influence of the finance and budgeting department which informs the other county departments. Once*

the development priorities for the year have been identified and the budgets tabled, various partners may see how to tap in resources into the budget. Partners may also have secured funding and want to invest into the county. Subsidies provided to private institutions are rare as there would be a need for a legislation to guide this. Furthermore, there is a fairly comprehensive Community Health Strategy which might inform on the lack of such legislation (KII participant 14).

4.2.4 Health Service Delivery

Number and distribution of health facilities

The health services in Siaya County were provided in a hierarchical manner but mainly through the facility and community levels. At the facility level available data from the Master Health Facility list showed that at the time of this study (2018), health facilities in Siaya County included 68 basic primary healthcare facilities, 20 comprehensive primary healthcare facilities, 109 dispensaries, 15 hospitals and three voluntary counselling and testing (VCT) centres (Table 4.1).

Table 4.1: Distribution of link health facilities

	Alego Usonga	**Bondo**	**Gem**	**Rarieda**	**Ugenya**	**Ugunja**	**Total**
Basic primary healthcare facility	34	5	12	12	2	3	**68**
Comprehensive primary healthcare facility	5	7	1	4	1	2	**20**
Dispensaries and clinic-out patient only	13	26	23	20	16	11	**109**
Hospitals	1	-	-	-	-	-	**1**
Primary care hospitals	1	3	3	1	2	1	**11**
Secondary care hospitals	1	2	-	-	-	1	**4**
Stand Alone	1	-	-	-	-	-	**1**
VCT	-	-	-	-	-	3	**3**
Total	**56**	**43**	**39**	**37**	**21**	**21**	**217**

Source: Health facilities master list (County)

HIV service provider collaboration

These structures include both government and non-state health facilities already indicating the potential synergy between the systems irrespective of ownership. The community health units, with which the community-based health programs work, were linked to the nearest health facility for advanced continuum of care. Health providers interviewed however observe that,

> *"Although by policy and intent all the facilities were expected to provide primary care services including SRH and HIV to everyone without discrimination, in their current state they are not adequately functional to provide equitable service to AWDs… lack of appropriate staff trained in special healthcare needs of AWD was a*

big deterrent to access to care for this population across the levels of care (FGD Participant 2).

Lack of policy framework for HIV services for AWDs

The study revealed lack of policy framework regarding HIV programming for all adolescents especially those that were within the key populations but were under age . A key informant health provider interviewed observed that,

> *"…One key challenge that leads to this is the lack of clear legislation on how to treat adolescents who fall within the key populations such as female sex workers (FSWs), injecting drug users (IDUs) and men having sex with men (MSMs). …nonetheless, the infected adolescents still receive the services that are modified to suit them, that is, the group can access services on specialized days as suits the health facility. Some of the services available to them include: contact treatment, ARVs, health education and support health clubs. One such modified intervention is the Operation Tripple Zero (OTZ), a biomedical intervention that aims to reach 90% of adolescents 10-19 years old infected with HIV with ARVs old program, 100% suppression rates for those on ARVs and 100% retention rate for those on ARVs. This is implemented with behavioral interventions such as support groups and one-to-one contact...*" (KII Participant 10)

Barriers to accessing services

Furthermore, the study also observed that although AWDs and were infected by HIV receive the same package as other adolescents, there remained considerable barriers to accessing the services. Probed on any more barriers to services for this age group include: Inadequate staff with appropriate skills to handle adolescents including those with disabilities. For instance there was limited staff trained in sign language (deaf friendly services) at the Patient Support

Center (PSC) located in the Siaya County Referral Hospital. There were also HIV Testing Services (HTS) counselors who were deaf. However, the number of staff trained in special needs was still not sufficient to handle large referrals. Currently, the only other health facility in Siaya with such staff was Nyang'oma in Bondo.

Physical infrastructure was also assessed for accessibility. From observation of the hospital through a checklist, a few ramps had been provided for in some places in the health facilities. The study however noted that these were in isolated places that further restricted AWDs on wheelchair to just a few places in the hospital. Moreover the study revealed lack of signs to show directions for the damp and deaf were scarce, no sound and Braille were available for the visually impaired. Moreover available social amenities like toilets did not consider people with disabilities, the implication being that autonomy of those affected appeared highly curtailed. A health provider noted that,

> *"People like the AWDs have to depend almost entirely on other people to be able to access care and services to access services here"* (KII Participant 15)

NGO support for HIV services

The HIV programs in the study area were largely supported by Center for health Solutions (CHS) a local non-governmental organization in partnership with the Ministry of Health (MOH). The Center for Disease Control (CDC) also funded community based HIV service as a KII participant - NGO-provider explained that,

> *"Although the organization had ensured that the facilities do not run out of commodities such as antiretroviral (ARVs) and HIV testing kits, they did not provide for drugs for opportunistic infections (OIs) and SRH related services. The donor community stopped supporting supply of OI drugs hence clients are expected to buy OI drugs regardless of social or economic status. There are non-formal discussions*

on the significance of promoting social health financing among clients to help them buy these drugs more affordably. This has not affected uptake of services by clients as defaulter rates still remain low" (CHS-KII participant 1).

The HIV departments across the sub-counties worked with all hospitals whether mission, government or private in delivering HIV intervention using a common package. There was however very limited involvement of the CBOs or community strategy due to policies on patient confidentiality. MOH has therefore retained peer educators who do follow-ups and referrals of defaulters.

4.3 Community Health Structure

Community health structure constitutes subsystems of the community health strategy (CS) for the delivery of community health services. The study identified and assessed community health service delivery components in the sub-counties consisting of the level 1 unit (community health unit) to link health facilities in the care continuum. The services were reviewed with respect to their capacity to reach AWDs with essential health services, in particular, SRH and HIV. Key components of the structure CHU, being part of the county health system were also reviewed in the frame of health systems building blocks. The following was established:

Function of Community Health Unit

The study established that although the Community Health Strategy implementation has been organized around Community Health Units (CHUs), the units were still in their early stage of development. The structures which consisted of community health committees, community health extension workers (CHEWs), community health assistants (CHA) and community health volunteers (CHVs) operating in geographically delineable areas that coincide with the lowest administrative unit, the sub-location. The CHEWs facilitated the

delivery of community health services, and CHVs were the frontline healthcare providers at Tier 1 (level 1) working under the supervision of the professional health workers designated as CHEWs, and the CHCs are the governing arm of the Community Health Unit. The study established that,

> *"…most of the preventive and promotive health service provision to the AWD was largely left to us CHVs and the families to address. At the family, mothers and guardians (grandmothers) were the key caregivers…although they did not have so much on SRH for young people. We the Community volunteers extended basic health services to the households, including those hosting AWDs. However, the capacity of the CHVs to discharge their duties with a focus on adolescents with disabilities was still a challenge, as the CHVs are not trained in various categories of disability. (FGD Participant 1)*

It emerged during the interviews that the curriculum for training health professional does not envisage the end clients as being disabled, with the CHVs also needing to be empowerment to work with the cohort. A key informant thus observed that;

> *"…. It is therefore paramount for CHVs to be trained on how to map disabled adolescents. They should also be equipped with necessary skills including; counseling skills for disabled people, communication skills including sign language, and braille and awareness creation and rights of AWD. Additionally, parents and guardians dealing with the AWDs should be capacity built. The county government should offer structured counseling towards special needs, create forums for both families and disabled adolescents to talk about their needs"* (MoH, KII Participant 2).

CHV work relations with the stakeholders:

The study sought to establish the relationship of the CHVs and the various structures and stakeholders who interact with the various structure and community stakeholders. Asked how they related with other systems in the community the CHVs were unanimous that they,

> *"…are the link between the households and the link health facility. They refer community cases to the facility, and where the get the supplies/commodities they need to support their work in the village/community"*

Regarding Partnerships,

A focus group participant aptly explained the close working relationship that NGOs and implementing partners have with the communities where they work,

> *"…CHVs work closely with various NGOs and Implementing partners working in the communities since they are well known to the community members; the NGOs and implementing partners in many occasions offer training and capacity building opportunities to the CHVs; in the same way CHVs work closely with other community and local leaders so as to ensure effectiveness of some of the community health interventions in the community…" (CHV-FGD Participant 3).*

Household, CHVs,

Moreover, a community health assistant in a key informant interview also explained that CHVs

> *"…directly work with the various households in their respective villages, and provide direct preventive and promotive health services to the households. Example of the services rendered to the household by the CHVs include screening and treatment of malaria, referrals to the health facility, offer health education on disease prevention, HIV and STI awareness creation (KII Participant 13).*

Community Health Assistants (CHAs)

The role of CHAs was clear and affirmed in the community health structure, with separate interviews with SCHMT, CHVs, CHAs and those in charge of facilities confirming this position. Within the community health system, the CHAs facilitate the delivery of community health services at Tier 1 (Community Health Unit). Asked to explain their role as CHAs, a participant responded as captured here:

> *"As CHAs we act as the link between the community and the health facility, and oversee the selection and work of CHVs; train the CHV, collect and compile reports received from the CHVs, organize community health outreach, coordinate dialogue and action days, and represent the community during the link health facility meeting. We forward community health issues to the facility, and offer feedback from the health facility to the community health units during dialogue days that we hold monthly" (CHA-KII- Participant 13)*

The study revealed that one CHA took charge of 3-5 community health units due to staff shortages, with potential risks of poor delivery of services

CHV Compensation

According to the Ministry of Public Health and Sanitation (MOPHS) Circular dated 8th March 2011, where funds are available, community health volunteers are entitled to a payment of Ksh. 2000 (20 USD) per month as performance based incentive. The study sought to find out if the CHVs are being compensated or appreciated for the services offered. Currently, they receive a stipend of Ksh. 3,000 (30 USD) a month but not on regular basis. They lamented that this amount was not proportionate with the level of effort they put and it was their wish that the county government would offer them a package of Ksh. 10,000 (100

USD). In addition, they said that the amount they are receiving currently should be given on regular basis. The researcher probed to find out what motivates the CHVs despite not being well compensated and whether they have any income generating activities (IGA).

Moreover, it was found that some of the CHVs were engaged in income generating activities, but in conjunction with other community members, including women and other community groups. In an FGD session, a participant said,

> *"Some of us CHVs… are members of Vegetable Growers which is a community based organization (CBO) that is supported by an NGO called Community Initiative Support Services (CISS), it provides the members with dairy cattle and goats, and as well as capacity building then on tree growing, bee keeping and general modern agriculture methods. We also do table banking and share out the savings every end of the year, with the dividends calculated on the basis of the amounts each individual saves…(broad smile in the face)… as CHVs our main motivation comes from the fact that we are recognized and respected by the community* members (CHV-FGD Participant 5);

Another participant in the group interjects,

> "*…have opportunities for capacity building through trainings; are able to solve some community problems thus improving health standards of its members and are able to test and treat malaria, while the IGA and stipend were also source of motivation*.

In spite of the above efforts to by CBHC programmes to sustain CHVs work in the delivery of primary health services, challenges remain. For instance, some of the challenges faced by the CHVs in executing their mandates include inadequate capacity to advocate for justice on behalf of victims of SGBV. Moreover, they are not financially facilitated to help the AWDs

to promptly access healthcare attention as required as one CHV in a FGD observed

> *...the money given to us as stipend is not adequate and regular for us to be able to share with clients...especially those needing referrals''* (CHV FGD participant 3).

Synergistic Service delivery: Link Health Facility (HF)

The community health strategy defines link health facility as any referral level available to a local community unit, and includes basic, comprehensive primary clinics to referral hospitals. According to the respondents interviewed, the link health facilities are not adequately prepared to provide services for AWDs, with a shortage of staff trained to handle the PLWDs, which mostly leads to misdiagnosis due to lack of proper communication. It was also noted that key indicators on disability in the community tools are missing at the facility based tool. Referrals from the community health units are generally not recognized at the link health facility. In terms of construction of the health facility, such as health centres or hospitals, the concept of the law in regard to access to services was not adhered to. Political influence was a factor that limits the space for implementing access to friendly services by the disabled. The buildings were not disability friendly and there needs to be advocacy for professional space to deliver services.

4.4 Functionality of Community Health Services

Despite the government's effort to put in place mechanism for assessing functionality of community health units (CHU) in the delivery of level 1 services, this had not been comprehensive enough to capture the disability friendliness of the community health services provided through community structures. The indicators were limited to whether the community health units were conducting consecutive monthly dialogue day, quarterly action days and the availability of four nationally approved community health information system (CHIS) tools (GOK, 2013). The CHUs that met all three criteria were considered as fully

functional, while those who did not meet any one of the criteria were termed semi-functional, and any CHU that did not meet any of the three criteria was termed non-operational. According to the Master Health Facility list reviewed, there were 175 community health units in Siaya County, only 64 were considered fully functional, which less than half, and five were considered completely non-functional. The state of CHUs from the three sampled sub-counties (Alego Usonga, Bondo and Ugenya) is summarized in Table 4.2

Table 4.2: Community Health Units in Siaya County

Sub-County	**Fully-functional No. (%)**	**Non-functional No. (%)**	**semi-functional No. (%)**	**Total**
Alego Usonga	23 (57.5)	5 (12.5)	12 (30)	40
Bondo	2 (6.9)		27 (93.1)	29
Ugenya	5 (21.74)		18(78.26)	23
Total	**30**	**5**	**57**	**92**

In the three of the sub-counties sampled (Alego Usonga, Ugenya, and Bondo), more than 50% of the community units were considered at least semi-functional. Bondo County had the lowest percentage of fully functional community units (6.9%) compared to the rest of the sub-counties. From the point of view of this researcher, however, the criteria for assessment was exclusionary with respect to adolescents with disabilities.

Moreover, as was explained by the community health assistants and workers interviewed,

> *"…only one community health information tool gathered information on disabilities (household register MOH 513), which was cleaned at the next level of reporting at the CHEW summary register (MOH 515). Therefore for AWDs to access care,*

functionality of community system that delivers such care was not adequate but a barrier" (In-depth interview Participant 4, CHA)

Further analysis concludes that the functionality of community health units across the sampled sub-counties, even without including AWDs issues, was sub-optimal. For instance, Alego Usonga only has 57.5% fully-functional, 30% semi-functional and 12.5% not functional at all, yet it was closest to the county headquarter where the county health management team (CHMT) are located. In Bondo, only 6.9% were fully-functional and 93.1% are semi-functional, while in Ugenya, 21.74% are fully-functional while 78.26% were semi- functional. The implication was that overall, less than 50% of the community units, which were the backbone of government community health service delivery approach, were functional, weakening lower level delivery, despite this being where primary health care services were interfaced for vulnerable groups, such as AWDs.

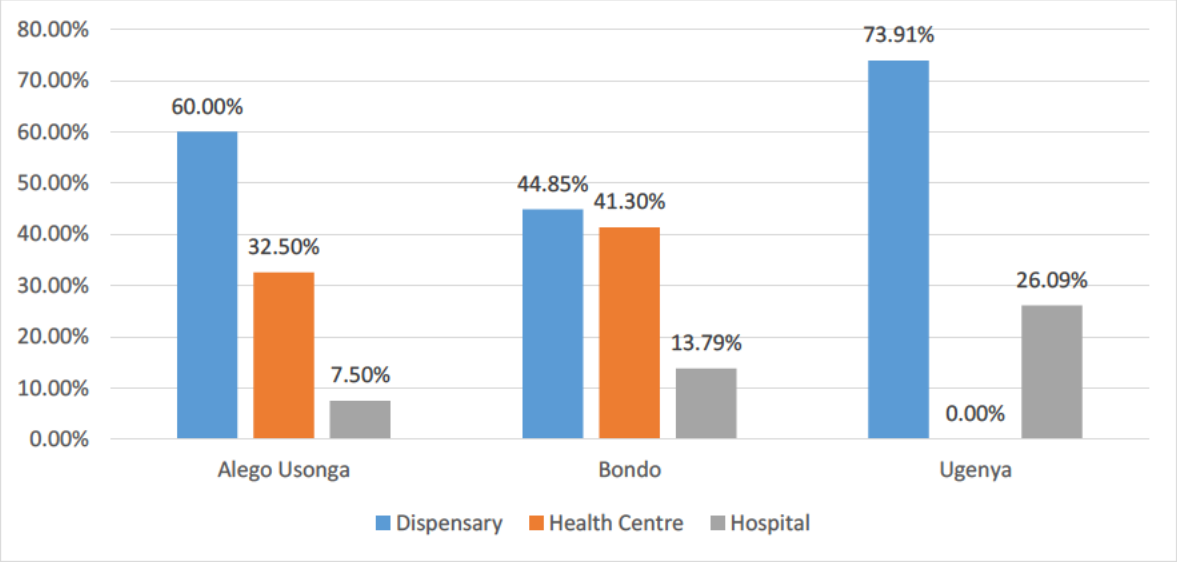


Figure 4.1: Community Units linkages to health facilities

Figure 4.1 shows the linkages between community units and link health facilities. With regard to continuum of care, Alego Usonga and Bondo sub-counties enjoyed at least fair distribution of the CHU linkages to the health facilities. The dispensaries claimed the majority of CHUs were in Ugenya (73.91 %), Alego Usonga (60%) and Bondo (44.83%),

followed by the health centres in Alego and Bondo. Ugenya CHUs had no linkages with the three care services, which put pressure on the dispensaries (level 2) and the hospitals (level 4). Ugenya patients, particular those seeking quality safe motherhood care at the primary care levels, were most likely to miss out, with referrals being enhanced through ambulatory services. Pregnant adolescents with disabilities who needed skilled deliveries were highly exposed to poor pregnancy outcomes due to delays that reportedly occurred before decisions were made to refer the client/patient to the hospital.

4.5 Assessing Access SRHR Services by AWDs in Siaya County

Expected standards of adolescent and youth-friendly services/care with regards to SRH for young people including AWDs are defined by the government as: "*sexual and reproductive health services that are accessible, acceptable appropriate, effective and equitable for adolescents and youth.* " Therefore, the service delivery quality was further analysed under the standard rubrics as follows:

a. Accessibility

The study revealed that a lot of challenges were impeding AWDs' effort to access SRH services. From the FGD with adults living with disabilities in Alego Usonga for example:

> " *…lack of appropriate facilities for the disabled in institutions, including schools, banks, hospitals and government offices…in most cases this becomes a problem, especially for the family and community members who have to carry, accompany or offer them assistance to reach the needed receive services…''* (FGD-PWD Participant 5)

b. Acceptability, inequity and inequality

The study established that there was a lot of discrimination and stigmatization of the AWDs, with families and communities where they live not having accepted them. They were called

names, denied opportunities, given limited chances and faced difficulty getting a life time partners.as a participant in an FGD explained that,

> *"... disabled children were not involved in decisions made by their families and community, are denied job opportunities, are not welcomed at their relative's residences due to perception that they were perennial beggars, blocked from financial assistance, and even abandoned by their family members and relatives. Furthermore, AWDs were dis-inherited without recourse, especially those who are not married and are considered as children, their lands are taken away by relatives"(FGD Participant 4).*

Inadequate Responses

Response to the plight of AWDs, especially with respect to sexual violation, was found to be inappropriate. From the focus group discussions with outpatient department health staff and community health volunteers, it was established that the constitutional rights of AWDs were violated and that they seldom received justice. Sexual abuse was widespread for AWD, yet society seemed not to care about their rights, with justice not being sought on their behalf. This was consistent with findings of the National Commission of Human Rights study on access to sexual and reproductive health and rights of AWDs (KNCHR, 2014). A key informant observed that,

> *"...when defiled/sexually abused children with disability are not able to secure justice, cultural mechanisms of settling disputes are widely used rather than the legal mechanism of dispute resolution. Moreover, cases that take a legal direction take a long time and rarely end in conviction of the defiler. In other instances, the affected are considered not able to respond to the issues pertaining to sexuality. Additionally, disabled males are used by widows for cultural cleansing... other challenges include*

poverty and illiteracy, with disability being seen as a disease and in public places it is common hearing people referring to a disabled person as sick (KII Participant 4).

However, a brighter side of the situation emerged, as some of participants working with PWDs interviewed indicated that in the last two decades, the government had put in place a number of interventions to reduce the vulnerability and improve the plight of the disabled children. However, the participant could not identify key improvements that the government had made with respect to AWDs.

A participant in KII observed that

"There have been policies and disability acts, among other frameworks, which have enlightened the disabled and society about the rights of the disabled". (KII Participant 5)

According to the community members interviewed from the right based approach, the disabled were now seen as 'normal', and are perceived to be able to compete and stand up for their rights. However, there was much more that could be done in the area of awareness creation and sensitization on the rights of the disabled within communities and beyond. An informant observed that,

"…It's the community that makes disability eminent, otherwise in a community where disability is perceived normal then it cease being an issue, sensitization was help reduce the discrimination among other vices muted on the disabled. There are competing citizen needs that guide governments" priority in resource allocation; disability is an area that requires government investment, or otherwise looks for supporting partners to help with the gaps in disability…" (KII respondent 3)

The cultural implication, according to key informant care providers across the study, was that

no-one in the community should raise a voice outside the community circles in the event that such matters are perceived to be a threat to the very fabric of societal relationships between and among kindred.

The participant in a FGD that:

> *"The common scenario is when a disabled girl becomes pregnant, the man responsible often come from around the family, such as an uncle or any other close relative. The matter is settled at the village baraza (referred to as community kangaroo courts) presided over by jodongo (elders), whose words are a law unto themselves* (FGD Participant 3).

Unanimously, from the FGDs and KII information gathered the fear was that if such cases went to court, the matter would take a different turn in the interest of the victim. In a community where disability was largely still conceptualized around myths and misconceptions that purport to explain the causes and consequences of the phenomena, the SRH rights of the victim ('not normal') should not be allowed to supersede and erode the dignity of a 'normal' person. A seemingly agitated key informant expressed her anger in trembling voice say,

> *"…it is sad that if a woman had a disabled child… who has been defiled… (paused), she should hide the child… or take her to a different place, or take child back to her parents, the disabled adolescent being denied all her sexual reproductive health rights and left at the risk of adverse consequences from the abuse…as the abuser walks free…"* (KII Participant 2)

The concept advanced here was *odhitueyong"twayawa"* (remember it is our person at the brink, you dare not commit him to jail). This had made reporting on such actions imposible as

a participant in an in-depth interview explained and captured here that,

> *"...this sentiment scared many, including parents of the victim who might had been contemplating taking some form of action against the perpetrator apart from that which was culturally sanctioned. Children were not involved in the discussion nor their interest considered in out-of-court settlement. It was the family that received the compensation without considering the emotional, psychological and physical damage inflicted on the victim"* (In-depth interview Participant 3)

4.5.1 SRH Service Delivery to AWDs

Sexual and reproductive health and HIV services for young people in Siaya County were confined to youth-friendly (YFC) and patient support centers (PSC). These were either in government facilities or NGO/FBO sites run by non-governmental bodies, with the government having only provided space for the services, the rest were facilitated by private bodies. It was in this respect that six typical YFC and PSC were identified and analyzed for adolescents and disability friendliness. Government standards and guideline frameworks were used, including research adapted checklist, to assess the friendliness in the above respects (**See checklists under appendix 4**). In each of Alego Usonga, Bondo and Ugenya/Ugunja, two YFC were evaluated as below.

Accessibility and Disability Friendliness in public facilities

In Alego Usonga, this study analyzed three link facilities: Mulaha dispensary, Kadenge health centre and Siaya County Referral hospital .The facilities in this sub-county were different in terms of access, with many not being easily accessible to the AWDs, some lacking the necessary facilities to make them disability-friendly. Kadenge YFC was not disability friendly in all parameters of the assessment; for instance, the center had no sign language interpreters to serve clients who were deaf or dump. For instance from the observation

checklist data, the study revealed that, the facility like the rest others observed, lacked essential services for the disabled, such as ramps for access, railings along corridors or in outside areas, directions on key areas, a disability desk, information on braille or audio format, beds that could accommodate the physically challenged or simplified information access systems. The doors could not easily fit wheelchairs; they had no wheelchair access toilet, and did not offer preferable treatment to people with disabilities. Mulaha Dispensary, like Kadenge health center, lacks essential facilities that would make it disability friendly. Equally as the researcher observed, the health center lacks ramps, railings along corridors, directions on key areas, disability desk at the entrance, sign language interpreter, information in braille or audio forms, or beds to accommodate physical disabilities. The facility does have doors that can fit a wheelchair. Sadly, the situation of disability friendliness was the same at the county referral hospital, which was both a primary link facility for community units around the hospital and a higher referral facility for other lower facilities, and could have been more inclusive in character. However, disability friendliness generally was not observed with the other facilities

Within the sub county, another observation was with respect to service delivery in the s including SRH and HIV services for adolescents with disabilities (AWDs). Although the important services in both Kadenge and Mulaha were on the ground floor, they were not disability friendly. From observation, for instance, the health information at the health centers were not simplified for people with disabilities, neither were there simplified ways for AWDs to report abuses or demand for services in less intimidating ways. The medication boxes at the health centers did not have symbols, pictures, or Braille to accommodate special needs and neither have staff who are trained to assist those with disability.

In Ugenya Sub County, while there were no specific programs targeting AWDs, the sub-

county hosts a community- based health program called Matibabu Foundation Kenya (MFK) that offers disability services. As explained by a key informant interviewed captured below,

> *"…this is a privately owned and run facility under the non-governmental organization that started as community-based organization…operational model providing fairly comprehensive primary healthcare program...*" (KII participant 6).

The facility was serving young people within Ugenya and Ugunja sub-counties, although there were other health centers and hospitals with YFC for the same population, a client who was mature AWDs interviewed expressed dissatisfaction with services at the public facilities, as captured below:

> "*…..we prefer Matibabu because they have most of the services I as a young person would like to have…the people working here are explaining everything to us…like HIV, problems with unprotected sex. I keep coming to learn more about my health" (KII Participant15)*

The Matibabu Foundation provided general healthcare, including SRH and HIV services for all adolescents and youths, including those with disabilities. The quality of services to AWDs was analyzed, as per government prescribed standards, and aimed to provide equitable access to youth and adolescent friendly services without discrimination. Observed through a checklist, the facility has ramps to access the building and outside areas, although they are not in all the buildings, and some of the doors of the facility can fit a wheelchair. Beside these basic amenities that permit access for the disabled, the facility lacks other essential facilities, such as wheelchair accessible toilets, railings along the corridors, and directions on key areas. The facility has essential services on the ground floor, which makes it easy for people with disability to access like everyone else.

In Alego-Usonga Sub County, both Mulaha and Kadenge Health facilities do not have any

form of links to ways of alleviating poverty among the people AWDs. Mulaha dispensary has a referral system for disability services to reproductive health services. The facility lacks screening tools for identifying disability and arrangement for referral to HIV testing and treatment. Moreover, both the facilities lack rehabilitation team that was trained and equipped to address HIV-related disability issues for AWDs. The study further observed through checklist that, both the health facilities link to community services- home-based care and community-based rehabilitation targeting people living with HIV-AIDS and as well as all ages of disabled persons, in-depth interviews with health providers indicate inadequate capacity to deliver SRH and HIV services to adolescents with disabilities (AWDs).

In Ugenya, the Matibabu Foundation facility had back-to-work programs for people who acquired disability, and a referral system to social work, disability grants and business loans. The Community based health program however lacks screening tools to identify disability, including mental health problems, which affects program targeting. It also lacked food security programs that include people with disability, and sheltered employment opportunities. It had a referral system from disability services to reproductive health and VCT, from ART and VCT programs to rehabilitation as well as mental health services, and a rehabilitation department that was trained and equipped to address HIV-related disability. Moreover, the facility is also partly linked to community services in the areas of home-based care, community-based rehabilitation, disabled peoples' organizations and NGOs that focus or include people with disability. With regards to community services targeting AWDs, the organization links to the National Council for People living with Disabilities (NCPWD) that facilitates advocacy for social security and safeguards for registered members. This arrangement however, experienced episodes of exclusion since not all program participants were registered with NCPWD to qualify for government subsidies; the process of registration remain cumbersome and expensive for the AWDs, who are often very poor.

4.5.2 Human Resources for Health

Acute shortage of human resources for health is widespread across the region. In Alego Usonga Sub County, SRH services are affected by lack of staff with erratic support by volunteers who were mainly peer educators and sometimes community health volunteers. Staff shortages were not uncommon in the sub-county primary care facilities reviewed. The staff at Mulaha and Kadenge health facilities was generally not adequately trained on ways to screen for disability and refer to the right services. While the staff at Mulaha dispensary was trained on disability screening, including mental health in general services such as antiretroviral therapy (ART), the staff at the Kadenge health center (HC) had training on health rights of people with disabilities though not specific to AWDs SRH and HIV service needs.

4.6 Financing

Health financing remains a big challenged for the sub-county as for the rest of the county. While the county government contributes to the employment of human resources for health and infrastructure provision, most of the community activities are funded by partners. For instance, financial support in Alego Usonga subcounty was reported by a key informant to be from;

> *"…Essential health services (EHS), World Vision and AMREF, JICA and STIPA. EHS and JICA provided chalk boards for one of the units interviewed, Amref support capacity building (training and refresher training) and RH, Maternal, Neonatal and Adolescent health, World Vision supported Maternal health and STIPA support community- based health financing" (CBHF) (KII-SCHMT-member).*

Furthermore the community financing scheme offered by STIPA also contributed to health financing in the county, albeit in a small way. A key informant who is a chairman of the

community health committee explained that,

> "… *in this scheme those registered as members pay varying subscriptions of between Ksh 1,500 to Ksh 2,700 yearly to be able to access health services through the link health facilities in the county. With this scheme, the members have been able to pay for premiums about 17 orphans and vulnerable children (OVC) including adolescents with disabilities alongside elderly people in the community (KII-CHC.*

In Bondo sub-county, financing community health services, such as SRH and HIV care in, has remained inadequate, with the sub-county relying on the county for funding. In line with budgeting, annual work plans start at the county level, although their implementation rates are usually low as they are not funded adequately. A SCHMT-FGDs participants expressed that,

> "… *most of the activities at the sub-county level are partner driven, which was a considerable challenge, as partners had their own interest and do not necessarily fund the sub-county priorities. Currently, the non-state actors supporting the area of children rights include: Plan International, CHS, Impact research, AMURT, World Vision and CBOs. Although the support from partners has contributed to accessing services such as family planning, maternal, child adolescents and youth services, none of the support provided has directly and adequately targeted SRH and HIV services for AWDs"(SCHMT FGDs Participant, Bondo)*

In the sub-county, the health facility was responsible for ordering commodities on behalf of CHVs, who provide treatment, and have a tracking register and a commodity inventory book, which records the commodities issued. The commodities include atemetherlumethrine, malaria rapid diagnostic testing kits (MRDTK), zinc and oral rehydration solution (ors) for

managing children with diarrhoea, male condoms, family planning pills, and chlorine tablets. However, there was no way of monitoring the stock.

4.7 Health Commodities /Technologies

In Alego Usonga, at the youth friendly centre (Siaya Hospital), no commodities or equipment had been supplied, which should include family planning commodities, HIV testing kits, cancer screening equipment and health education materials. Gaps in relation to commodity supply were not well articulated, with such crucial information including when and how regularly they receive supplies, what was done when there are stock-outs and how frequently this occurs. The study established that several commodities were received by the community health units through the community health extension workers (CHEWs). The supplies provided are inadequate and of limited range as a CHV in a focus group discussion observed

> "*…what comes from the link health facility to CHVs included malaria test kits and antimalarial drugs, condoms and data collection tools only…those clients who need contraceptives…we refer to the health facility. In addition, we are also provided with bicycles to facilitate our work around the village"(FGD Participant2)*

4.8 Health Information System

The data collection process from the community to the county based district health information system was very elaborate but not exhaustive. At the community level there were various tools use for data collection and reporting. The household register (MOH 513) was used to collect socio-demographic data from the households within the catchment of a community health unit; the register was updated after every six months to capture any household vital events that might arise within the period; service delivery book (MOH 514) contains the services delivered to the household members during home visits by the CHVs; community Chalkboard (MOH516); CHEWs summary book (MOH 515) ; Referral book

(MOH 100) and MOH 711 which the CHA uses to collate from the other tools and make a summary in the MOH 515. A key informant explained that,

> "*The reports prepared by the CHA were organized to address specific cohorts of the population including adolescents, adults, expectant mothers, children (an example of such a report could be about high rates of teenage pregnancies in a particular area). The information from the CHVs was eventually summarized using CHEW summary (MOH 515) and entered into the district health information management system (DHIS). In the DHIS indicators monitored include;-WASH (for public health); malaria (pharmacy/malaria coordinator); reproductive health (family planning in the reproductive health department); teenage pregnancy (also RH department). Disability is not in the indicators monitored by the DHIS" (KII Health Provider, Bondo)*

At the community level there are various data collection and reporting tools, which includes a household register updated after every six months (MOH 513) that contains all the vital household information, including disabilities; a service delivery book (MOH 514). Where the CHVs record all the health interventions they offered to the household members, including counselling, malaria testing and treatment; a community Chalkboard (MOH516) that was used by the community health unit team to record and share CHEWs summary book (MOH 515); a referral book (MOH 100) and MOH 711, which the CHA used to collate data from the other tools for summary in the MOH 515.

In the DHIS, indicators monitored include: WASH (for public health); malaria (pharmacy/malaria coordinator); reproductive health (family planning in the reproductive health department) and teenage pregnancy (also RH department). Disability was not included among the indicators that were monitored by the DHIS, making it difficult to obtain data for

programing. Furthermore, such gaps on disability data would affect policy decisions on matters that affect AWDs. Other challenges identified were related to health data collection by the CHV, who may sometimes have integrity issues with data and may modify data from the households.

In addition, the reporting rate of CHV was below expectation due to the over involvement with personal commitment, such as burials, taking children to school, changes in the national school calendar, the weather and the farming calendar, which was influenced by seasons. A seasonality calendar was therefore key in planning community activities, including dialogue and action days where pressing community issues were discussed and adopted for execution. Additionally, it was explained by the CHAs that as the CHVs were not permanent staff but volunteers, who sometimes worked without strict schedule time, accountability was a big challenge.

The study found that the primary source of information on disability was the household register (MOH 513). This had a column for each member of the household in terms of gender, age, disability and disability type. However, the data on the type of disability had remained at that level and did not find its way into the CHEW summary sheet (MOH 515). The CHEW summary disabilities were grouped together with chronic illnesses, with only mental illnesses being mentioned, which essentially leaves out all other forms of disabilities. As the information on specific type of disability was not escalated to the CHEW summary, it means it does get included into the district health information system (DHIS). This was an information gap, as the system cannot desegregate disability into various types, which means that the county government and other relevant authorities cannot develop specific interventions for each disability type.

4.9 Key Challenges of the County Health System

Although different challenges abound in the discharge of roles in service delivery by SCHMTs, leadership and funding gaps were the main issues that were expressed across the sub- counties. The following constitute some of the pressing challenges the teams face with negative consequences for community health services, including SRH and HIV for AWDs.

a. Leadership and Management Challenges

A number of challenges were cited with regards to leadership, such as poor coordination due to inadequate capacity of SCHMTs to effectively supervise programs at sub-county and lower level due to lack of institutional support from the central management (CHMT). Furthermore, there was an apparent disquiet among the sub- county health team members with regarding how functions are demarcated in the county health system. The county level team was viewed by the sub-county health management as having apparently taken over the role of supervision of the facilities, although this should have been a function of the SCHMTs. As a participant expressed in a FGD,

> *"…there is no facilitation from the county to enable the sub-county level teams to move around…the CHMT occasionally integrated some of the SCHMT program managers in supervisory visits for the sub-county units, but such sessions were also rare and uncertain"* (SCHMT-FGD Participant 2).

The sub county teams mainly depended on partners to fulfil their functions. As observed in a FGD with SCHMT members:

> *"…SCHMT, however, do it only when they are facilitated by partners who have their own interests…so SCHMT program managers who do not have partners supporting their programs stay in the cold waiting to be unfairly judged for non-performance by the superiors".* (SCHMT-FGD Participant 1)

The implication was that the lower level health facilities were not regularly supervised to ensure the quality delivery of health services, despite being the levels that form the bulk of primary care delivery for vulnerable groups such as AWDs. Moreover, integration of healthcare services needed at such levels was reduced to vertical programs, as was favourable to the partners.

b. Funding Challenges

Financing for sub-counties was also a big challenge to the functioning of the SCHMTs with serious consequences for service delivery across all levels of care. Since the devolution of health in the county, mechanisms of financing have not appropriately adjusted to facilitate optimal functioning of the SCHMTs. Currently there was funding kitty for the SCHMT that run day to day operations of the health facilities under their jurisdictions. According to SCHMT members interviewed, there was also inadequate resource allocated to support supervision, with the team relying on support by partners, a situation that was usually skewed in favour of the interests of the development partners, hence diminished certainty for supportive supervision by SCHMT. For instance it was observed that:

> *"…The SCHMT have not had funding since devolution – All health facilities have to bank their collections in the county revenue collection account after which they are supposed to receive an allocation from the county, which doesn't happen. Previously, before devolution when 25% of the revenue collected by facilities (user charges) was sent to the district health office to facilitate movement of the teams especially when conducting supportive supervision activities. The 75% of the collections remained at the source health facilities for maintenance of the facility and payments of casual staff. The only sources of funding for health facilities currently are free maternity and NHIF"* (SCHMT- FGD Participant 10)

At the time of the study, there was no budget for the sub-county teams. The authority to incur expenditures (AIEs) which used to be there before devolution was no longer available. The respondents felt that the electronic financial system (IFMIS) had made it difficult to access money for use by SCHMTs. Although such grievances and other issues of potential conflicts affecting health facilities are normally addressed in quarterly review/performance meetings by sub-county MOHs with the CHMT, satisfactory solutions were yet to be found.

The research observed that there was general discontent among the various health teams due to limited support from the County Health Management Team. Although the SCHMTs were eager to work, they were limited by institutional barriers that were causing difficulties among the team members, and require support from the CHMT to conduct effectively supervision. A SCHMT member participant explained that,

> *"Things have changed for the worst since devolution, with structured supervision not having been done in a long time. There was also a need for adequate financing, as without realistic financial input into health services production and distribution, effectiveness of healthcare for poor people such as AWDs had remained untenable. Moreover, staff capacity development was needed for SCHMT members to all go to the School of Government to learn leadership, management and financial management" (SCHMT-FGD Participant 6, A/Usonga)*

Accessibility of health facilities in deep rural areas of the county was a challenged, with transport being a major need for the teams to provide health services. Adequate transport and equipment including, vehicles and motorbikes, to specific departments was needed, with pooling of vehicles to support field activities. Offices need to be improved to remove the pressure on the limited office spaces available at the various sub-county hospital premises. Worst hit by the lack of offices to operate from was the Ugenya sub-county SCHMT. The

team was forced to work from their homes and only respond to agent matters when called upon (observed during this study). Traditionally, across the sub-counties studied, Annual Work Plans (AWPs) were rarely implemented to reasonable expectations of those involved, despite these being the tools used to mobilize and allocate resources to health activities. If not improved, this was likely to dampen the spirits of the SCHMTs to the detriment of the poor health seekers such as AWDs.

CHAPTER FIVE

STATE OF COMMUNITY-BASED HEALTH CARE IN SIAYA COUNTY

5.1 Introduction

This study established that a good range of the parameters assessed on the functionality of community-based programs in delivering SRH and HIV services for adolescents with disabilities were weak. This chapter presents findings on Objective 2 that set: to assess the functionality of selected community health models in delivering SRH and HIV services for AWDs. Consideration for variety was key to the selection that identified Support for Tropical Initiatives in Poverty Alleviation (STIPA) which is a community- based health financing (CBHF) organization, MATIBABU (Integrated services) and Nyangoma Faith Based Organization (FBO) (healing and wholeness). The approach helped the study to net any critical avenue that is necessary for comprehensive understanding of the phenomena.

The researcher sought to assess the state of the building blocks that constitute these organizations, with reference to the WHO Health Building Blocks model, which is composed of: 1). Leadership/governance 2). Staffing3). Financing, 4) Health Commodities, 5) Service delivery and 6) Health Information Systems and Subsystems for Assessment. This helped to provide an understanding of the state of each component and their implications for SRH and HIV service delivery for AWD, in conjunction with the county's government healthcare system. In-depth interviews were held with senior officers from the selected organizations, coupled with a review and analysis of secondary data, including financial and programmatic reports and plans. Table 5.1 presents the results of the assessments of individual organizations and their relative capacity for services delivery. The table 5.1 shows the types of community-based programs that were providing some form of care to the community, as well as the opportunities available that were created for AWD to access SRH and HIV care.

Table 5.1: Typical CBHC initiatives

PROGRAMS	SUMMARY OF SERVICES	ASSESSMENT
Community based rehabilitation (CBR) – vertical program	Largely physical rehabilitation services. Manipulating fractures, correcting bone structure deformities, providing devices-wheel chairs; crutches; orthopaedic shoes etc. Targeted persons with physical disabilities with main services providers being physiotherapist And occupational therapists.	1. In our observation, there are numerous opportunities for integration of primary care services including SRH and HIV into CBR. 2. By and large, CBR programs in the county have not adapted to deliver comprehensive care for its target population including AWDs. 3. The closed-posture of vertical-corrective model for disabilities continues slows down its interactions for holistic care. 4. Moreover, CBR is popularly viewed as a hospital agency for exporting medical model of disability into the community. 5. Households with children with disabilities only wait for CBR officials to fix their impairments. Lack of inclusive and human rights based view of disability thus limits CBR as

CBHF-Vertical programme	Provided pooled insurance health financing. Services catered for under the risk cover included access to ANC, safe deliveries at HC, county referral hospital.	1. Although the approach was universal to all poor households, the most vulnerable groups, such as AWDs, were not explicitly covered. 2. The false assumption is that once a poor household is enlisted, automatically, cases such as female AWDs would get services. 3. With inherent prejudice and stigma towards sexuality, adolescence and disabilities, the households would most likely exclude AWDs from benefiting. 4. Due to lack of a special fund in the programs earmarked for affirmative arrangements, affordability barriers are implicitly perpetuated against AWDs in poor households
Adolescent/ Youth Friendly Centres (AYFCs)	• AYFCs are providing SRH, VCT, STI/STD prevention and treatment services • Vertical programs although	1. Despite the government‘s elaborate policy and guideline on AYFS, no direct investment currently flows into YFCs to deliver services to AWDs. The

	efforts were being made to include other social services	centres are largely donor driven with non-state actors being the main champions. 2. The centres operated in between the health facilities and the community, although the link with community systems like the Cus and families was minimal. And are run mainly by untrained volunteers. Some, located in crowded places lacked privacy and confidentiality rights of the clients. Hence were not appropriate for those already stigmatized like the AWDs. 3. The targets are mainly young people of different age sets with services provided at flexible times to youths- throughout the week including weekends and late evenings. Although the arrangement is with the bid to capture both the youth in and out of school, the needs of AWDs were not catered for.

		4. The set ups were not AWDs friendly in many respects. The physical structures are not accessible to those on wheel chairs and the visually impaired. Information services could not be accessed by the deaf and the blind given the lack of appropriate communication materials and equipment. Sign language interpretation, audio tapes and Braille Staffing was inadequate and inappropriate especially with respect to AWDs needs. 5. In essence the friendliness of the youth centres as purported still lacks inclusivity and appropriateness needed to deliver SRH & HIV services for all
Disabled Peoples Organisations (DPO/CBO)	• The program offers advocacy services to its members • Mobilizes members for disability assessment and registration with	1. Interaction with and observation of the disabled persons' organizations revealed serious gaps that must be addressed for AWDs to access services. 2. The initiatives are run by volunteer

	NCPWD • Fundraises for the affiliate • Networks and CBOs on various aspects of livelihoods including table banking • Provided vocational trainings to the members • HIV awareness for members	officials who are also disabled and not adequately trained on health including SRH and HIV service needs of the members in particular the AWDs. 3. Funding of activities of the DPOs is very low/non-existent. This means the organizations are not able to discharge its mandate to their vulnerable members 4. Awareness levels of many aspects of health and development remain extremely low among the officials and even the ordinary members. 5. The leaderships of these organizations appeared overwhelmed by the recurring challenge from the younger children and the very old. 6. For children, adolescents include, essential growth and development needs completely down-weigh on these outfits. Daily demands for survival override other essential basic needs SR

FBO – Comprehensive	Targets the whole community with all health services	1. Stable leadership although health policy awareness is rather law 2. Had stable financing from the parent churches 3. Staffing was a big challenge given the demand of services 4. Data on disability was not a priority 5. Cordial referral arrangements with other link facilities 6. Depended on the government and partners on SRH and HIV commodities supply
NGO/CBH C – Comprehensive	Target all community segments in health and development	1. Depended on partners on SRH and HIV supplies 2. Have stable leadership, 3. steady financing although with donor reliance 4. Venturing into alternative financing- income generating activities (farming, charging, services, services contracting with government)

5.1.1 Support for Tropical Initiatives in Poverty Alleviation

Support for Tropical Initiatives in Poverty Alleviation (STIPA) is one of the identified and selected CBHC initiatives that were found to offer unique services to the community. The organization exists to enhance access to healthcare for poor households, including those hosting AWDs in Siaya County. The entity is a registered NGO in Kenya under the NGO‘s Act (Now Public Benefits Organizations’ Act), and was founded in 1997 to deliver programs focusing on health, economic empowerment and livelihood. The organization operates in seven counties in Western Kenya, namely: Homa Bay, Kisii, Kisumu, Migori, Nyamira, Siaya and Vihiga. STIPA’s vision is to empower communities and organization that are in control of their lives. Their mission is to work with communities and organizations to alleviate poverty through capacity building, advocacy and promotion of community development initiatives.

The organization was currently undertaking three projects, these being on Community Based Health Financing (CBHF), Preventive and Promotive Health, and Safe Motherhood. This was a unique healthcare model that leverages poor households’ capacity towards minimizing the considerable out-of-pocket expenditure on healthcare. The analysis looked into how such initiatives have managed to provide services and expand access to vulnerable groups, including what lessons that could be learned to address programming issues such as targeting, financing, and managing for lasting impacts.

- **Staffing**

The organization had 16 staff members with relevant qualifications and experience in public health, project planning, social work, environmental studies, development studies, rural development and accounting. The staff are employed on contractual basis, depending on the project cycle and availability of donor funding. The organization hosts fairly youthful staff

who may associate well with adolescents on matters related sexuality. However, the analysis revealed that none of the staff is trained on health issues, including the SRH and HIV care needs of AWDs. The situation thus makes it difficult for the organization to effectively provide inclusive services without discrimination. It is however noted that STIPA is working in collaboration with other health systems to deliver services for its target beneficiaries.

b. Experience in Community Health Strategy

The organization is present in five counties including Siaya County, the study area, with 25 CBOs, 64 CHUs and 34 health facilities enabling 14,000 people to access healthcare within the health facilities. They work through:

- Organizing periodic stakeholder strategic planning sessions involving CHVs, CHAs, local admin, ward admin, sub county MOH and CHMT,
- Work with CHUs in promoting prevention and control interventions in the different target community through community dialogues,
- Holding quarterly review meetings with CHVs, CHAs and health facility personnel to track project progress using the provided government tools (MOH 705A and B, AL register, and MOH 636). These meetings have enhanced quality reporting, quality data collection, filing and the usage

c. Financing

The proportion of grant funding has also been increasing from year to year, the amount received from grants between 2015 to 2017 having increased, which accounts for more than 70% of the total organization‘s annual income (Table 5.2).

Table 5.2 Source of Fund

	2015	2016	2017
Other income	23%	21%	11%
Grants	77%	79%	89%

d. Expenditure

Although STIPA was reaching out to poor households through CBHF to be able to access basic reproductive health services, less was mentioned about the role in facilitating access to SRH and HIV services by AWDs. The analysis demonstrates that organization like rest of the organizations studied is largely reliant on donor funding. Sustainability of the entity quickly becomes a matter for grave concern, hence the need to institute mechanisms to benefit from efficiency gains. However, the organization is building community resilience through financial support to scheme members for income generation initiatives for self-reliance. If expanded to scale, this may earn real dividends to poor households beyond the donor support periods.

5.2 Matibabu Foundation, Kenya

This was a community-based healthcare initiative that was established in 2001 as a self-help group aimed at addressing joblessness, poverty and disease. In 2006, the organization was re-established as an NGO and registered under the NGO Act. The organizations' vision was an informed healthy and prosperous society, and has the mission to provide a family centered health information and services that meet or surpass the expectations of its clients by working with individuals, the community and the government to improve health goals.

5.2.1 Comprehensive Primary Health Care Programing

The Matibabu Foundation, Kenya, ran a very comprehensive community-based healthcare program that covered Ugenya, Ugunja, Gem and Alegao Usonga sub-counties of Siaya County. Some of the programs, in particular FP and HIV/AIDS, spanned beyond the County of Siaya into Kisumu County. The programs that had developed over the years include the following key areas of focus for the organization:

i. Out- and In-patient Care services, which includes an ultra-modern health facility in Ukwala, the headquarters of Ugenya sub-county. The hospital provided major curative services, including maternity, diagnostics, MCH

ii. Youth friendly Sexual and Reproductive Health Rights (SRHR)

iii. Community Based Rehabilitation (CBR): Quality of Life for people living with disabilities

iv. Comprehensive Care: HIV/AIDS; TB and Malaria

v. Medical training

Table 5.3 provides a breakdown of community health services MFK was providing to support the county government of Siaya realize universal access to healthcare including SRH and HIV for the vulnerable groups in the county. The data was sourced from the project plans and records which were then corroborated with interviews with a key informant and community health volunteers interviewed.

Table 5.3: Key Programs being carried out MFK

Program	Target Beneficiaries	Some of the Achievement Organization had registered gleaned from the reports shared by the KII interviewed
Family planning and advocacy project	Women of reproductive age	Had reached of 70,000 female youth and adult women of reproductive age in Siaya and Kisumu counties with contraceptive services. 130 health providers and 214 volunteers have been trained 38 health facilities had been upgraded to modern contraceptive services and other SRH services. The organization has screened over 1,000 women on cervical cancer with over 75% linkage to treatment of women found with positive lesions. Over 100 young girls have also been provided with HPV vaccines through the school health program.
Quality of Life	People Living with Disabilities	Matibabu (MFK) had supported over 600 people living with disabilities with physiotherapy, provision of mobility equipment, medication and provided technical assistance to caregivers in construction of home –made physiotherapy equipment and facilitating corrective surgeries. Established linkages with Social Development department
HIV AIDS	People living with HIV	MFK had worked in collaboration with PEPFAR and reached over 61,000 people with HIV prevention information out of which 33% managed to receive full package of behavior change communication (BCC) messages; 29,000 people

		reached with HIV testing services (HTS). Established a laboratory network supporting 13 health facilities with HIV disease monitoring tests including biochemistry, full haemogram, CD4 among others 6,000 people living with HIV/AIDS interventions in Ugenya Sub county contributing towards the achievement of 90-90-90 targets and Accelerating Children's HIV/AIDS Treatment (ACT) initiative in the 12 facilities supported under its HIV program

Although the organization had resources and a combination of services in a comprehensive manner, they are yet to align to serve AWD. For instance, lack of staff trained in sign language and SRH needs of AWDs reflects a gap in the organization's delivery system. Moreover, although the Foundation was running a community rehabilitation program across the sub-counties of this research, its human resource capacity remained a challenge for SRH and AWDs.

5.2.2 CBR Programme Matibabu Foundation Kenya

Another program associated with the Matibabu Foundation that is directly linked to PWDs is their community based rehabilitation program. This too was assessed for its viability as an avenue to leverage SRH and HIV services for AWDs in Siaya County. The community-based Rehabilitation (CBR) program was initiated by the WHO following the declaration by Alma-Ata in 1978 in an effort to enhance the quality of life for persons with disabilities and their families, meet their basic needs, and ensure their inclusion and participation. While initially designed as a strategy to increase access to rehabilitation services in resource constrained settings, the CBR is now a multi-sectoral approach working to improve the equalization of

opportunities and social inclusion of persons with disabilities. In Ugenya, the CBR is implemented through the combined efforts of PWDs, their families and communities, and relevant government and Non-governmental health (Matibabu), education, vocational, social and other services. The CBR Program in the Matibabu Foundation began in 2014 with a partnership from a Belgium based organization (CBR Team International). Out of the five pillars of the CBR matrix, they have been dealing with health, which comprises physiotherapy, occupational therapy, providing medication to epileptic clients and mobility aids to PWDs within Siaya County. Although SRH and HIV needs are of great concern for this program, such services are not given direct prominence.

In Ugenya sub-county, Matibabu has a total of 45 clients. Out of these, 28 are under the age of 20, of whom two adolescents aged 18 and 19 were interviewed. The program mainly deals with physically disabled clients, including musculo-skeletal disabilities caused by cerebral palsy (CP), trauma, stroke, congenital malformations such as club feet (congenital talipesequinovarus).

> *"…We also have epileptic clients to whom we give anti-convulsant medication to control seizures and prevent mental retardation caused by frequent convulsions. Some of these conditions are acquired while others are congenital. Other forms of disabilities encountered include hearing, speech and visual impairments that are appropriately referred to other facilities for service delivery since the program lacks the capacity required."(CBR Co-coordinator)*

The Matibabu Foundation Hospital has other programs that deal with health issues, such as sexual reproductive health, nutrition and cancer. AWDs are included, as observed by a key informant, who said that,

> *"In case of a client with disabilities in need of these services we also refer*

appropriately. …We practice multidisciplinary approach in that, we work together with CHVs, CHAs, DPOs (disability support groups) in identification of PWDs, follow ups and appropriate referrals for service delivery. We participate in World Disability Day celebrations which are a good forum for AWDs; where they share their experiences, get to know about matters constitution, availability of financing institutions for various projects and many others…available services for them". (Male Key informant, MFK)

5.2.3 AWDs Friendly Services

The service delivery at the Matibabu foundation (MF) can be said to be a need that has not been fully realized. The service delivery points implement systems that ensure the adolescents are knowledgeable about their own health. While the facility is adolescent and youth-friendly in areas of health literacy, these facilities have not been focused to address the needs of the adolescents with disabilities. The facility has good stakeholder support that includes future plans, which are executed through legal funding. While the facility has appropriate package of services for counselling, diagnostic, treatment and care services that fulfill the needs of adolescents and youth, it does not address the needs of the disabled. The healthcare providers at the facility demonstrate the technical competence required to provide effective health services to adolescents and youth.

The competence of the healthcare providers is especially good in sexual and reproductive health; HIV and general health issues, but are not disability focused, especially on needs for sight and mental challenges. The health facility staff and delivery point provide quality services to all adolescents and youth, irrespective of their ability to pay, age, sex, marital status, education level, ethnic origin, disability status or other characteristics. These provisions for equity and non-discrimination have not however been provided for people

with mental illness or hearing defects. The facility has appropriate methods of data collection and quality improvement. They have specific tools for data recording in the youth-friendly center, but these provisions do not capture data and the quality improvement needs of people with disability, although there are plans to change from the paper-based tools to an electronic management information system, and to become involved in advocacy at the national level. Data from the observations of the facility did not involve adolescents in planning, monitoring and evaluation of the health services.

- **Equitability**: the facility provided a full range of services that all adolescents and youth could access, without discrimination. The county referral facility had maternity beds and staff dedicated to the needs of this group. The services were, however, not complete for the blind or deaf. The facility "concentrates on mobility issues".

- **Accessibility**: Although adolescents and youth were able to access the health services provided. It did not offer services freely to all youth and adolescents, except for those seeking SRH and HIV services. The timing of accessing these services was not flexible, as it was only open during working hours, when adolescents and youth may be busy. The facility had disability-friendly infrastructure, such as ramps in selected areas, with its location not being known to its intended clients, adolescents and youth. The Matibabu Foundation CBHC program is located deep in the rural area of Siaya County, and covers all the sampled sub-counties with both comprehensive as well as selective programs. As observed earlier, under the comprehensive model, the program provided integrated healthcare services to the local community of Ugenya sub-county and other neighboring communities on a regular basis. It extends selective program activities, such as HIV testing and treatment for HIV positive clients, rehabilitation services to people with disabilities, including adolescents. Although the program was

enjoying goodwill and a high demand for services from its clients, it was also experiencing some key challenges, such as inaccessibility of the area due to poor road conditions, in particular during rainy seasons. The most affected were the AWDs, young children and pregnant women, who were not safe to travel on the *boda-boda* (motorbike) local transport system to the healthcare facility during the wet season. Moreover, the program largely depended on donor support to run its operation and provide services, its sustainability remaining of concern, although local resources generation strategies were already in place. Another set of challenges was the poor adherence to treatment by some of the clients, including AWDs, and negative the experiences of stigma around disabilities. In the rural setting of Matibabu, culture defined disability is a curse, hence the high levels of stigma and isolation of children with disabilities.

- **Appropriateness:** While the NGO facility rated better on appropriate service provision, it also provided health services that the adolescents and youth need, but that were not specifically for the disabled adolescents and youth.
- **Effectiveness**: the health services were based on protocols, but none are defined to address the needs of the disabled.

5.2.4 Health building blocks

a. Staff

The Matibabu Foundation- a well-established CBHC program, and has a well-trained health and non-health team of workers. This ranges from medical doctors, nurses of varying cadres, clinicians, lab-techs, pharm-techs, HIV and CHVs among others. The staff are trained on community approaches to healthcare service delivery. At the time the study was carried out, there were only two staff running the CBR services in the county, one in charge of livelihood and the other of the health pillar, also being the project coordinator. This was observed to be

inadequate, given the considerable need expressed by AWDs in the coverage area.

b. Partnerships

The MFK espouses partnerships as a means of leveraging resources for its expansion and quality delivery of services. The diversity of its partners ranged from governments to non-governmental organizations: county, national, international and local, including institutions of higher learning, which attests to the adaptive capacity reserved for entities that are open to learning for lasting impacts on the lives of those served. From a systems thinking perspective, the organization has allowed its sub-systems to influence and be influenced by the environment to improve itself, and stay relevant and effective. The organization currently partnered with following institutions as was explained by a key informant interviewed;

> *…We currently collaborate with different organizations on different aspects. These include… County governments of Siaya and Kisumu county government through the health stakeholders forum; Government institutions: including National AIDS/STD Control Programme (NASCOP), National AIDS Control Council (NACC) and the Kenya Medical Research Institute (KEMRI); Local and International Universities: such as Moi University, Jaramogi Oginga Odinga of Science and Technology, Maseno University, University of Nairobi, California State University and other international universities to promote opportunities for research; Development partners: including Amref, USAID, CDC, Planned Parenthood Global (PPG), Tiba Foundation, European Union among others…" (NGO-HCP-KII Participant)*

The implications are that MFK had not adequately harnessed the potentials in the partnerships to avail material and non-material resources for SRH and HIV services for most vulnerable groups, such as AWDs. According to the key informant interviewed, staff capacity to handle AWDs issues, especially those with speech and hearing impairments, was the

biggest challenge, as finding individuals with sign language training was hard in a rural setting. Moreover, their experience as community health providers indicated that sign language varied from client to client, as there was no formal training of Kenya sign language to the families hosting children who were deaf or dumb. The organization runs comparatively effective community-based rehabilitation program in the county. The study established that staff had integrated SRH and HIV services into the CBR program to reach out to AWD.

c. Financing

The MFK source of funding is mainly from donors and service charges for health services provided. Donor funding makes up for the larger proportion of income within the organization, accounting for more than 70% of the total for most of the years in most years with the exception 2017. It is also important that while donor funding has been reducing, the organization has seen an increase in the amount of service charge collected, which has more than doubled in the last three financial years, from approximately Ksh 24 million in 2015 to Ksh 77 million in 2017, and currently accounts for 46% of the total funding, an indication that the organization is heading towards financial sustainability of its programs. (Table 5.5)

Table 5.4: Sources of funding

Sources		***2016***	***2017***
Grants		***77%***	***54%***
Other sources of income		***23%***	***46%***

d. Expenditure

The MFK expenditure goes into financing core and support activities. The core activities are made of the organizations main programs, which include medical surgical and diagnostics, HIV AIDS/TB, family planning, medical training and community health. Support programs include human resource, administrative cost and farm expenses, as indicated in Figure 5.1. From the analysis, MFK has been spending more on support activities than on core activities (with the exception of 2017). The programs however could benefit from efficiency gain to maximize on aid effectiveness in application of funds from grants to core program activities and less on the support activities. This would be one way of ensuring sustainability in the long run. Furthermore, it is also clear that from service charge, Matibabu was able to raise own revenue in remarkable way that remains incomparable to any of the typical CBHC programs that were only donor dependent. Unfortunately, as the study observed there was no designated fund that was available to address AWDs healthcare need in particular sexual and reproductive health. The respondent further explained that

> "….a good number of their partners had required focus on more easily achievable targets, since handling AWDs would pose a lot of challenges to reporting on targets that development partners expected."(FGD Participant 4***)***

Support activities dominated the budgetary allocation for the years 2015 and 2016 at 56% and 59% respectively, which changed to 45% in 2017.

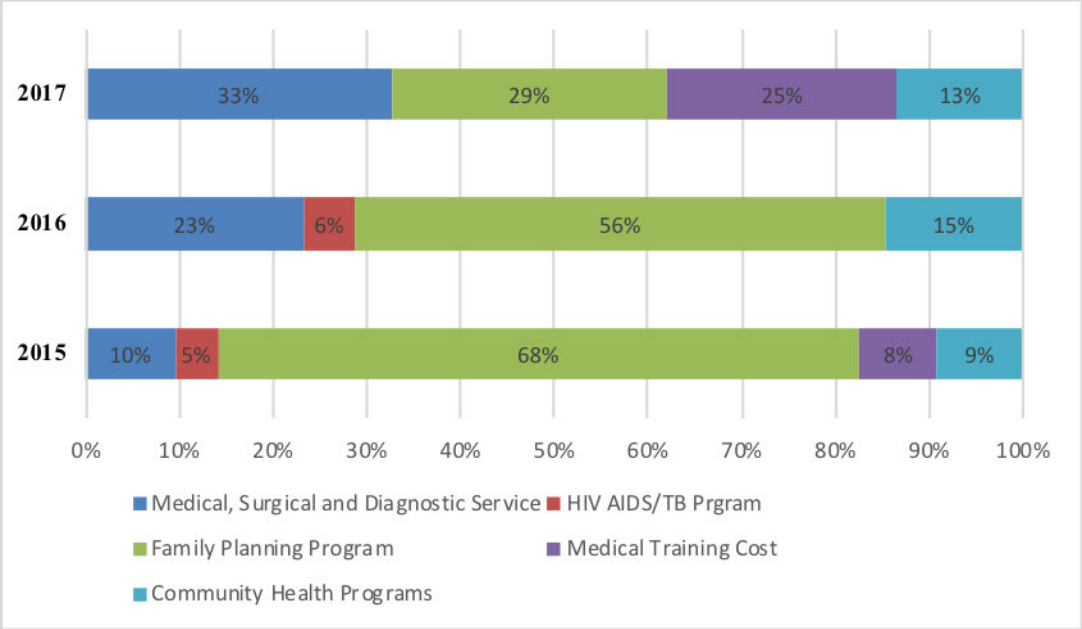


Figure 5.1: Allocation towards core activities

Table 5.5: Expenditure on Core Activities against support activities

	2015	***2016***	***2017***
Core activity costs	***44%***	***41%***	***55%***
Support activity costs	***56%***	***59%***	***45%***

5.3 NYANG'OMA MISSION HEALTH CENTRE

The Nyangoma Mission health program provided the study with a unique perspective of sexual and reproductive healthcare in a religious setting. The research could not readily obtain quantitative data due to time limitation and other factors, therefore the assessment largely relies on information elicited through FGD and Key informant interviews (KII) with the health facility team. The Nyang'oma Mission Health Centre is a FBO located in Bondo sub-county in Siaya County. The health facility was initially established as a clinic to carter for the deaf community within the Nyang'oma School for the Deaf. It was later converted into a public facility as it also served the general community within the area. The facility

currently offers curative in- and out-patient services, antenatal clinics, immunization, basic emergency obstetric care, HIV testing and counselling, as well as ART, elimination of mother to child infection (EMTCT) and sexual and reproductive health information for youth and adolescents with disabilities.

The community has embraced the role played by the church and the health facility, which has resulted in less stigma and much local support for young people with disabilities by the community. For instance, a respondent in a focus group discussion expressed that,

> *"...the unique thing about the people of Nyang'oma village is the way they have embraced the deaf persons in the community. You might find even the young children learning the basics like greetings. The boda-boda riders do slow down near the schools because the deaf cannot hear them when they hoot" (*KII Participant 6). .

The link health facility was a youth friendly environment that offers Adolescent Package of Care (APOC) and includes HIV Testing Services (HTS) for adolescents, including those with disabilities. The main disabilities in Nyang'oma area were the deaf and speech impairments, given the history of the site as the first centre for the deaf in the area. However, due to its linkage to the church, services such as contraceptives and distribution of condoms were not available, and they referred such cases to the sub-county hospital or other nearby health facilities. The facility also provided services for adolescents with disabilities (mainly those with hearing loss and the mentally challenged).

- **Health Commodities and Equipment**

Working in partnership with the county government of Siaya and other relevant agencies has ensured a steady and uninterrupted commodity and equipment supply chain. The respondent observed that although there were occasional shortages and stock-outs, this has never affected their SRH and HIV/AIDS commodities. The facility system has ensured adequate stocks with

an accompanied referral system to and from other facilities for services and commodities they do not provide to clients. This has included the commodities that were in conflict with their faith orientation on matters related to sex and contraception, much more so outside wedlock. According to the sister in-charge who was interviewed, they have maintained seamless succession planning for continuity of supplies.

a. Financing

This study could not establish in absolute terms how much money the programs and the health facility was receiving from its various sources and how this was being allocated across the budget lines. The main source of financing for the faith based program however is through a service charge (this was obtained from the narrative on case study), although the Kenya Conference of Catholic Bishops (KCCB) pays for the hospital staff. Additional support is obtained from partners, including the government and other non-state actors such as Kenya Aids Response Programme (KARP**)**, Mission for Essential Drugs and Supplies (MEDS) which supplies non state-actors with commodities and equipment at subsidized prices, and KEMSA, a government agency for medicine supplies.

> *"Our facility has also benefitted from the Linda Mama initiative which supports most expecting mothers who may not be able to pay for pregnancy related services including ANC as well as deliver services. This would make it affordable to cater for vulnerable groups like pregnant adolescents with disabilities who may not afford ANC services and eventual delivery under skilled health workers." (KII Participant 4).*

The facility draws its financial support from patients who pay for the basic services. However, it was noted that the community members were not ready to pay for services,

which posed a threat to the continued provision of services to most vulnerable people, such as AWDs. Furthermore, discussion with healthcare providers revealed that,

> *"…Out-of-pocket payment had made some of the poor patient (AWDs) stay away from the health facility. The recent use of National Hospital Insurance Fund (NHIF) cards has been of great assistance to the facility, although they found it frustrating as money took a while to reach the facilities. Due to some administrative inefficiency, as perceived by the community, the NHIF was facing some resistance from clients*" (FGD Participant 4).

A respondent in an in-depth interview with health staff in the facility said that;

> *"…Some do not want to pay for NHIF saying "instead of giving the government that money I'd rather give "Sister" (Catholic Nun) that cash to use in improving services for our care."* (In-depth interview Participant1).

The study found that there were other government efforts that augmented the work of non-state providers to deliver affordable care to women in reproductive age. For instance a KII explained that,

> "*… the new 'Linda mama' initiative is an expanded programme for free maternal care that was launched under the NHIF in October 2016. Its aim is to improve access and quality of free maternal, new born and child healthcare services for one year. This initiative is helping Kenya achieve Universal Health Coverage (UHC), the health goals defined in Vision 2030 and the Sustainable Development Goals (SDGs) 1, 3 and 10 associated with poverty, good health/wellbeing and reduction of inequalities. Under Linda mama, women received a package of care that includes both out- and in-patient services for the mother and new-born for a one year, inclusive of nine months' pregnancy period and six months after delivery. Many mothers, especially adolescent*

mothers with disabilities, who did not attend ANC and were only brought to the hospital in labour for delivery, would not readily access the 'Linda mama' health cover" (In-depth Interview Participant 1)

It was revealed that some AWDs in labor faced challenges with the cover since they needed to have registered with the program in time before they could be covered by the scheme. The study established from the CHVs interviewed who agreed that,

"...that part of the reason for lack of access is that they need their own original identity card and a copy of their guardian's identity card. Yet they did not have such documents (ID or even birth certificates) since some were underage or were not registered at birth. Furthermore it was explained by a SRH service provider that although those who did not have either Identity Card or any other valid document were allowed to present their ANC profile, for AWDs who had never attended any ANC sessions the profiles were not available (FGD Participant 5)

b. Staff

The Nyangoma health center was run by a Board and the administration has HIV Service Lead (HSL), lead clinician, accountant, 14 nurses, a longitudinal officer, lead Nurse, patient attendants, cleaners, drivers and a guard. They had a challenge working with the deaf and dumb, as many do not know sign language appropriately, and they were planning to hire staff with sign language competency. Moreover the group had a service charter posted outside the offices with sign language in alphabets. During this study, the Nyang'oma health center had links with 16 CHVs that connect the facility to clients from 16-20 units of the community. They had monthly meetings with the CHVs where they submit their reporting and referral tools, both from the government and the facility. The staff and the community health workers linked to SRH and HIV services were not trained on issues affecting adolescents with

disabilities. The health providers applied the same method of service delivery to all without considering special needs of AWDs. Inadequate capacity of the staff and CHVs was therefore a barrier to access to SRH and HIV services for AWDs.

c. Information system

Although they had no qualified medical records personnel the task was performed by another staff from a different department who also provided supervision and supported reporting activities. Regarding data on AWDs, an FGD participant explained that,

> *"…Our facility uses reporting tools that captured disability data, as they had a column for type of disability to be recorded compared to that of the government. It was noted, however, that the data on disabilities was not sufficiently used for targeting the services for persons with disabilities, especially adolescents. Neither was the information from the system shared with the government or other partners to influence decisions on services or resource allocation since none had asked for the data, although the government DHIS had no provision for the AWDs related data*. (FGD Participant 3).

d. Service Delivery

Although the owners view the facility to be youth friendly serving age group of 10-19 (with more 10-14 year olds than 15-19 year olds), much restrictions abound. The facility offers a range of adolescent and youth (AWDs included) friendly services, including HIV Testing and HIV services (HTS), (at the time of this study there were two AWDs; one mentally challenge and one deaf). During the visits they were segregated by into two groups of 10-14 years and 15-19 years. In addition, there were other youth leading positive lives from various schools who visit the facilities that were physically challenged and grounded on care. The facility also had an adolescent peer facilitator who links the facility with the youths from the villages. The FBO facility delivers Adolescents Package of Care (APOC). Given the religious values

the owners espouse however, the facility did not provide condoms and contraceptives to any clients and hence make referrals to Bondo District Hospital and Nango Health Center. Previously, the facility worked with other organizations, such as Nango to provide counselling, while Catholic Relief Services (CRS) provided home-based care and nutrition from 2010 – 2011. The organizations had since left, evidence that sustainability of healthcare, particularly among CBHC programs, hangs delicately in the hands of external donors. The situation was a threat to the sustainability of services, especially those that require lifelong commitment, such as SRHR and HIV care for AWDs.

e. Linkage with Community Health Units

Although the program was aligned with a community health strategic approach, challenges of motivation the community health workers remained. In a focus group discussion held with staff, the study revealed that the health centre was working with 16 CHVs that linked the it with 16-20 community units. Apart from the government reporting tools, the facility had also developed its own reporting tool with provisions to capture data on people living with disabilities. Monthly meetings were usually held with CHVs where they submit both tools (MOH and facility). The study established that the organization was leveraging the number of government trained CHVs to deliver on basic services at the community level. Some of the CHVs from the surrounding community units were seconded to the facility by an additional motivation (stipend) by the mission. The effort was not appreciated by some of the CHVs and the community health committees that were currently not being paid stipend. A participant explained that,

> *"…The main challenge we are facing with the current arrangement with the community strategy is that the CHVs were no longer as enthusiastic to work without pay as before…Now days they are easily demotivated whenever the payments delay"(FGD Participant 7,)*

The lack of enthusiasm by the CHCs is affecting the supervision of the CHVs, this being the missing link in the alignment effort of CBHC programs to deliver through the CHS framework. Although monthly meetings were being held with CHVs, the role of CHCs is lacking across the sub county. A health worker interviewed observed that,

> *"We have observed that CHC are not active, they seem reluctant to work,. they are not being paid stipend by the county government as their counterparts- CHVs…this could be the main reason" (KII Participant 8)*

Although the Nyangoma health Centre is an FBO, it has the trust of the community to deliver community based services, such as SRH and HIV care to AWDs**,** although the unclear financing position and value system, if not properly aligned, might compound exclusion of AWDs with respect to SRH and HIV services access. Due to its affordability and accessibility, it may be the only one available to meet the need of AWDs, while moral barriers may never allow for the needed services. Furthermore, the sustainability of services, including SRH and HIV, may not be guaranteed unless the mission improves on its fundraising efforts and options.

CHAPTER SIX

SOCIO-ECOLOGICAL FACTORS THAT AFFECT ACCESS TO SRH SERVICES

6.1 Introduction

This chapter is concerned with objective 3 of this study that sought to explore the experiences of adolescents with disabilities (AWDs) with regards to institutional barriers to their access to SRH and HIV services in the community. The chapter therefore observed the state of alignment of Community Based Healthcare programs to deliver quality sexual and reproductive health and HIV information and services to AWDs. These were hinged on access factors at the link health facilities. Although the study observed the significance of link health facilities to the continuum of care as prescribed by the government with respect to youth friendly-services, barriers still abound. Varying categories of facilities were assessed with respect to youth and disability friendliness in services delivery in this study. These included Siaya County referral, Matibabu Foundation, Ukwala sub-county hospital and Bondo sub-county hospitals; Nyangoma health center and Kadenge Health Center, Mulaha dispensary and youth friendly centers (Bondo hospital, Siaya referral, Matibabu Foundation hospital, Nyangoma health centre). The comprehensive care clinics (PSC) were also assessed, with a semi-structured health facility checklist being used for observations, and interview for verifications of unclear areas. The parameters of access assessed revealed the effectiveness of community health service delivery depended on the access to referral services at the next level of care.

6.2 Physical Access to the Health Facility

Physical access to health facilities come in many dimensions, with the findings indicating that accessing the health facility remains a major challenge for people living with disabilities. First was the geographical location of the facility, and although the government has tried to establish healthcare facilities at least within 5 km of reach, for people with impairment of

whatever nature, the distance remains far. Worse so, for some AWDs from poor households, for whom transport and the associated discomfort of getting to the health facilities constitute a real barrier to access. Moreover, access to various sections within the health facilities were reported to be equally a nightmare. Whereas 100% of the health facilities having doors that could fit wheelchairs and open easily, and only 40% having access to ramps outside the building areas. Furthermore, only 40% had wheelchair accessible toilet, neither of the facilities had railings along the corridors or outside the area, nor where key directions available on in braille for the blind. Physical exhaustion and psychological stress were the experiences of AWDs and their parents/guardian as they seek help from health facilities that were geographical far from them. As in the distressful expressions observed during the in-depth interview, with a mother of AWDs noted:

> "*…The distance to the hospital is too far especially when I am alone with my son to take him for treatment. Over the years he has grown big and heavy, he has to be on a wheelchair…you have to carry him on your back as to enter a matatu (public transport van)…very difficult for one person…Sometimes the people refuse to help or even to stop to pick you with your helpless child…there besides the road waiting for a „good Samaritans" to help…in the hospital you still need people to help you lift wheelchair to enter some places" (KII Participant 10).*

Being accompanied to the hospital, especially when it was far away, remains costly, thereby limiting physical access by AWDs. Difficult choices and decisions had to be made by parents/guardians to seek healthcare for their disabled children, while another form of dilemma in access to healthcare for AWDs from health facilities was also noted as one parent expressed

"Distance from home to where we seek health services is far and expensive. The two of us have to pay not less than Ksh. 200 (2USD) one way for a distance others would pay ¼ of the amount. The boda boda (motorbike transport) owners argue that they spend more time helping me to load my disabled child on the bike and deliver us right into the hospital…this is like a special higher…I must pay more. I would have to think really hard, if I would really have to take my child to the hospital." (KII Participant 9).

Figure 6.2 presents the state of access to care in health facilities by AWD, and showed that conditions needed for AWDs to access health facilities were inadequate. Doors were the only infrastructural aspect that was adequate with a bit of services being on the ground floor by default since there was however no storied building.

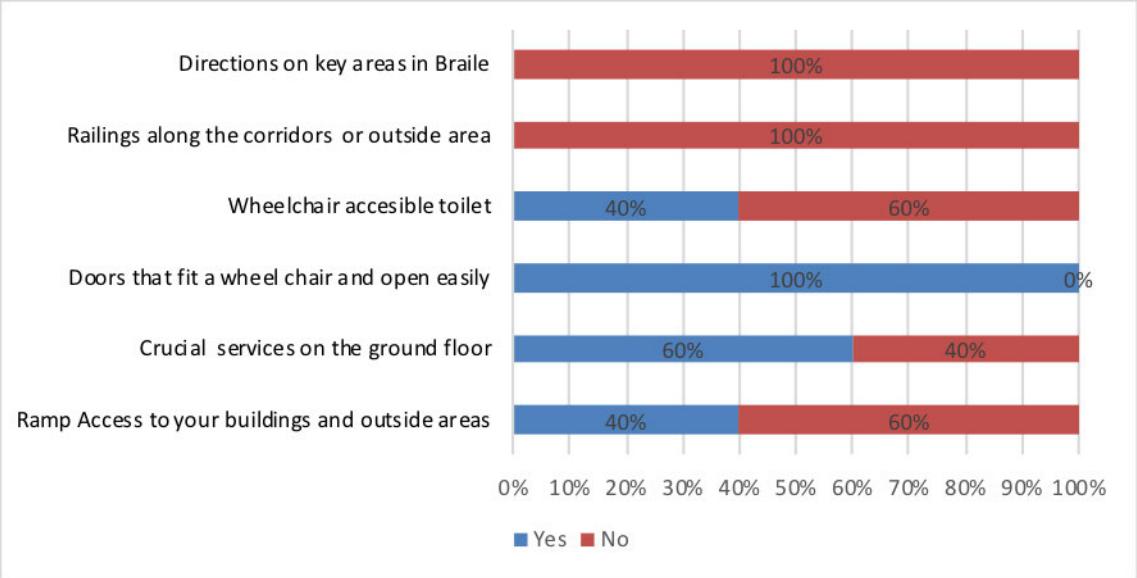


Figure 6.1: Physical access to the health facility by AWD (n=9)

6.2.1 Access to Health Information by AWDs

Access to health information remained a challenge, with only few of the health facilities providing access to health information services to AWDs. From the findings, only 20% of those visited had simplified information for people with disabilities related to abuse,

treatment and counselling, and sign language interpretation and information in pictures (for the deaf) and in braille or in audio format (for the blind) (Figure 6.3).

"As disabled people we meet a lot of problems to get health information and services. Hospitals use materials that are not easy to read for those with visual disability, or hear for the deaf. For instance, there are no translators…you are forced to write your problem for the doctor explaining how you feel… very hard if you don't know how to read and write…." (KII Participant 11)

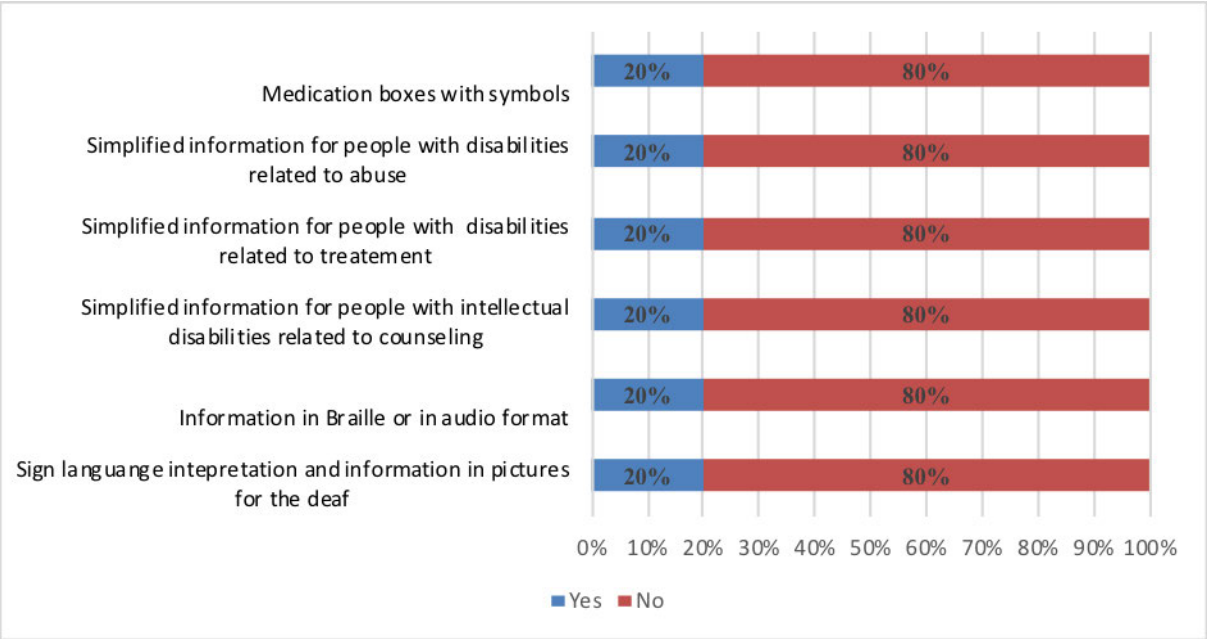


Figure 6.2: Access to health information services for AWD

6.2.2 Staff Training to Screen for Disability and Refer to the Right Services

As seen in Figure 6.4, 60% of the health facilities visited had referral systems to rehabilitation services and had trained their staff to screen for disabilities, including mental health in general services, such as ART. However, only 40% had trained their staff on sign language interpretation and Braille. Nearly all the facilities (with the exception of one) had trained their workers on the health rights of people with disabilities, while 60% have had their staff underwent anti-stigma training on disability and HIV. Although training remained

important at all levels of healthcare delivery, use of the skills acquired by those trained equally could not be underrated, as observed by one health official:

> *"The challenge here, however, is in the implementation of what is learned from the training. Moreover, the training was not cascaded to the community structure to ensure that quality care is provided to AWDs without interruption. Noteworthy, most of the facilities lacked staff that was trained on how to handle health needs of people living with serious forms of impairment- hearing, speech, blindness and mental" (FGD Participant 4).*

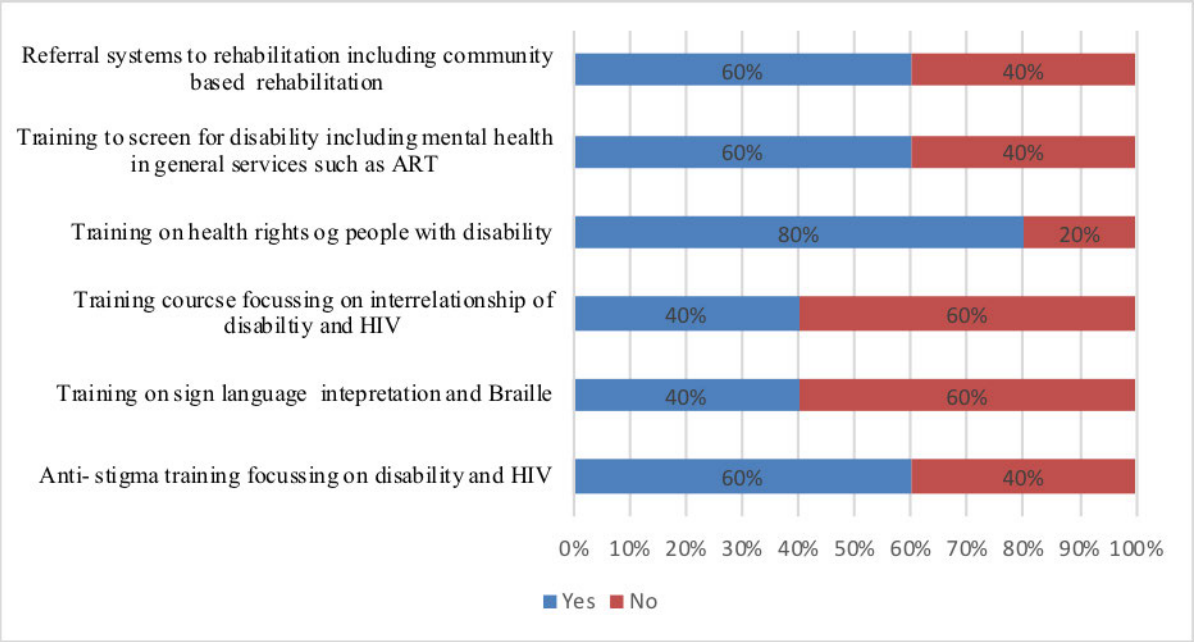


Figure 6.3: Staff training to screen for disability and refer to the right services

Access to care by adolescents with disabilities in the county was influenced by the level of training of health providers on disability-related skills and links to the right services. Assessment of the level of preparedness of the staff to ensure AWDs access services revealed that the majority of the staff were trained on the rights of AWDs (80%),

6.2.3 Health Services Linkage to Poverty Alleviation Services for AWDs

Linkages of health facilities to non-medical services were limited, for instance, to poverty alleviation services for AWDs, the findings show that very little had been done, with only one in four of the health facilities linked to social services, disability grants or business loans and back-to-work programs for people who acquired disability. Moreover, none of the link health facilities assessed had food security programs that include AWDs, nor do they provide sheltered employment for people with disabilities in general. A health provider interviewed agreed that,

> *"…for sure in this area we are not doing anything…ours is to provide health services, …we only hope other development organization was take over…although we are currently writing proposal for more holistic programs that was include nutritional services…some of the patients are so poor that taking medicines (ARVs) in empty stomachs in itself is a torture" (KII Participant 5*).

Figure 6.5 indicates that a good proportion (75%) (n=9) of the health services were not linked to non-medical services. This implies that most of the programmes run were vertical in nature only focusing on single health condition for intervention hence restricting AWDs access to wholistic care.

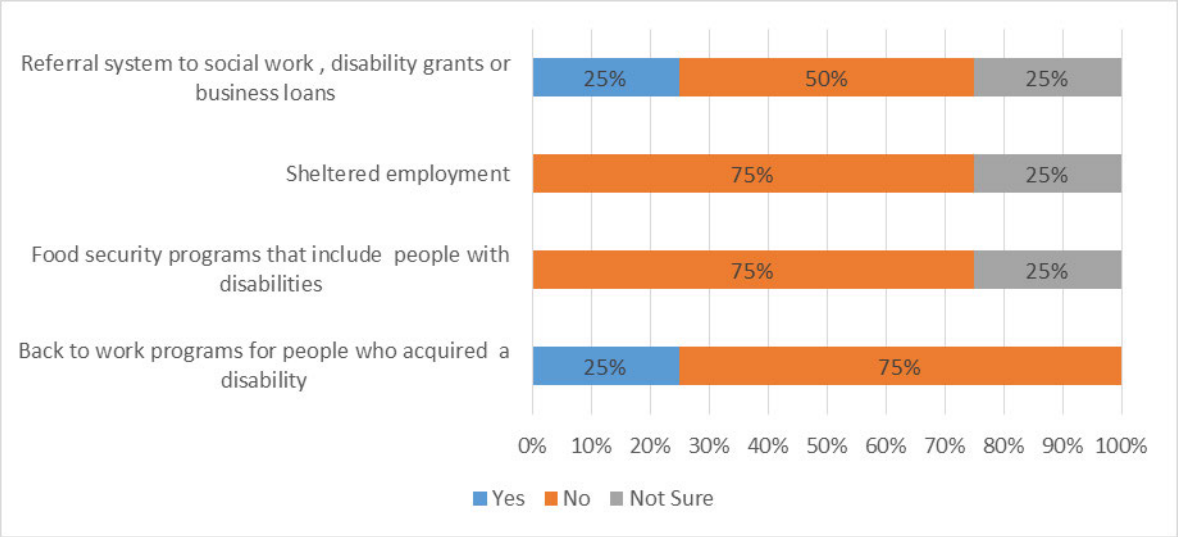


Figure 6.4: Health Service linkage to poverty alleviation services for people with disabilities

Health services linkages to disability and rehabilitation services were common for all the sub-counties that participated in this study. For instance, all the facilities visited reported having referral systems for disability services, reproductive health services and VCT, while 80% had referral systems to ART and VCT programs to rehabilitation and mental health services. In addition, 60% of the health facilities indicated that the rehabilitation department is trained and equipped to address HIV-related disabilities, while only 20% had screening to identify disability, including mental health problems in their ART programs (Figure 6.6).

> *"Yes we refer them to the next level of care…especially when we cannot provide the services they may need…due to our inability to communicate with them…sign language…you know? Unfortunately, we cannot know if they would really go…CHVs may at times escort them…" (KII Participant 12)*

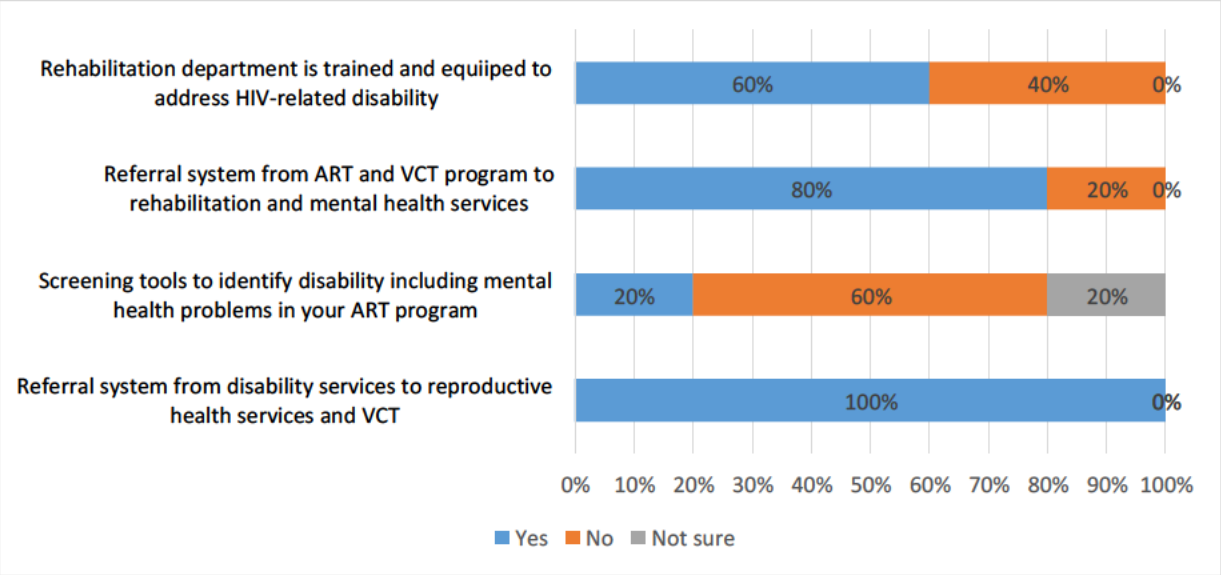


Figure 6.5: Health services linkage to disability services and rehabilitation

6.2.4 Linkages to Community Health Services

From the findings, 80% of the health facilities visited had linkages for home-based care, while 60% had linkages to community-based rehabilitation programs. Similarly, 60% had linkages to NGOs that focus or include people with disabilities and to disabled people's organizations. However, none of the health facilities reported having linkages to livelihood programs that focus on people with disabilities, nor did they have linkages to food security programs (Figure 6.7). A key informant explained that.

> *„.... Essentially, although opportunities for linkages to community services exist for AWDs but other deterrent factors including stigma, cost of services, transport and minders/company would still block individuals to access the services" (Key informant, services provider).*

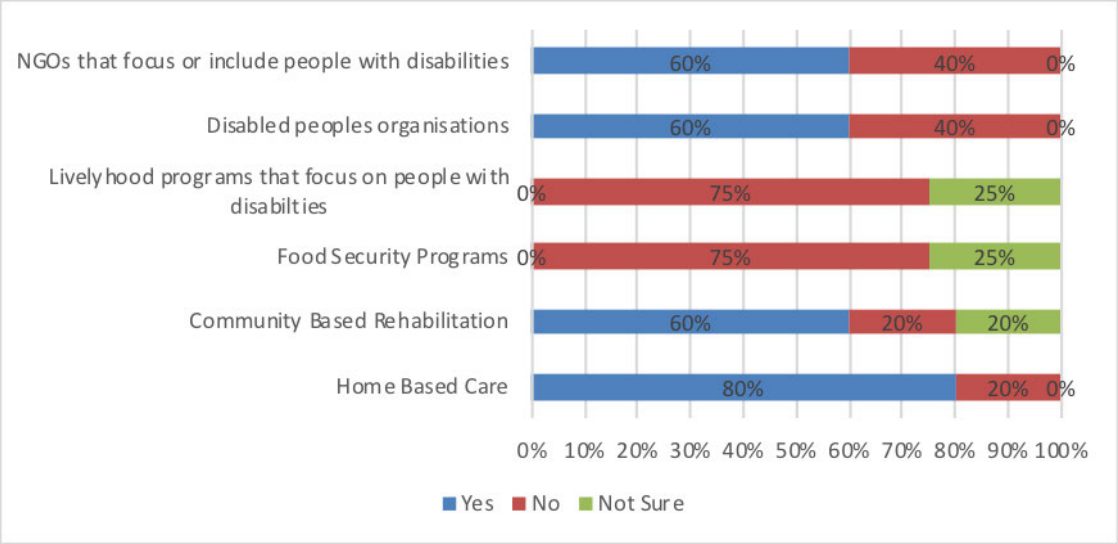


Figure 6.6: Linkages to community health services

In summary, services at the health facilities were not AWDs friendly. The fact that health facilities were located far from some of the neediest people, such as AWDs; were ill equipped and poorly staffed presented barriers to this cohort. Moreover, the inadequate linkages to other services organizations, was a testament of exclusion.

6.2.5 Health and abuse in relation to SRH /HIV among the disabled

There were many challenges around AWDs and SRH rights, with community/societal perception not promoting the free discussion of sexual issues, including not recognizing children as individuals who had rights. An in-depth discussion with the sub-county children's office staff revealed that they dealt with general protection of children's rights, including those with disabilities. However, this blanket approach had sometimes contributed to negligence of groups, such as children with disabilities, who required much more attention given their conditions. The respondent observed that although the rights of children were enshrined in the UN Charter on Children's Rights, the CoK 2010, Children's Act 8 of 2001 and the Disability Act 2003, their inadequate enforcement continue to undermine those rights.

The Kenyan laws consider sexual activity with a child as illegal, although the laws did not adequately cover this aspect, its neglected leading to abuses. Moreover, all the cases were filed in general and no special attention was given to AWDs. There was no financial support for children or adolescents living with disability from the county government. Children with mental disability who were defiled or sexually abused may not give coherent testimony, thus making the case difficult to bring before the courts. Police investigations were poorly done, as they did not act promptly and most of the accused were acquitted based on technicalities. This had made it very difficult to determine the magnitude of the sexual abuse for adolescent living with disability. In addition, from 2016, the Child Protection Information Management system was to be used by all agencies that dealt with children issues, however, there was currently no consistent way of reporting. There was a high probability that the majority of the cases were not reported, with discrimination against AWD, stigmatization and negative community perception being some of the reasons that contribute to the fact that most of the cases may go unreported and people opt for out-of-court settlements.

6.3 Experience with justice system and sexual gender-based violence

Denied access to justice for sexual violation characterizes the daily life of AWDs in Siaya County. The study established unacceptable sexual experiences of AWDs against the backdrop of poor recourse to effective justice systems. Moreover, it found two antagonistic justice systems that ran parallel to each other with inadequate sanction against sexual violation of AWDs in the study area. These were the official justice system that operates under the Sexual Offenses Act (SOA) of 2006 and the community‘s own local justice mechanism based on cultural imperatives. To understand the operations of the two systems and their interaction with AWDs need for sexual and reproductive health (SRH) related justice, the study collected and analysed data from the court of law records on occurrences

and episodes of sexual and gender-based violence against children, including AWDs. Furthermore, the process entailed in-depth interviews with health workers and AWDs, focused group discussions with community health volunteers, key informant interviews with community cultural leaders and court officials from the three sub-counties. This chapter provided a comparative description of the two justice systems identified, interaction with cases of sexual violence and the experiences of AWDs, as gleaned from the various sources consulted. I here present a thematic character of barriers that informs access, or in-access, to justice by AWDs. At the time of this study, SGBV cases seem to be taking a long time to be reported and to be determined, hence travesty of justice across the county.

6.3.1 Alego-Usonga: Sexual Offences Cases

The Alego-Usonga Law Court is an old judicial institution that existed before the new constitutional order of devolution and decentralization of government services, including health and legal justice. Previously, the court in this region, then the Siaya District Magistrate's court, had jurisdiction over the greater Siaya region, which consisted of Alego-Usonga, Bondo, Rarieda, Gem, Ugenya (Ukwala) and Ugunja Divisions. In terms of functional experience and preparedness, therefore, this old court should stand out on such cases, including those of sexual offenses in nature. Furthermore, it would therefore be expected that this court had the judicial experience, capacity and orientation to turn over cases in the shortest period possible for justice not only to be done but also to be seen to be done. Justice delayed was justice denied, more particularly for those who were vulnerable and marginalised, such as AWD. The court established a special registry for Sexual Offences (SO) registry to help track their trends that had otherwise been neglected before the enactment of Sexual Offences Law (SOA) in 2006. The study reviewed the records of the SO at the Alego-Usonga Law Courts' registry from 2017 to the time of this study. The SO registry had become operational in 2017, hence the timeframe of the period under review of

the nature of cases, their frequency of occurrence, determination, and how long the cases would last. There were three categories of cases reported at the Alego-Usonga law courts, these being rape and attempted rape, defilement, and child trafficking. From the data gathered a total of 46 cases had been reported at the Alego-Usonga Law courts over a period of 3 months. Among them, defilement was the most common case reported, with 37 of the 46 cases (80.43%), while eight (17.39%) were reported under rape and only one (2.17%) was reported as involving child trafficking.

Defilement/Attempted Defilement: 37 cases were reported under Defilement and attempted defilement. Of these cases, three were determined and the accused persons convicted, seven of the accused were acquitted of all charges while two cases were withdrawn. However, 24 cases were still open and one was recorded as 'discharged'. The cases involving defilement that were convicted, all received a maximum penalty of life imprisonment, but were allowed to appeal their cases within 14 days of the conviction. The study could not however determine what happened thereafter, since this was not captured in the registers available for public review. The cases in which the accused were acquitted of all charges took an average of six months. The shortest duration for a case to reach acquittal took one month, while the longest lasted 10 months.

Rape/Attempted Rape: There were eight cases classified as rape and attempted rape, with two resulting in convictions, one offender receiving a sentence of 10 years while the other received a life imprisonment. One case resulted into an acquittal, one was withdrawn and four were still on-going. The single case that was withdrawn had lasted for a total of six months.

Child Trafficking: There was one case classified under child trafficking offences, which remained open during the course of the study period.

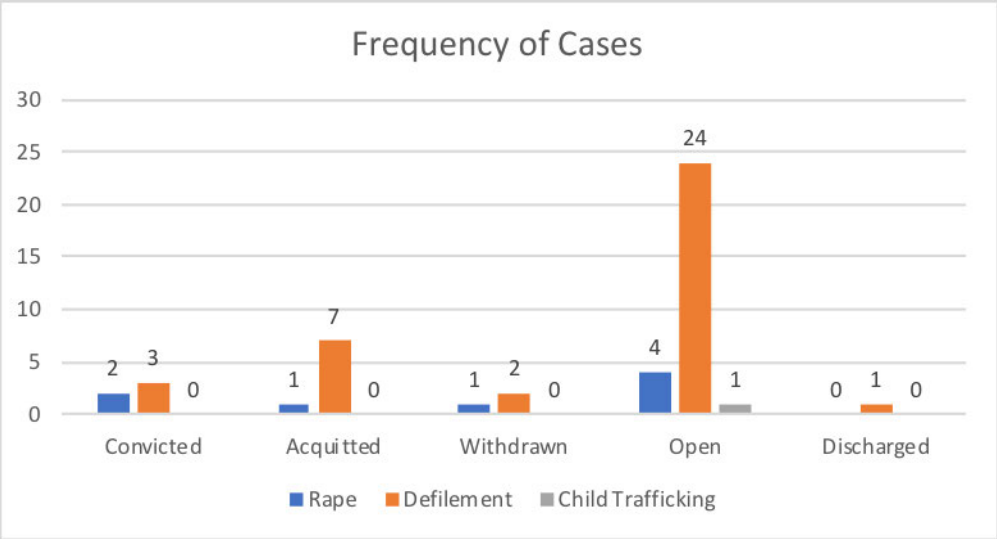


Figure 6.7: Frequencies of Cases reported at Alego-Usonga Law Courts

From the number of cases reported at Alego-Usonga law courts, it was clear that only a small proportion ended in convictions. In this case, five (10.87%) resulted in convictions, eight (17.39%) resulted into acquittal, while three (6.52%) were withdrawn. There were no cases reported as having affected adolescents with disabilities. Numerous challenges were experienced, including situations where the minor girls reportedly had consented to sexual activities. Other challenges reported include errors that occurred at the hospital during examinations of victims due to poor work by the hospital and the police. Parents and community members also at times hid victims (complainants) at home, in some cases there were failed reporting: The manner, in which the courts dealt (not very effectively) with sexual offenses, as observed earlier in thesis, was a considerable issue for AWD. For instance, there was a great risk of justice denied/delayed for AWDs who in terms of vulnerability at every station of the staircase.

6.3.2 Bondo Sub-County Sexual Offences Cases

Young children, including AWD, were not safe in the sub-county with regards sexual

violence. The range of sexual offences registered at the Bondo Law Courts varied from indecent acts to rape, with defilement forming the bulk of the cases reported. Resolution of the cases and sentencing were subject to court processes although this was also subject to the evidence and the actions of the accusers, such as withdrawal or failure to attend the court sessions. For instance, the study established that at Bondo Law courts, 59 sexual offence cases were registered, which consisted of 88% (52) defilement and attempted defilement, 8% (5) indecent and unnatural acts, 3% (2) rape/attempted rape and 2% (1) child trafficking were registered with the court. From the cases registered, there was only a single case of defilement against a child with a disability. The majority of cases (88%, n=52) were defilement and attempted defilement reported at Bondo Law courts, most of which were withdrawn or the accused acquitted of all charges. Of these, 8% (4) were completed through a conviction of the accused, three (6%) accused were acquitted of all charges, 42% (22) were withdrawn and 44% (23) were still open at the time of this study. From the interviews, the study established that the cases take too long to be completed in court, which could be traumatizing and gives the accused the chance to tamper with evidence. In cases where children were victims, it can be difficult to get full details, especially if they were sexually abused. Another challenge was that many cases were withdrawn from the court, with families opting for out-of-court settlements. Figure 6.8 provides the type, frequency and the status of cases with respect to executions and determination.

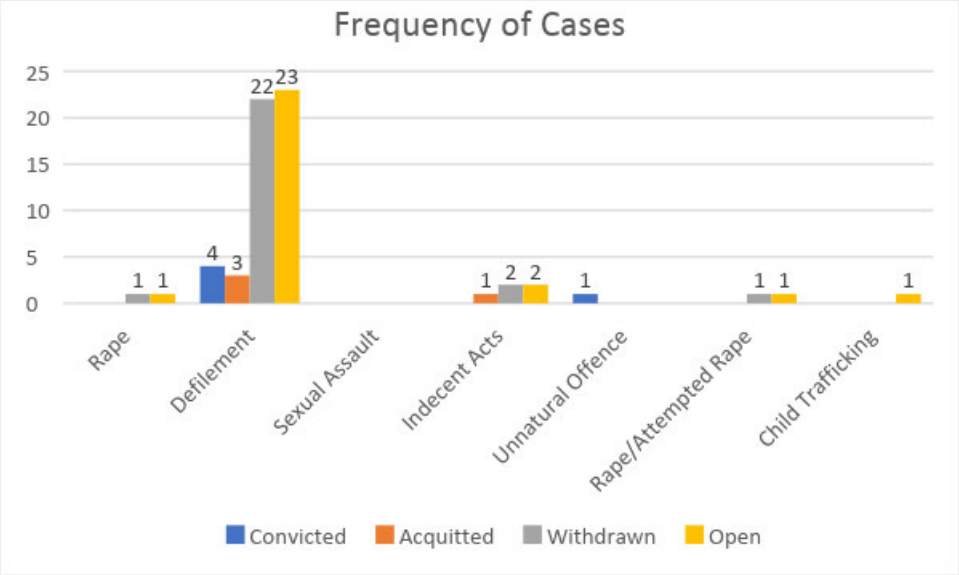


Figure 6.8 Type, frequency and status of cases

The study also established that there were cases of destruction of evidence due to cultural beliefs, and the resulting concerns from families of the victims on issues, such as embarrassment, to talk publicly about the cases. The police take a long time to give complies the report as that the doctor can take a sample or evidence from the victims, with dockets being compromised, witness not well prepared by the state counsel, and the accuser being given little or no legal aid. The cases registered had only recorded one case of defilement against a child with disability. The implication could be that cases regarding children with disability, as was explained in the FGDs held with the CHVs and interviews with leaders of the organization, those for persons with disabilities (OPDs) did not reach the courts or if they did, they were not desegregated as combine with other cases to the disadvantage of this vulnerable group, which had no capacity to compete for justice in a crowded field designed for the fittest.

Defilement/Attempted Defilement:

The majority of the cases involving defilement and attempted defilement had remained

withdrawn or the accused was acquitted of all charges. There were 52 cases of defilement and attempted defilement reported at Bondo Law courts, with only one being against a child with disability. Of the cases, four were completed through conviction of the accused, three accused were acquitted of all charges, while 22 cases were withdrawn and 23 were still open at the time of this study. The cases involving defilement and attempted defilement took an average of seven months for the accused to be convicted. The longest case resulting in a conviction took eight months while the shortest took five months. Cases resulting in acquittal took an average of four months, with the longest lasting for seven months while the shortest took three months. The cases that were withdrawn took an average of five months, with the longest taking 10 months while the shortest took two months. The oldest on-going case involving defilement was 11 months old at the point of this study. The implication was that children and parents seeking justice had to wait for a longer period. Under such circumstances they would easily get fatigued and intermittently begin to skip the court sessions, until the cases were dropped altogether. Essentially, then justice was denied through prolonged hearing of the cases that only worked in favour of the perpetrators.

Indecent Acts and Unnatural offences:

There were five cases classified under indecent acts, none of which had resulted into a conviction. There was a single case classified as an unnatural offence that resulted into a conviction of five years, while two of the cases classified as indecent acts were still open at the time of this study, two others were withdrawn after running for two and ten months respectively, and one resulted into an acquittal after a period of five months.

Child Trafficking:

There was one case classified under child trafficking offences and remained open throughout the study. Adolescents with albinism were the main targets of child trafficking. For instance,

in a key informant interview with an official of the network of disability organizations in Siaya County, it was revealed that,

> "*such AWDs lived in fear of abduction. The situation has confined a many albino children to the household, which has caused them not to seek care including, SRH and HIV services, they…get abducted and sold off to the neighbouring countries, especially Tanzania. (KII –DPO participant, Alego)*

The respondent explained that there were myths and traditional rituals associated with albinism and HIV/AIDS cure in Tanzania.

6.3.3 Ugenya Law Courts Sexual Offences Cases

Long distances and poor infrastructural development, especially roads, determined the level of utilization of court services by poor households in Ugenya sub-county. The court was recently established in Ukwala, which previously was the headquarters of Ugenya Sub-county of Siaya County. The area was in a remote part of the county, with inadequate infrastructure, including poor road network, which makes access to services rather difficult, especially for poor people, including AWD. Court systems therefore generally were only available for those living nearby and with easy access to public or private transport. The common transport system was mainly *Boda Boda,* commuter motorbikes ridden by young people as means of income generation, which transport people through the sub-county, sometime at a very high cost, depending on the distance.

The situation can be worse when emergencies occurred and transport was urgently required, with one of the riders indicating that this was the time when people died, during emergency transport situations. From discussions with community members, defilement or any form of sexual gender-based violence was common in the sub-county, but due to the distances and complications with transport, the cases remain unreported. At Ugenya Law courts, a total of

27 cases were reported during the time of this study and include rape, defilement, and indecent acts. Among the cases reported at the Ugenya law courts, defilement and attempted defilement are the most recurring cases with 23 of the 27 cases reported, representing a proportion of 85.19%.

Defilement or Attempted Defilement: The majority (14) of cases involving defilement at Ugenya law courts were still open at the end of this study, two were withdrawn, four resulted into an acquittal while three accused were convicted. The duration taken to hear and determine the cases appeared to be shorter than in the other studied courts. The fastest case heard and determined was completed in one day, the case involving defilement was heard and determined between May 18 and 19, 2017, and the accused was convicted and sentenced to 15 years in prison. The shortest sentencing by this court was a 3-year sentencing to a correctional facility while the longest sentence was life imprisonment.

Rape/Attempted Rape: There were only two cases involving rape, one was withdrawn under the provisions of Section 87 (a) of the Sexual Offences Act of 2006. The other case is was still open at the time of the study. Two cases of indecent acts were reported, one being withdrawn while the other was still open.

The average duration of cases that resulted in acquittal at Ugenya law courts was four months, with the shortest taking three months and the longest five months (Figure 6.10). The cases that were withdrawn took an average of 1 month in court. It was reported that;

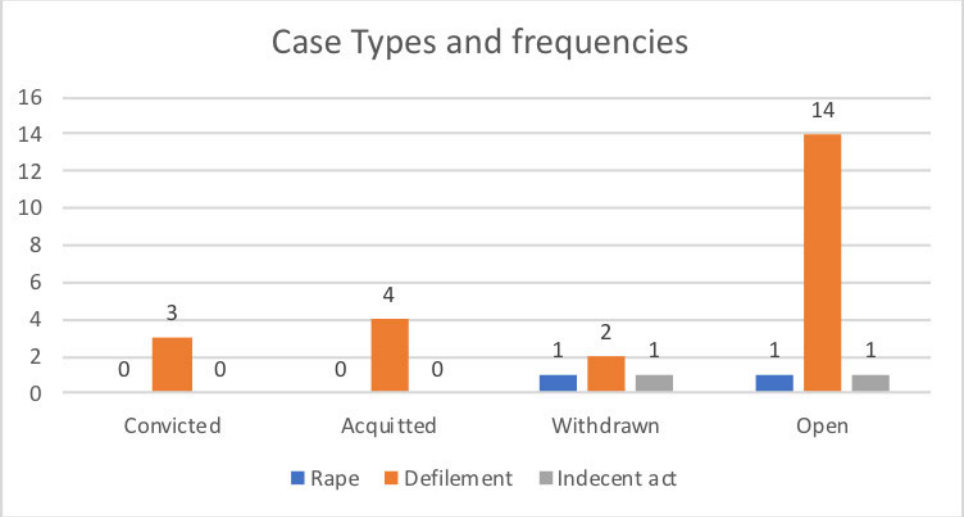
> *"…some parents, especially those whose children (daughters), fall victims of defilement and related abuse use the cases/situations as opportunities to extort money from the perpetrators. The complainants thus choose to skip court sessions; this may be as a result of collusion between the parents of the victim and the perpetrators side so as to sabotage the hearing of the case…cases are never meant to last forever.*

*Therefore, where the accused person keeps coming for the hearing while the complainant does not, in such situations, the cases are withdrawn pending warrant of arrest, but if situations change the accused can be rearrested and the case continued. In other instances of worst scenarios this ends in acquittal and the case is closed (*KII Participant 13*)*

An informant from the courts explained that, in some cases that were already in the court, the parents of the victim devised ways of averting justice for the perpetrators of SGBV against AWDs s follows

"…They made the victim to disappear such that the accused had to keep going to court until the case was withdrawn". (KII Participant C1)

A warrant was usually issued to both the parents and subsequently the case could be reopened and proceed again as seen in Figure 6.10 a good number of cases remain open for reasons explained above.



Due to delays, the evidence had become stale, especially in cases where the victim was intellectually impaired and therefore may not be able to recall what had happened or who defiled them. Shame and stigma played a part as key obstacles to access to disability and

SGBV lined justice. From key informant interviews, it was however explained that defilement and related cases of sexual offenses (SO) was applicable, and the chiefs were not allowed to adjudicate in such cases, although they can be involved in cases where the Alternative Dispute Resolution (ADR) applied. For SO, the case had to proceed and the court decides whether the person was acquitted or committed to jail term. In such cases, the police usually had the most contact with the children. In only one case that was brought before the court were both the victim and the offender below 18 years old, for which they involved the children's department and borstal institutions come in, and the offender may therefore not be jailed but taken to a rehabilitation facility

6.3.4 Justice on Trial: Normative Culture on SGBV- 'Thuol Odonjo EiKo'

The concept of '*Thuol Odonjo eiko'* was found to be dominant among the Luo community in the study area. Key words in this concept as explained by a key informant that was well versed with Luo culture include: *Thuol* meaning the snake, *odonjo:* meaning has entered and ei*ko:* means inside a guard (vessel) used to keep milk. He explained that:

> "…e*ncountering a poisonous snake and milk in a guard can be serious dilemma for the family. The snake was the detested sexual act, the milk was the victim of sexual violation, and the guard being the perpetrator. This explains the community's approach to justice for sexual offenders, as the perpetrator was often closely related to the victim, being a father, uncle, brother, sister, aunt, mother and others in the category of relations. From the onset of such unfortunate occurrences, the fate of the victim, with regard to recourse, was already sealed by the normative culture*"(KII Participant 4).

The perpetrator seemed to be judged with a lot of mercy and lenience, ostensibly to preserve kinship (not breaking the precious guard). The box 6.1 below is a narrative of how justice for child victims of SGBV was perverted to the disadvantage of AWDs.

Box 6. 1 Cultural Manipulation of Justice

Negative cultural beliefs were found to be strong barriers to access to justice in cases involving victims of SGBV, in particular AWDs. For instance, the study revealed that the family members often willingly withdrew before the courts of law, SGBV related cases that were seen to be against their kin facing such charges. The consideration of kinship bond stood strong to frustrate any possibility of success for a case that threatened to send a kinsman into prison for committing sexual offence with a disabled minor. The respondent in a key informant interview narrated his experiences in relation to the home based resolution of issues/offenses that were of sexual violation in nature. He gave an example of a case whereby his daughter had been defiled by a nephew, a case he promptly reported to his relatives to advise on the course of action that was needed to be taken against the perpetrator (his relative). A family meeting would be convened to discuss the matter, and any indication of opting for legal action in pursuit of justice for the daughter would quickly be emasculated, he would be told that since the incident had occurred 'within the home' (Thuol Odonjo eiko) the issue should just be resolved within the family level. The respondent then invoked a local song that was commonly sung by community members to shame anyone who would dare contemplate reporting a culprit and eventually leading to their imprisonment. The lyrics of the song would suggest that he who had sent a kin to prison was like a witch; and that such a person should be treated as an outsider or outcast. The contemptuous undertones from the lyrics were to make one guilty of any imagination of sending a close relative to court for SGBV within the family circles. Moreover, it was considered that once the culprit would be out of prison he would be forced to marry the daughter (the victim) whom he had defiled, and as such the

original relationship would become obsolete. The lyrics would continue that, since the initial relationship had been destroyed, the perpetrator now had become a stranger who could marry from the family (from the Luo community, culturally only those of different ancestry are allowed to marry each other). Thus the allusion that the perpetrator of sexual violence from the same ancestry would marry a kin's daughter was likened to witchcraft. Especially, when a person chose to take legal action to punish or resolve the issues with close relative that might have led to offender's imprisonment.

When cases of defilement had occurred among close relatives therefore, the offender would often not be subjected to major punishment to resolve the curse but instead a ritual (kihosro) is performed by the elders. This was an example that in more traditional times, when brothers fought, they could come to eat together to help quell the bitterness and resolve the issues and move on together, unlike the current times, in which a misunderstanding between brothers can lead to a lasting animosity.

The other scenario would be when a brother's cow strays into his farm and destroys the crops. He could resort to legal action to get compensation from the owner of the cow, but would be prevailed upon to settle with the brother as a people from a common place. In relation to SRH for the AWD, he gave an example of having a beautiful daughter with mental disability or epilepsy who may not easily get married due to her condition, but may be admired and eventually raped by the nephew. If the lady and he confront the offender (boy), he would likely deny the crime. If reported, he would invite close elders, who were his relatives and those of the offender to a joint meeting to solve the issue at that level, at which the boy would be rebuked and

warned by both elders/relatives of both sides.

The respondent gave a true life experience in which he was attacked at night and cut on his way to a disco, his aunt having married into the perpetrators home. He later went to have a talk with the boy who had cut him, who was very arrogant and unapologetic, and challenged him to report the case. He said this reaction was based on the fact that the boy‘s father was an influential person in society and had connections with the authorities. He reported the matter to the police, and unexpectedly the boy was arrested and was to be arraigned in court. The father tried negotiating for his freedom but failed.

The grandmother of the victim, who was a close relative of offender, then came to plead to the victim to forgive her brother in-law so as to ease the pursuit of securing his freedom before he was arraigned in court. He accepted, and a team from the offenders’ home came, including the Auntie, and he mentioned to her of the boy that he had boasted about the her influence and connections with the policy hence he could not be arrested, and that if it were not for the aunt, he would have not accepted the money offered to him.

He indicated that a case in the courts cannot be dropped easily unlike in the past, where the courts cases could be dropped by the victims. He said that currently, if a case was to be settled out of court, this would only be done before it had been taken to the court. However, if the case was resolved at the home level and it happens that the female victim was both HIV infected and pregnant, the offender had to bare all the costs of treatment, while the guardian/parent of the victim would take care of the

child. A child born out of such a relationship could not go with the mother to the mothers' matrimonial home. There were chances the child could develop a mental problem and never prosper in life, and had indicated that in their village, five out 10 ten premarital pregnancies occurred between relatives, and that such cases were associated with mental handicap for the children. These children were perceived differently in the village, and to a large extent, they were never considered as potential threats or competitors for resources such as land.

The community perception of the right age to get married was between 20-25 years, but there were individuals who get married at the age of 18 and below, something the community and village heads were outwardly opposing but quietly supporting. Although some child rights organizations, mainly Plan International, were helping the community to put measures that would help to prevent child marriages, especially AWDs, however, "*community cultural forces were too strong, even for the government*". The narrator noted that there were cultural consequences against a close relative who married children from close relations. According to the Luo culture, as the narrator explained, such marriages tend to result in mental incapability. For example, a man marries a lady from his mothers' home, with something being placed at the centre of the roof top to help prevent her from giving birth to children who were insane/foolish. In addition, if a daughter was married in a home in which the father previously had sexual relations, then the likelihood that children born out of that marriage would be insane or had psychiatric issues were high. In line with these, he gave a true life example where a lady was married in a home where her father had sexual relations with her mother long before, the ordeal only being revealed several years after the marriage. The narrator continued to expound on the outcome of the

marriage, with the four resulting children, who had attempted to attend primary school to standard 8, being unable to construct and write down a logical statement.

The belief in the narrative was that childhood disabilities, especially those of a mental or intellectual nature, were caused by unacceptable parental sexual involvement with a close relative. AWD were thus first and foremost perceived as the "guilt of their parents" and secondly as the "well deserved punishment to the family". With that kind of disability concept espoused by the community, access to care and support, including sexual and reproductive health for AWDs, becomes impossible. Cultural barriers were quickly erected on the path to access any form of care, including education.

The expert narrator lamented that nothing much could be done to help the children who were born out of such relationships, "they were barely and grudgingly tolerated by the community," he said. Moreover, he further explained that most of the parents, especially the fathers, preferred to disassociate themselves from their children with disabilities. Asked why the parents did that to their own children, they viewed the disabled child as "*evidence of their evil past or spoiler in marriage... the consequences are grave...some decide to take them to the old parents to conceal the stigma*", he noted with pain on his face. Asked if such repercussions deterred would be violators, he answered 'no', adding that kinship was closely guarded yet "*those things still continue*". There was a societal conspiracy of silence in the circumstances of violated children with disabilities, as deduced from narrations of the community normative cultural expert, gauging from his in-depth knowledge of Luo culture on sexuality, disability and reproduction. As a senior member of the community and a

> parent of a disabled child, the respondent was opposed to the idea of recalling cases that were in court in relation to defilement of the disabled, and children in general. "*If that was done, then there are chances that the victim may not be adequately served with the deserved justice through the other mechanisms*" he said

The narration brings to fore a number of issues that plague AWD as well as their families. These include: family and societal heaping of parental guilt on the disabled child; interpreting the burden of care for AWDs by the family as a punishment for guilt; mental/intellectual disability as a consequence of parental illicit sexual behaviour with a close relation, and the silent societal conspiracy to save a well-bodied kin at the expense of a vulnerable disabled child. Under the circumstances, AWDs may never enjoy their basic rights, let alone SRH, the above issues being serious obstacles to accessing their rights.

6.3.5 Justice at the Altar: Disability, Age, Culture and SRHR (personified)

Beyond the normative cultural considerations related to issues of disability and age, including sexual, reproductive health and rights, the Luo community of Siaya County were also found to be deeply religious. For instance, all manner of religious groupings had emerged from the traditional healers to diviners who cure disabilities. The study found that due to the shift of once traditional and cultural people to Christianity, the once powerful witch doctors and magicians had started their own churches to entice Christian clients back to their spiritual origins. From the discussions held with community health volunteers and the faith based health providers, a good number of families and clients subscribed to religious groupings of varying doctrines. Christianity was the dominant faith professed by many people in the study area, although Islam was also starting to grow, especially in Alego Usonga and Bondo sub-counties. The sub-counties had rapidly urbanized and were increasingly becoming

cosmopolitan, largely due to the devolution of government the lower levels. In the knowledge of this researcher, who was borne and has lived in the study area for many years, religion had a great influence on people's lives. For instance, life experiences of children, such as AWD, which could not be explained by cultural beliefs, or even by medical means, were referred to religious doctors for the faith community to handle. This study established that AWDs' rights to autonomy were denied, even at most of the sacred places of worship for the child seeking help. The desperation of parents to ward off the disability tag from the family was found to push them to seek spiritual intervention from religious leaders, under a false impression of the condition of the child and the possibility of having to pay a fee. This revealed the multi-dimensionality of injustices laced in myths and misconceptions of disability and sexuality, as experienced by AWDs. Box 2 outlines a harrowing life experience of a female adolescent with disability seeking care.

BOX 6.2: Typical Case Scenario

The story was an 19-year girl full of charm and innocence. The girl was the third born in a family of six siblings. Salvonatia (not her real name) suffers memory lapses, which were diagnosed when she was 16 years old. This was later confirmed to be a result of mental disability that affected her movement. She would present with hallucinations of being persecuted by people unknown to her. Her mother would wake up only to find her back asleep. Further, when she was taken to school, her concentration span was discovered to be slow and she would often run away from school and go back home. The uncle advised that she be removed from school and now she stayed at home doing farm work. The girl, who was in very jovial mood, simply laughed at every answer to questions she was asked. She was a bit incoherent in speech hence could not respond to explanation of our mission. Her uncle, welcomed us and accepted to consent on her behalf, explained that the daughter was unable to remember even simple things like her age, name or the day of the week. The research asked for an assent from the girl her female guardian could speak to which she verbally assented. The uncle then left and gave space for confidentiality and privacy of the girl

The girl participated fully in family activities, such as washing clothes, cleaning the house and also taking care of the younger siblings, especially her 2-year-old brother. The mother of this orphaned girl however, removed her from cooking responsibilities or sitting near the fire due to potential risk of falling on it and injuring herself. Access to healthcare has included being taken to the dispensary for her medicines, which she takes twice a week at night and early morning, which had not been satisfactory. The parents seemingly had accepted the condition of their child after "wuothone ka jolemo" seeking religious remedies on her behalf, including jalamo (diviners). The respondent explained that

although they had preferred to take their daughter to any traditional healers, such remedies were disappearing from the community, as traditional healers were turning to 'churches', since most of their clients increasingly were now seeking help from religious outfits in conformity with the changing culture. Traditional remedies, therefore, were laced with religious camouflages for acceptance and evasion of stigma and judgment of one as being pagan or barbaric.

Salvonatia had an experience of being taken to such sects for 'prayers' where she had to stay in the shrine for one week. The myth and misconception about the condition of the girl was shocking but not entirely unique to her case. This was a common occurrence to many families, especially when it involved a disabled child. In Salvonatia' case, as explained by the respondent, 'Jalamo' (the diviner) had discerned that, "someone of bad intension must have picked soil from where the girl had walked and used the same to bewitch her". This interaction captured the interest of the parents to the core and they agreed with the diviner that 'nyathiwani nyakalosi' (our daughter must be fixed/corrected). This, however, should involve serious 'prayers' in a secluded place (church) and must be away from the family. The conditions further required that the family should be registered as members of the sect and that they should be ready to supply daily portion of food for the period the child stays at 'karloso kata karlamo' (the shrine). Furthermore, the parents were asked to go and 'jowolowo' (collect the soil) from a nearby ground where the girl had stepped and left some foot print. The soil collected would then be accompanied with 'ywechmanyien' (a new broom) supposedly to sweep away the evil spirits that had been meted on the girl through 'lwedomarach' (evil hands).

Salvonatia' managed to gather all the paraphernalia that was required by Jalamo and took their daughter to him for the services of 'prayer', ostensibly to reverse her 'evil inflected' impairments. After one week of 'prayer' rigmarole at jalamo's place, Salvonatia would be brought back home in the company of the sect members with celebrations and claims of total restoration to the joy of the family and immediate community members. The incentive for such remedies, as explained by the respondent, could not be hidden, as the community received back in 'sound health' their daughter who had passed through evil hands and now Jalamo had to loose her (made her well). Asked if such cases still existed in the community, the mother of the girl said that those who attended the reception of the home-coming of her daughter were particularly pleased with her that at least now the remedy against evil inflected disabilities was within reach at affordable cost. Considering that the whole treatment of the girl had costed the family only US $5 with such positive result in her condition, compared to high hospital bills the family had incurred earlier, this, according to the respondent, was a good deal.

To ensure the girl fully recovered, the parents decided to take Salvonatia to the grandmother's place, away from the public eye, as she had now become the talk of the village. This refuge however would not last for long, the mother explained that the condition of the child had relapsed albeit now, more violently. The grandmother could not cope with the need for care and demands of this adolescent girl. She decided to return her back to the parents on hearing that the girl had been defiled by a close relative living in the neighbourhood. The respondent said she was at a loss on what next to do for the girl. Her worst fear was that the girl could be pregnant after the sexual violence ordeal, something the uncle of the child would never take kindly, as she felt that he would beat up the girl.

The grandma narrated that she was relieved when her daughter escaped pregnancy but

never checked for any injuries or sexually transmitted infections ,such as HIV and STDs. Asked if the incidence was reported to any authorities to bring the perpetrator to book, since he was known to the child's grandmother and herself, the respondent sarcastically smiled and casually retorted something to the effect that such cases would normally end nowhere for it was a 'thuol odonjo eiko' (a snake in family milk jar) situation. It could not be pursued through the court of law system as it would be withdrawn immediately on arrival. 'Janyuol neno matek!' (One passes through tough moments as a parent), she sighed in resignation and kept quiet for a few seconds. At this juncture, she was given some time off from the interview to give her space to go through her emotions. Her pain, she explained, was what mothers like her had to go through with an adolescent girl with disability.

> "*I have to go and look for food to feed the family, yet at the same time, I am expected to keep watch over my disabled daughter, who is in constant risk of being defiled by people who would never face justice whatsoever."(In-depth-interview Participant*)

Women were mothers, providers and caretakers at the same time, a balance that was difficult to maintain in contexts of poverty and disabilities. Social support mechanisms were inadequate to ease the burden care and provision for families with children with disabilities. The cost of schooling did not favour such families, the only schools available for such children, including Joyland in Kisumu, Nyangoma in Bondo County, were very expensive, at US $180 -360 per a year.

Membership of disability organization has not yielded much in advocating for the plight of the disabled children with respect to universal free primary education, as enjoyed by their non-disabled counterparts. The parents, especially the mothers, would have a bit of relief from care while their children were at school. Such times they would use in productive activities to improve household economy. Faith-based organization and Community Health Volunteers (CHVs) were not readily extending their SRH and HIV service to adolescents with disabilities. The respondent observed;

> *"…currently, only adults benefited from community health services. FP services are only accessed through the facilities, yet adolescents with disabilities stay far from such facilities. Some faith-based facilities, like Nyangoma, were not providing such services but merely referring clients to other facilities due to their faith and spiritual values with regards sexuality and contraception (FGD Participant 3)*

Inadequate awareness of the needs of AWDs largely affects access to any form of care including SRH and HIV services.

> *"…people here are ignorant about issues of disability among the young people and how hard it is to handle their sexual needs. As mothers, we find it even harder, but we just have to do what we can because it is our children…it is tough, we require support from the community and the county"(In-depth interview Participant)).*

Generally, interaction of AWDs with various institutions and structures of care and services pose myriad challenges for access to SRH and HIV services by the study target.

CHAPTER SEVEN

ATTRIBUTES TO POOR ACCESS TO SERVICES

7.1 Introduction

This chapter is aligned to objective four of the study that aimed to explore experiences of AWDs with regards to barriers to their access to SRH and HIV services in the community. The chapter therefore presents findings on varying attributes across the levels of the socio-ecological model that was used to frame the study. The model had helped in exploring the nature and outcomes of the interactions between and among the attributes towards AWDs' access and utilization of SRH and HIV services. Part of the finding was that although some community-based health programs were providing SRH and HIV services, inherent limited interaction of the AWDs with the systems to access care was also observed. Therefore, in this chapter the researcher presents AWDs related attributes and the nature of available services with attendant barriers as follows: (Micro, meso and macro-systems levels of interactions).

i. Socio-economic status of AWDs in Siaya County

The study found that a good number of the adolescents living with a disability lived with their family members and with the high rate of poverty within the county, meant that most of the adolescents living with disability came from poor households (this was also revealed in the interviews with guardians and parents). The research also showed instances where parents could not afford to take of care the children; they had to relocate to live with other relatives especial the grandmothers who would take care of their needs. This exposed the adolescents to several challenges mainly:

- ***Lack of proper education***- The level of education of AWDs was quite low compared to the general population. As most parents were poor, they could not afford to pay for schools that provided specialized care for the AWD. This left most parents

with the option of either taking them to normal schools or leaving them at home. For instance a county level official interviewed expressed thus;

"…the rate of drop out of AWD who attended normal learning institutions was quite high, this might be attributed to the fact that learning in most of these institutions had not been tailored to meet the needs of disabled. Cases of stigma from both their fellow's students and teachers were common with these institutions (KII Participant 7)

There was limited access to medication, assistive devices and other commodities as explained by a participant in FGD captured below,

"…*part from medication and the constant medical checkups, adolescent with disabilities often require other items that would aid them in carrying out their day to day activities with minimal interruptions (including wheel chairs, crutches, and diapers). These present an extra cost burden to the household who most often cannot afford items" (FGD Participant 4).*

ii. Experience of self-stigma

Self –stigma among adolescent living with disability was common. From the interviews and discussions, it was revealed that most AWDs due to their situation often felt helpless, frustrated and unwanted. This led to low self-esteem, depression and in some cases thoughts of suicide as it was revealed in a key informant interview that;

"…Self –stigma was mainly attributed to lack of proper support structures counseling as one of the respondents interviewed stated as she was going through medical procedures, she had hoped for reassurance from the doctor that she would get well but this did not come which led her to feel even more hopeless on her situation".(KII Participant 13)

From the discussions it was also revealed that due to the self-stigma, AWD had locked themselves from many opportunities as they feel that they are not capable of handling many functions. The society has also not provided avenues for the AWD are not able to freely express themselves. The study established that a number of AWDs had ended up alienating themselves from the society which resulted into a positive feedback that further worsens the situation.

iii. Experiences of access to social security support

The government of Kenya had also established the ***National Council for Persons with Disabilities (NCPWD)*** mandated to implement policies geared towards mains streaming AWD into the national economy and create an enabling environment in which AWD could operate effectively and efficiently. The commission had set up offices at county levels and work closely with other organizations for PWD and county governments. Under the People with Disability Act number 3 of 2014, AWD were required to register with NCPWD to receive benefits such as tax exemptions, educational scholarships and issuance of assistive devices. Moreover, the study found through the AWDs, the guardians and officials of the networks of PWDs interviewed that the registration for membership was not an easy process. The AWDs seeking to register had to pay between

At the time of this study, there were 4250 registered PWD in Siaya County and an approximation of 15% of 86,400 PWD in the county.

The Social Assistance Act of 2013 states that the social assistance authority should provide social assistance to

a) Person suffering from severe mental physical disability

b) The persons disability renders them incapable of catering for their basic needs and there was no source of income or support person.

c) a **National Development Fund** was established under the perpetual succession act Cap 164 of the Laws of Kenya to provide financial support to organizations and individuals living with disabilities and currently provided funds to support the Assistive devices and services to improve mobility and access, educational assistance, economic empowerment and revolving fund, infrastructure and equipment and Cash transfers. (***Need more information on disbursement to counties).*** The constitution of Kenya also lays out the right of Kenyans to social protection. In line with this the government on Kenya put in place five cash transfer programmes which were currently being implemented under the National Safety Net Programme (NSNP). These were namely Cash Transfer for orphans and Vulnerable Persons, Older Persons Cash Transfers, Persons with severe Disabilities Cash Transfers, the Hunger and Safety Net Programme and the World Food Program. Table 7.1 shows the cash transfer trends

Table 7.1: Cash Transfer programmes under the National Safety Net Programme (NSNP)

Programme	**Year Launched**	**Implementing Agency**	**Transfer value per month**	**Households (as of 2017/18)**	
Cash Transfer for orphans and	2005	Department of Children's Services	2,000	359,000	

Vulnerable Persons					
Older Persons Cash Transfer	2006	Department of Gender and Social Development	2,000	345,000	
Persons with severe Disabilities Cash Transfer	2011	Department of Gender and Social Development (MLEAA)	2,000	51,000	
Hunger and Safety Net Programme	2007	HSNP Secretariat(NDMA)	2,550	304,000	

Source: **National Social Protection Program, 2018**

In s Siaya County, there are about 939 and 8,281 households registered under the persons with severe disabilities (PwSD-CT) and Orphans with and Vulnerable Persons (CT-OVC) cash transfer programmes respectively. Alego Usonga has the highest number of registered households under persons living with severe disabilities (239), while Rarieda has the highest households registered under CT-OVC.

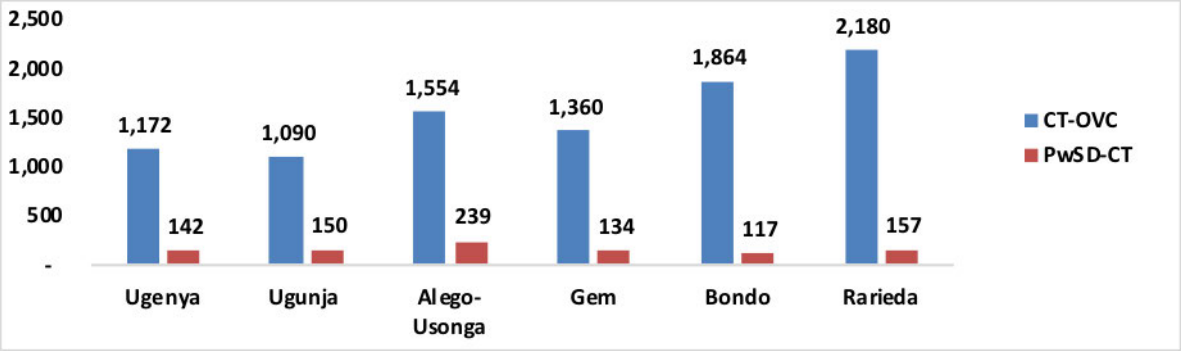


Figure 7.1 Registered Households under the NSNP (PwSD-CT and CT-OVC only) as of year 2017/018 in Siaya County (Report)

Apart from the government institution support for people living with disabilities also comes from the following:

- **Disabled Peoples Organization (DPOs) –** There is a number of DPOs that were advocating for the welfare of the PWD. This includes advocating for free medical services or services at subsidized fees (it was reported that this was yet to be successful). The DPOs also provide capacity building on various issues surrounding the welfare of PWD.
- **Self-help groups-** PWDs had managed to form self-help groups which apart from support they had also managed to set up table banking as form of income generating activity
- **Mission Hospitals and churches:** There were a few mission hospitals that offer waivers to persons with disabilities. Churches had also supported the adolescent especially in provision of education opportunities.

i. ***Awareness of Sexual and Reproductive Health and sexual experience by AWDs***

Sexual and reproductive health needs and experiences of adolescents living with disabilities were different from those normal adolescent and may vary depending on the type of disability. The challenges faced by adolescents with disabilities include

i. **Inability to engage in social and romantic relationship** –Due to their disabilities, communication is usually a challenge thus it not easy for them develop relationships with the opposite sex. The stigma and discrimination faced within the society had led to low self-esteem issues thus most often feel not worthy enough to engage in romantic relationships.

ii. **AWDs were more vulnerable to sexual exploitation** and thus they could be easily lured into unhealthy sexual relationships or in some cases be victims of defilement. This had led to an increased risk of early pregnancies and contracting sexually transmitted infections including HIV/AIDs.

Most adolescent living with disabilities were not aware of sexual reproductive health rights despite being educated on sexually transmitted infections and how to prevention measures. SRH education was usually provided in schools, youth forums, and through awareness campaigns by community health volunteers. Providing education on sexual and reproductive health and safe practice was usually a challenge and thus there was a significant portion who were not aware of some of this risks. A particular group that was mostly affected were the mentally handicapped as providing such information from them may present a challenge.

Community Perspectives (Meso and macro system)

i. Cultural Norms on Adolescent Sexuality

The research revealed that within the society, persons were viewed as either children or adults with the middle group (where a larger percentage of adolescents fall often ignored. Furthermore, as most of the adolescent were within the school going age (upper primary and secondary school) most were thus seen as children. This implies that the society often fails to recognize that the needs of the adolescent despite being the age where they begin to experience a lot of both physically and psychologically changes. In most cases the work of provision of sexual and reproductive health education was thus left to schools where the adolescent attend or through youth groups

ii. State of stigma and discrimination of Adolescents with disabilities

Despite sensitization and awareness efforts being carried within the community, the stigmatization and discrimination of the adolescent with disability, and generally people with disability was still common. Causes of discrimination and stigma were mainly due to the society lacking proper knowledge on people living with disabilities. **Disability was seen as a disease and in most public places it was common hearing people referring to a disabled as a sick person.** This was further exacerbated by retrogressive traditional and cultural beliefs on disabilities. For instance, mental disability was often viewed as curse within the family. The research revealed that AWDs, faced both direct and indirect discrimination in nearly all facets of their lives within the community. This included:

- **Neglect by the household and community**-As AWDs need special care, they were viewed as burden and were often neglected not just by the society as a whole but also at household level. From the interviews that the research held across the sub-Counties that were studied, cases where AWDs were sent to live with other relatives and mainly grandmothers. In extreme cases, there were parents who had attempted to

abandon their children; there were two cases on one of the case the father upon realizing that their son was blind had wanted to abandon him in the forest. In the other a case a mother had attempted to abandon her child until she was compelled by the local administration to raise the child. In one of the extreme cases an AWD was forced out of his home by the father and therefore had to live outside in the bushes. There was a reported case of an adolescent being left out inheritance because of his condition. In another of being left out of a scholarship opportunity in preference to his sibling

- **Physical and verbal abuse and harassment**-AWDs living with disabilities were often subjects to physical and verbal abuse. Verbal abuse was mostly directed towards their disabilities with most being assigned nicknames based on their deformities. In most cases the abuse was usually from their peers especially within the learning institution. Bullying was also common which most often results to physical abuse as they deemed unable to fight back. Physical attack especially for those suffering from albinism was common, this was as a result of the myth that they were a source of cure for certain ailments including HIV/AIDs

- **Social exclusion –** From the interviews and discussions, AWDs complained that they were excluded from the daily decision- making processes both within the household and at community level. There was the perception that having a physical disability would also imply that one was also mentally challenged. AWDs were also often left out of social gatherings; this made them feel that the community members were embarrassed to have them around. They also reported that the community took them as beggar, thus they were rarely welcomed within other households and social gatherings.

- **Employment based discrimination –** Due to the community the perception that those with disabilities were not able to carry out some functions. AWD were locked out of certain jobs which limited their opportunities for employment. This had made them more vulnerable to sexual abuses including being used for sexual favors.

iii. Understanding of SRH rights of adolescent with Disability

The interviews and discussions held revealed that in most cases the community failed to respond to the SRH needs of adolescents living with disability.

Access to Sexual and Reproductive Health Services

i. Access Sexual and Reproductive Health Services by Adolescents

Health providers interviewed opine that,

> *"Access to SRH services is guaranteed right, under Article 43 of the Constitution of Kenya, which states that every person is entitled to the highest attainable standards of health which includes the right to reproductive health services. In line with this, the National Reproductive health policy states that RH services providers must strive to eliminate financial , social , cultural and political barriers that impede equitable access to reproductive health information and services especially to the vulnerable member of the of the society which includes youth , adolescents and people living with disabilities "(FGD Participant1)*

Analysis of county data showed that services were available to Adolescent including ANC , Family planning, PAC, Post Exposure Prophylaxis (PEP) in Sexual and Gender Based Violence (SGBV) cases, counseling and cervical cancer screening . However access to these services was also dependent on the age group of the adolescent. From the interviews held it was revealed that provision of services to adolescent between 10-14 years was much more difficult compared to those of 15 years and above. Looking at ANC services, there were

about 10,557 recorded cases of adolescent presenting with pregnancy with the county in the years 2016 out of which 3.6 %(389 cases) were adolescents of age 10-14 years. In 2017, the number recorded of adolescent presenting with pregnancy within the county increased to 10,971 out of which 3.4% were adolescents of age 10-14 years as can be seen in Figure 7.2.

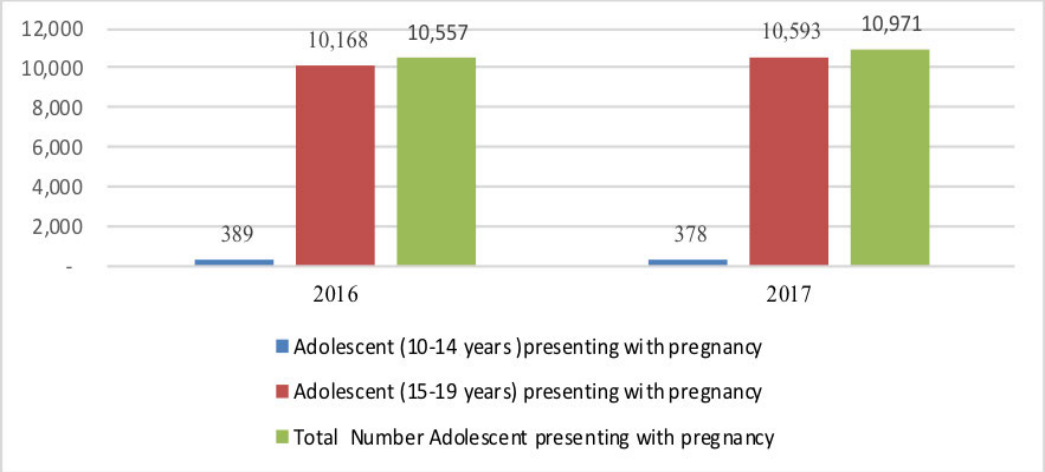


Figure 7.2: Adolescent presenting with pregnancy in Siaya County for the years 2016-2017

Source: Siaya County Health Records

Although access to SRH services especially contraceptives for AWDs above 18 years was guaranteed in law their service consumption data did not feature in health records. For instance family planning services, of all types of modern contraceptive methods including LTMs, injectable, Depo-Provera, condoms and pills were being accessed by adolescents but not being segregated by disability. From the records, there were 9,998 recorded cases of adolescents receiving planning services in 2016, out of this 12.14% (1,214) were between the age 10-14 years with 87.86 (8,784 cases) between the age 15 -19 years. In 2017, the number of adolescents on family planning increased to 11,707 out which 9.68% were between the ages of 15-19 years. Figure 7.3 below shows access to FP services by age of adolescent.

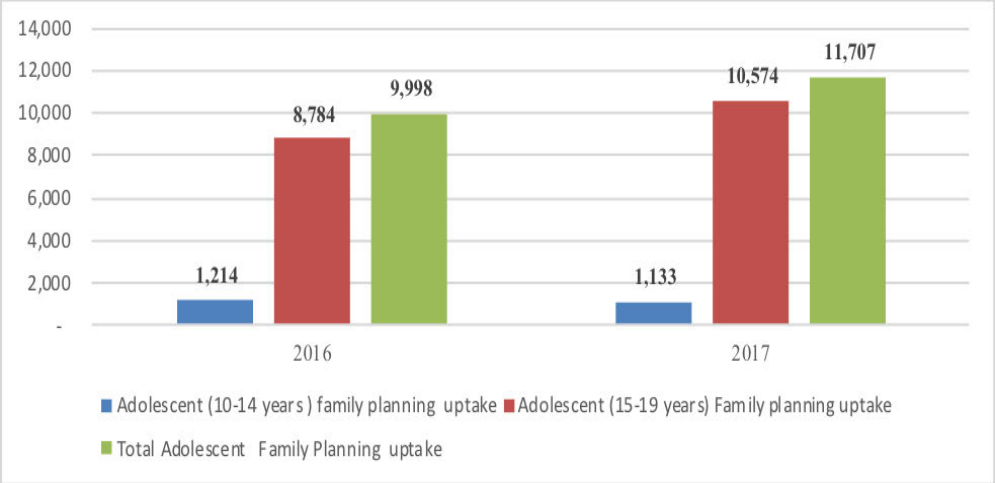


Figure 7.3: Adolescents accessing Family Planning Services
Source: Siaya County Health Records

Despite abortion being illegal, adolescents can access Post Abortion Care (PAC) services in emergency situations only. However, in the interviews it was revealed that this has led to people initiating abortions privately then going to facilities for PAC services sometimes too late at the risk of infections and deaths of the victim. AWDs were most affected due to associated stigma. Figure 7.4 provides the trend for PAC from 2016 to 2017.

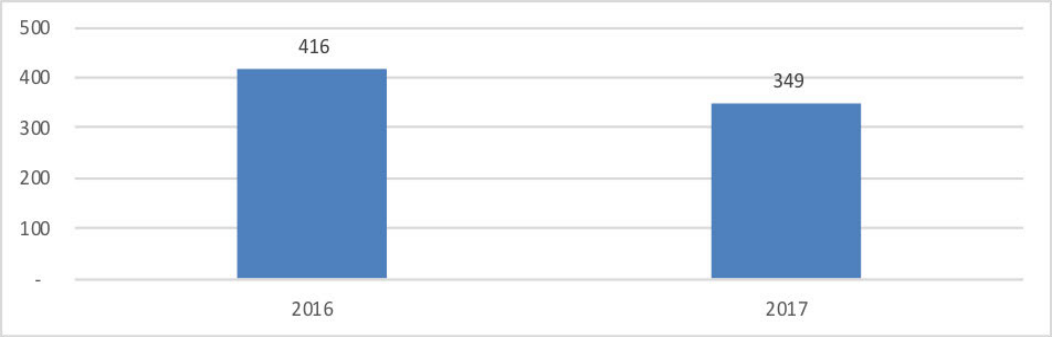


Figure 7.4: Adolescents (10-19 years) accessing PAC Services
Source: Siaya County Health Records

For HIV services, despite having adolescent with disabilities in the county who fall within the key populations such as Female Sex Workers (FSWs), Injecting Drugs Users (IDUs) and men having sex with men (MSM) services do not target them.

"...However, the infected adolescents could still receive services that were modified to suit which includes contact treatment, anti-retroviral therapy, health education and support from health clubs. One such modified intervention was the Operation Triple Zero (OTZ) a biomedical intervention that aims to reach 90% of adolescent 10-19 years old infected with HIV. Data however was not desegregated for adolescents with disabilities which pose weakness in targeted programming" (KII participant, health provider, Alego Usonga)

Access to Sexual and Reproductive Health Services by AWDs

From the data provided by the county, there were health facilities that provided counseling and physiotherapy services for adolescent receiving ANC services. The cases of adolescents with disabilities only came to the fore whenever they got sexually violated. In such cases the health facility received those referred by community volunteers, police or the children's department. In the event of violation the facility provided services – examination for injuries, post exposure prophylaxis (PEP), treatment for STDs and counseling where possible. From the interviews the following challenges were mentioned include:

"...Lack of proper linkage between sexual and reproductive health and disabilities is glaring in the County. For instance, despite the policy outlining measures to be undertaken to ensure the special SRHR related needs of the marginalized and vulnerable adolescents, counties are yet to develop comprehensive strategies on how these services are going to be effectively provided. Furthermore, data on AWDs and including assessment of SRH needs is also lacking within the counties. Without this information, then prioritization of AWDs needs and investment towards to ensures SRH services adequately responds these needs then becomes difficult"(FGD-HCP Participant 2)

Moreover health facilities still lacked sufficient capacity both in terms of staff, equipment and commodities for AWDs as observed by a health worker in focus group discussions with health providers:

> *"Inadequate capacity is still a challenge not just for provision of SRH services to AWDs but for health services in general. It was reported that communication is a major barrier in accessing services, especially when dealing with hearing, visually and mentally handicapped with health facilities not having adequate personnel to address this. There are facilities that do not have personnel trained in sign language at the Patient Support Centre (PSC) and HTS counselors. (FGD Participant 3)*

The cost of accessing services was high as explained below by a key informant working with persons with disabilities:

> "*As most AWD are from poor backgrounds; the cost of seeking services within the health facilities has become prohibitive. Additionally, AWD have to incur extra cost such as transport cost which is often charged at higher rate given their state of disability to get them to and from the health facilities. This has resulted to AWD seeking services from other unqualified persons or they simply do not seek services at all."(KII Participant 4)*

Adolescents still faced stigma and had limited access to SRH and HIV information from health workers within the health facilities: From the interviews, AWDs in in-depth interviews complained that they were treated differently by health care workers when they went to receive SRH services. Asked to explain, a participant said that,

> *"...for instance most SRH information and communication material are not well adapted for us living with disabilities. Some written materials are not very visible, has no pictures of a disabled also trying to access a service and even in demonstrations of*

use of related SRH components like a condom the facilitators are never keen and patient enough to find out whether the disabled in the room also understood; (In-depth interview Participant 1).

CHAPTER EIGHT

DISCUSSION

8.1 Introduction

Without a well-functioning and equitable health system, access to, and utilization of sexual, reproductive health (SRH) and HIV services for adolescents with disabilities (AWDs) in Siaya County remain limited. This chapter discusses the findings on the adequacy and utility of community-based health care (CBHC) as a means to address the unmet SRH & HIV needs for AWDs in Kenya. The aim of this study was to understand the capacity and utility of the CBHC model for AWDs, using CHBC programs in Siaya County as the empirical basis for the research. The study was motivated by the fact that Kenya continues to progress slowly towards achieving universal access to essential healthcare for its inhabitants (KPMG, 2013) and, specifically, for marginalised vulnerable populations such as AWDs. Indeed, the Kenyan Ministry of Health acknowledges that AWDs have limited access to, and use of the government run public SRH and HIV services (MOH, 2015).NGO-run CBHC programs have generally been promoted as a way to remedy this problem but there has been little research on their utility in relation to AWDs.

The research used the WHO health systems building blocks (WHO, 2007) as a framework for investigating the supply of health services and a socio-ecological model (Bronfenbrenner and Morris, 2007) as to frame the investigation of the demand for SRH and HIV services among AWDs. The purpose of these frameworks was to enable a focus on processes and outcomes in the delivery (supply) of services on the one hand and, on the other, the experiences (demand) of AWDS with the government health services and the CHBC programs. The following

discussion is organised on the basis of the methodology outlined above. I first cover the supply side of processes and outcomes in six sub-sections, using the WHO buildings blocks (i.e. Leadership, Human Resources, Health Information System, Health Commodities and Technology; Service Delivery; Health Financing). Thereafter, I discuss the demand side of processes and outcomes according to the experiences of AWDs and their families in their interactions with the health services.

8.2 The supply of services for AWDs

Kenya, like the rest of African countries requires well-functioning health systems and including governance and equitable distribution of health professionals who are adequately trained and skilled to provide quality care to patients. A system to control medicines and prevent material shortages and a strong regulation of the financial system for rebate payments to health professionals is also recommended. Effective continuum of care for vulnerable children like AWDs through CBHC is hinged on adequate functionality of link-facilities that support referral mechanism;- to next levels of care as often would be needed. Currently the functionality of the facilities at various levels as the study established is sub-optimal. This is consistent with findings from other studies in the region. For instance, a study in Nigeria found that mismanagement and poor inter-government funding, often characterise healthcare system, in effect thwarting the investment in the critical health system building blocks including staffing, supply chain and equipment; thereby compromising the coverage and quality of PHC services in Nigeria (Oyekale, 2017; Abimbola et al., 2015; Olatubi et al., 2018). Similarly the findings in my study reveals general weaknesses in the health system that ranged from inadequate staffing, poor financing, uncoordinated leadership, failed supply chain of health commodities, underperforming health information system (HIS) and exclusive service delivery has grossly affected access to and utilization of effective and satisfactory essential care like SRH and HIV services for AWDs. Indeed, the argument is that the

government-run SRH and HIV services barely serve AWDs due to these systemic obstacles that hinder synergistic leverage across the building blocks as I outline and discuss here below.

8.2.1 Leadership and Governance

Poor leadership and governance of public health systems are core barriers to accountability and equity in health services distribution and use by vulnerable groups in Siaya County. The difficulties experienced by the AWDs to use the government-run services as this study revealed are largely due to structural impediments; including poor policy environment that govern resource allocation for services targeting vulnerable groups like AWDs, failure to provide adequate disability friendly physical infrastructure to facilitate access to services; and non-adherence to, dissemination and enforcement of policies that are favourable to AWDs. A number of studies have shown that although Kenya has enacted a number of policies to govern access to health by the vulnerable citizens like AWDs, such policies are not adequately reinforced. For instance, although the government has enacted social security policies including waivers for user fees for vulnerable groups such as AWDs, these are not implemented. As described in chapters four, five, six and seven, prohibitive health financing mechanisms has excluded vulnerable groups like AWDs. These findings are consistent with the findings of KNHCR, (2012; 2014); MOH, (2015); Hervish and Clifton (2012)

Moreover, overlap of functions between the county health management team and their sub-county counterparts is found to weaken the supervisory role to primary care facilities where most vulnerable groups access care. Notably, SCHMT exercise less management authority to provide supportive supervision to primary care facilities as envisaged in the county health structure. Instead, the county level management teams had largely taken over that responsibility under the guise of their responsibility to supervise and build capacity in

primary health care facilities. For example, as is described in Chapter four, the SCMTS' view across the study area is that they lack logistical support (transport, field allowances and equipment) necessary for their fieldwork in supervising community level health services providers (CHVs and primary health care facility staff). Further still, systemic weaknesses reflected in poor leadership and governance is also in the failed annual planning for prioritized resource allocation to devolved health care units. As captured in the same chapter (four), annual work plans are not being used by the county leadership as primary basis for allocating health resources and benchmark for over- sighting sub-county based functions.

Furthermore, there are evident weakness in the leadership and governance of community health units (CHU) by SCHMTs and of the community health committees (CHCs) which are managed by designated leaders within the CHUs. An indication of these problems is the high drop-out rate of CHCs from the government-run CHUs partly due to the lack of remuneration and recognition by the government. Furthermore, the absence of physical infrastructures for CHUs indirectly contributes to the leadership and governance challenges. The net result has been inconsistent delivery of services that CHVs are supposed to provide for all at community level, let alone for AWDs.

8.2.2 Inadequate Human Resources for Health

Regarding staffing the current deplorable state of human resources for health has negatively mediated against access to health care in particular SRH to AWDS. As was observed, shortages and ill preparedness of services provision both at the community and health system structure levels are main challenges that must urgently be addressed. Perpetual health staff strikes and general poor attitudes of health staff continue to diminish health seeking behaviours of AWDs and their families who directly confront with wrath of demotivated staff. Such coupled with inadequate training AWDs pressing concerns have caused barriers to

access the SRH+HIV care for AWDs.

Availability of adequate, competent and well-motivated health workers (HRH) is central to effective delivery and access to health care in particular SRH & HIV services for AWDs. Suffice as this may be, this study demonstrates gross inadequacy and ill-preparedness in human resources currently available for such services for children with special needs as seen in chapters four, five and seven. The implication is that the situation has conferred real challenges to the overall health system in Siaya County to the disadvantage of most vulnerable groups like AWDs. The malady of staff shortages and inadequate training runs across the public and CBHC systems of services delivery for AWDs. One consequence is that staff at primary health facilities is not able to cope with the general demand for health services let alone the service demands of disabled people. This had affected outcomes of referral systems as a significant group of those referred to the next level of services often choose in despair to forfeit the service.

Moreover, disabled people, including AWDs tended to be further excluded because staff does not have time to provide the frequency of care that disabled persons often need. In addition, staff at primary health care facilities frequently do not have health care training on disabilities or have limited training. For example, as is described in chapter four and five none of staff, including CHVs, public and CBHC service providers had training on how to provide disability friendly services more so those dealing with AWDs and SRH. The implications are that such unprepared staff is more likely to avoid or refer AWDs that require special attention than to spend more time to attend to them.

8.2.3 Health Information System

Despite the importance of vital health data for decision-making at various levels of the health system, the Siaya county health administration actually has very little data on disabled

persons generally and AWDs specifically. In particular, data with respect to SRH and HIV services for AWDs were not available to assess need and consumption patterns of the services. This is because health planning currently does not include disability as an indicator of services access and use of services that ought to be monitored. Furthermore, although CBHC programs collect data on activities performed and targets reached, the purpose is primarily for reporting to their funders as this study demonstrated in chapter five of this thesis. They do not provide data that could help the country officials to monitor the health of AWDs and their access to health services Arguments were advanced at various heads of CBHC and county primary care levels that targeting AWDs related indicators was a moving target. Notably, disability indicators in the household register of the population in Siaya County do not get transferred via community level workers' reports in to the district health management information system (DHIS).

8.2.4 Health Commodities and Technologies

Poor supply chain management for health commodities is a major barrier to access and utilization of health services needed by AWDs. This study observed perpetual shortages and stock-outs of health commodities in Siaya County, especially those associated to SRH and HIV/AIDS services characterize the systemic weaknesses observed in the community health services provided in the county. Interacting with the other components of the health system building blocks, the weakness at this particular block confer real barriers to access and utilization of such services by AWDs in the County. For instance, the study observed general inadequacy in the distribution of such commodities, notably condoms and contraceptives with frequent stock-outs at the community level or at the Youth-friendly centers where AWDs were expected to access services. This has necessitated unnecessary referral of individuals AWDs to clinics to obtain SRH services which they should otherwise access locally through

the CHVs. Moreover, some faith-based CHBC programs in the county did not access SRH related commodities such as contraceptives and condoms based on their religious values. This meant that AWDs living around such program catchments that required SRH services especially the commodities would have to be referred of to the next facility that would provide services. In the process of referrals, as demonstrated in chapter five of this thesis, the referred AWDs however would simple forfeit their need and right for the service. In effect therefore, poor access to adequate SRH and HIV commodities compounded with other barriers at varying levels of the socio-ecological model to access and use of related services by AWDs in Siaya County.

8.2.5 Service Delivery

Equitable distribution and universal access to basic health services for all is a hallmark of quality health services delivery. In spite of the foregoing however, as this study demonstrated, marginalised groups especially AWDs in Siaya County are not adequately included in the SRH and HIV services offered by government and NGO CBHC run health programs. For instance the study revealed significant systemic weaknesses in the delivery of SRH and HIV services for AWDS. A major weakness is that both sets of services work according to the model of delivering essential service packages rather than comprehensive care packages that would have accommodated vulnerable groups like AWDs. Consequently, the service providers are not drawn towards taking into account what sort of services need to be provided for whom.

Likewise, for instance, some services are still delivered via the model of vertical programming like malaria, HIV, FP, and non-communicable disease such as diabetics and cancers. In these programs the focus is primarily on generally preventing (and treating) the county population; there is little consideration of addressing the specific needs of and

challenges faced by some sub-populations such as AWDs to access, the services provided by these programs. This study, as captured across the finding chapters in this thesis has demonstrated that challengers at the subsystems levels like poor distribution and suboptimal functionality of health facilities including community health units had significantly contributed to poor services delivery to and access to AWDs.

Notably, the absence of any form of preferential treatment for AWDs reflected this weakness.in the local service delivery systems. Another systemic weakness is the poor management of linkages between health facilities which in practice hamper the referral of patients from the CHUs to relevant health facilities and communication between facilities and AWDs and their caregivers. Nonetheless, as is described in Chapter five despite the severe limitations of services provided to AWDs, CBHC programs are a vital institutional addition to the primary health services in Siaya County. They enable the ethic of voluntarism; individuals become CHVs to help others. The CBHC programs provide a structured means to organise that humanitarian ethic. Furthermore, as is described in Chapter five, the case of Nyangoma Mission exemplifies the value of CHBC programs. They have existed often for many years and they have gained trust in communities.

8.2.6 Health Financing Building Block

Moreover, the other health system issues were observed at the financing component. The study observed that although production and consumption of quality health care services is premised on adequate health financing, currently the health care system remains poorly financed; with devastating burdensome financial catastrophe to poor households. Those hosting AWDs are particularly disadvantaged as they have to meet the cost of health services from own pocket like any other well off families. Although the government has attempted earmarked mechanism or universal health cover to ensure universal access, health financing

is still limited to out of pocket, public and tax based mechanisms. Poor public financing and exclusive tax based methods. Poor public financing and exclusive tax based approaches like NHIF have ensured that vulnerable groups met their own costs of health care needs. The lack of accurate targeting criterion for exemptions remains a considerable challenge to health administrators that are charged with the responsibilities of ensuring revenue collection but also expected to reinforce waiver policy for destitute families.

This study makes serious observation on the impact of poor healthcare financing in the lives of vulnerable citizens. Whereas the expectation is that with the prevailing public financing, the out-of-pocket financing should have been increasing, the opposite is true. For instance, financing for CPHC programs in low- and middle- income countries has continued to be a challenge, compared to the high-income countries, the former invariably failing to allocate as much funding for health as the latter (Rifkin, 2018;Obimbo, 2003). This was explained by the fact that most of families in Siaya County were refraining from consuming paid up services at the government facilities. AWDs with disabilities were opting to stay at home without seeking health care services even extreme cases of care needs such as SRH and HIV/AIDS. In view of points raised above (in this sub-section), despite apparent mechanisms to support poor people to use the services, this was not happening to any great extent and certainly not by AWDs and their caregivers for the simple reason that the mechanisms were not working. CBHC programs are dependent on external funding. The implication is that the reach of programs and the sustainability of their projects are compromised and short spanned. Likewise, health financing is a significant challenge for many families. Although community-based health financing schemes do help families as was described in chapter five, as observed however, their reach is often limited and there with no specific focus on financing health care including SRH related services targeting AWDs.

8.3 The demand for disability-focused care services

This study has shown that many factors define AWDs and their caregivers' experiences of government and NGO run health services. The study viewed these experiences and how they affect demand for services in terms of two broad categories: personal and environmental factors. At the fore is the dilemma of sexual exploitation and the SRH and Rights of AWDs. I here discuss the varying experiences in the order below.

Sexual exploitation

Lack of self-efficacy and autonomy were found to predispose AWDs to risks of sexual exploitation. The demand for disability focused SRH and HIV/AIDS care for AWDs unfortunately opens from negative reasons rather than from positive desires by AWDs to fulfil their sexual and reproductive rights. Unimaginable proportions of cases of AWDs needing care as a result of being sexually exploited go unreported as this study revealed. For instance, this study established that the community were the parents covertly encouraged AWD (girls) to bear children as a proof of "being normal" sexually despite the impairment other SRH and HIV risks notwithstanding. In such cases the parents or society tended to overlook situations of SGBV against adolescent girls with disabilities. In fact, they were pleased when such sexual encounters resulted into a pregnancy whether wanted or not by the victim. The perpetrators would escape unpunished with a sense of achievement for the family. The finding further explains the extent of societal violation of the sexual rights of AWD with regard to autonomy on sexuality including decision on bearing of children (UN, 1995;UNCRPD, 2006;WHO and World Bank, 2011).

The family (Interpersonal)

The family as the basic unit of care with mothers and fathers as the principal caregivers of AWDs is both overwhelmed with care needs but also accused of being part of SRH related risk faced by AWDs. It emerged from the findings that parents are vulnerable in the

circumstances where I did this research in the face of social norms on parental behavior and economic circumstance of poverty of many families with disabled children. In such circumstances they too suffer emotionally and physically with the challenges of rearing disabled child in these conditions alongside limited reach of services for AWDs. Many families are therefore poor facilitators of the AWDs support, thus CHVs remains responsible for AWDs. In many instances, the CHVs are responsible of making transport arrangements for the AWDs from community to the next level of care. In additional, CHVs literally accompany AWDs to the health facility when the parents fail to take responsibility.Family as an entity within the community care system is overwhelmed especially with competing needs for care not only with respect to health care for the AWDS but as well for the family survival needs as a whole. The high poverty levels expressed by various participants in particular those hosting children with disability dims every effort for SRH and HIV care for the AWDs (Braithwaite and Mont,2009;Bronfenbrenner and Morris, 2007;Carew et al., 2017;Hanass-Hancock et al., 2013). Mothers being the primary caregivers were suffering burnouts due to the intense and prolonged care needs of the family and worse so when disability situations intervene among the families. As this study observed, normative cultural demands and blame weighed heavily against women with regards to children with disabilities in the family. The gender roles as constructed by the community ensure that the woman is held accountable for anything perceived as wrong in a child. The implication is that as the children with disabilities enter the age of adolescence, the care demands including sexuality issues become difficult to address especially where a boy child is involved. The demand for a male figure to step in would become obvious as was explained in FGD with local leaders with disabilities.

Father figures as culture shapers were critical as mentors to the family members. Where a father figure is present in a household, not even imagination of sexuality and contraception issues would be discussed more so with an adolescent boy or girl let alone a disabled one.

Fathers were largely away from home; and when present, exhibit remote emotional attachments that make their AWDs miss on parental guidance and supply of essential basic needs. The foregoing could be part of the reason for low self-esteem deduced from observed reactions of AWDs during the in-depth interviews. Some were withdrawn- spoke in low tones and would not want to move closer to the interviewer; and most of the time they would not readily respond to questions that appeared to explore on their sexuality. Self-sympathy could be discerned from such cases which in our intuition could be attributed to a number of factors including poor parental care and support. Moreover the study observed that since a good number of AWDs faced demeaning references from the family, peers and community, they were pushed into inadequacy and low self-esteem born out of feeling and seeing that they are 'different' over a course of many years.

Low Socio-economic Status

The social effects of family/household poverty on AWDs contribute to their limited access to services. For instance with regards to education, the lack of money to pay for school fees was only one of the reasons poor AWDs did not attend school. For instance, not attending school was also associated with parents in households hosting disabled children sent them to live with their grandparents. This was perceived as a way of alleviating the care burden of the mother which had several children; also parents keeping children at home, even hidden as a consequence of social stigma (or to protect child from social stigma). Poverty related inability to pay school fees was clearly only one part of the problem that family poverty created for AWDs**.** In the exploration of the subject of education among the study participants, the highest class attained by AWDs was merely class four. The children had dropped out of school and were merely at home with multiple risks of abuses as they unsupervised. Exposure to SGBV was common among the AWDs who were not attending school. In worst case scenarios, they were used as pawns for the guardians/ parents to earn money for survival.

Structural or Institutional Factors

Multiple factors negatively affect AWDs SRH and, collectively, present significant barriers against them and threats to their SRH the discussion below is divided into four sub-sections to highlight the principal factors.

Lack of sexuality education

Access to education regarding sexuality for AWDs continues to elude policy makers in Siaya County. Although there had been an attempt to have a curriculum on comprehensive sex education in Kenya, this had remained contentious. Religious bodies and some parents were not in support of the curriculum; they had preferred that sex education be handled under social education ostensibly to prevent "over exposing" the children to sexual issues that might make them indulge into early sexual activities. Moreover, the antagonists had argued that teachers were not adequately prepared to deliver the curriculum more so to AWDs. From a key informant who was a teacher also living with disability, the study revealed that only a few staff were trained in special education to handle children with special needs. Those with intellectual and hearing impairments were the most affected. This finding was consistent with a study in Nigeria with teachers (Aderemi, 2014). Furthermore, the study also contrasts the Nigerian study finding with regard to right of adolescent with intellectual disabilities to bear children.

Sexual violence –SGBV

Exposure to SGBV was common among the AWDs who were not attending school. In our exploration of the subject of education among the study participants, the highest class attained by a number of AWDs was merely class four. The children had dropped out of school and were merely at home with multiple risks of abuses as they remained unsupervised. In worst case scenarios, they were used as pawns for the guardians/ parents to earn money for

survival. Although this was gross violation of the rights of the children as per CRC; UNCRPD, (2006); KNCPWD, (2008) and COK, (2010) enforcement remains a big challenge as the violators continue undeterred. This finding was consistent with the study carried out by the Kenya Human Rights Commission (KNCHR, 2012) on sexual rights of young people including those with disabilities (Furthermore, whereas comprehensive sexuality education curriculum being debated by the public is hoped to provide age appropriate sex education for school- aged-children, a good number of AWDs as revealed in this study, were not school going hence still would be excluded from such an opportunity.

Lack of access to justice

Lack of adequate justice for sexual violation of AWDs dominated the gaps in their need for enjoyment of sexual and reproductive health and rights. This study demonstrated in chapter seven the harrowing experiences the AWDs go through in search of justice and protection against SGBV meted against them. Adversarial criminal justice system had equally failed to ensure justice for AWDs who were constantly violated mostly by their close relations. The observation was that even though the legislation on sexual offences Act (SOA 2006) prohibited alternative dispute resolution mechanisms (ADRM) in such cases, the ADRM was the norm in the county of Siaya. Again this is consistent with findings of other studies in the region (KNCHR, 2012; KNCHR, 2014). Moreover, this study noted a lack in broad based community oriented mechanism sensitive to sexual rights of AWDs and positive cultural norms consequently, incoherent justices systems that do not serve the interest of the AWDs .Although currently, as the study observed, organizations like Plan International were involved with comprehensive child right issues in the county including SRHR. Such organizations were training county-based paralegals with an aim to help advance the right of all children irrespective of (dis)ability status. The research however noted that such initiatives were not anchored on any community-based structures to ensure sustainability and cultural

relevance. The trained paralegal teams soon dissipated due to lack of motivation as they worked as volunteers wrestling with cultural-moral-legal conjunctions of divergent views among key stakeholders. Although this is gross violation of the rights of the children as per CRC; UNCRPD, (2006); KNCPWD, (2008) and COK, (2010) enforcement remains a big challenge as the violators continue undeterred. This finding is consistent with the study carried out by the Kenya Human Rights Commission (KNCHR, 2012) that revealed inadequate protection of AWDs sexual violation.

In contrast, as earlier stated, the study also observed inherent cultural/spiritual model of disability that was even more intriguing. At the county level disability was still perceived as a curse or bad omen. As such, families with disabled children tended to hide them away from the public eye to avoid social stigma (captured in depth in chapter six). The consequences of this that such children would not go to school or seek for health services under the false verdict of a curse. Furthermore, they would be at risk of sexual abuses they were used as antidote to other peoples supposed curses- sexual/cultural cleansing at the risk of HIV/STI.

In cases of SGBV the victims were normally kept in homes unattended until the condition got worse in case of injuries to the organs or infections /pregnancy. Where pregnancies occurred, they were most likely not to attend the antenatal clinics (ANC) peradventure the perpetrators be discovered. Their plight according to the community members was a matter of fate of which planning, or programming is only in the hands of the gods. This fatalistic view of disability by the society limits the enjoyment of SRHR by AWDs. All disabled persons did not receive any salaries save for only those with severely disabilities. These people were chosen by the chiefs to receive the Ks.2000 per month and were people with severe disability.

Although courts of law formed a key context for AWDs interaction to secure their rights, the impact on SRH and HIV was minimal. The observation was that justice for a defiled child in

particular AWDs was replete with challenges is an indictment of the obtaining justice systems in the County – whether cultural, judicial and otherwise (Mikton et al., 2014). The study for instance, found that the process of getting legal redress for SGBV among children was encumbered with a lot of barriers along the way. It is agreed that sustaining a case involving a minor to a conviction of the offender was a nightmare. Similar to other studies around sexual offences, the researcher observed that right from the onset point of violation, reporting was always delayed as efforts were directed towards concealing the evidence (KNCHR,2012; KNCHR, 2014). Prosecutory flaws were abounding due to poor investigation of SGBV cases involving AWDs. The police for instance was found to be less proactive or enthusiastic to take up such cases which ended up being dismissed by the courts on grounds of lack of evidence especially those with wheelchair disability would normally weaken the cases letting the violator go scot free. Evidence provided by the perpetrators in collusion with the police was commonplace. Justice delayed is justice denied, so goes the dictum of justice. Time concept in the justice process was therefore of great essence.

As discussed, societal and organizational cultural factors that inhibit AWDs access to services permeate the social and economic factors. For instance, faith -based NGOs do not assist AWDs substantively with access to some SRH services such as contraception. Within government-run services, there is little initiative to serve AWDs because the service protocols and procedures do not overtly direct staff to acknowledge them as special needs category.

CHAPTER NINE

CONCLUSION

9.1 Introduction and overview

What I have discussed with regard to supply and demand side of services delivery shows how multiple factors interact to entrench/exacerbate vulnerabilities of AWDs that, in turn, constrain both their access to services and provision of services by government run and NGO run health services. From the perspective that despite the heightened SRH and HIV related risks the adolescents with disabilities (AWDs) face, the public health system has failed to deliver SRH and HIV services that targets them. Furthermore, despite the documented success of the CBHC programs in the delivery of HIV and AIDS services, the efficacy and utility of such approaches had remained unexplored in the context of delivering SRH and HIV services to AWDs. Against this background, the study assessed the adequacy and appropriateness of the community-based healthcare (CBHC) approach as an option for improving persons with disabilities (PWDs') access to and use of Kenya's state- run Adolescent Sexual & Reproductive Health (ASRH) and HIV services. From the discussions of findings, the study firmly concludes that community based health care (CBHC) approach is a viable option to augment delivery of sexual reproductive health (SRH) and HIV services for adolescents with disabilities. Overall, based on the four key rubrics of the study, namely: a) Adequacy and appropriateness of CBHC approach; b) access to and use of SRH and HIV services; c) Inequity and inequality; and d) Utility of CBHC, the following conclusions are made; Moreover, it should be noted that these rubrics are encapsulate the building blocks and ecological models discussed in the previous chapter – chapter 3; and hence should be viewed against that backdrop.

9.2 Adequacy and appropriateness

This study concludes that although there exists massive opportunities for the use of community based approach to SRH and HIV services in the County, these have remained fully untapped to address unmet SRH and HIV care needs of AWDs. Furthermore the interaction between and among the health systems components, namely - leadership/governance, financing, human resources, commodities, HMIS and service delivery and other subsystems is sub-optimal and un-integrated making the entire system inadequate to deliver the services. Further, although CBHC approach could be entirely appropriate for delivery of SRH and HIV care to the AWDs, its potential is under applied due to rigidity in health system policies, programs and attitudes that are insensitive to AWDs needs. Therefore, there is need for a community based health strategy that is inclusive for the provision of SRH and HIV services for AWDs.

Furthermore, it is clear that availability of a well-functioning public health care system is critical for effective CBHC delivery of continuum of SRH and HIV care for vulnerable children like AWDs across the county of Siaya. The public and the community systems are bound to work together at all levels of services delivery to leverage efforts. Such an approach as the study revealed should be able to support referral needs through linkage mechanisms that facilitate access to enhanced care from one level to the next level without inhibition. Although individualized and complex in range of SRH and HIV services provided along the chain is desirable, such should yield to easy access and utilization for all including AWDs. Moreover, such is found consistent with the philosophy behind the policy environment for community health strategy of 2006 that remains for the delivery of KEPH to all citizens including AWDs in the country. However, despite the forgoing aspiration, in the currently, suboptimal functionality of the overall health system from its individual parts has

grossly weakened community responses that depend on public systems to cope with care needs of vulnerable groups like AWDs.

Across those subsystems including leadership, financing, human resources, supply chain/health commodities, infrastructure and equipment, health information systems (HIS) and service delivery as observed, the deficiencies in the components both individually and corporately, have negatively affected access and use of services in particular, SRH and HIV care for the target group. Moreover, viewed from the ecological perspective, the building blocks above, though apparently at distal position in to the individual child (AWDs) at the center, the interaction however, is found to be fairly close and personal; as the services needed portend the very essence of life and child development. The study posits that the interaction of the AWDs with the institutional level issues of the model; in view of the phenomena of this study, must collapse the intermediate concentric circles that intervene between the individual and the care system. In my view, this could be achieved by removing the associated access barriers at the individual building block both at the community and health system levels. This would mean recognizing the inseparability of sexuality and reproduction from the individual, but rather as part and parcel, hence pursuit for deliberate re-orientation towards system wide-individualized -person-centered SRH & HIV services.

In the above respect, the study advocates for systems development and strengthening both at the community based approach and the public health system levels. This would mean that in instances where person centered models of care are glaringly lacking, efforts are initiated to build the same. In cases of inherent weakness as established by this study, appropriate actions towards addressing the gaps should be taken as a matter of priority

9.3 Access and utilization of services

Access and use of services through the public and CBHC health systems in Siaya are faced with numerous gaps that require urgent attention. Consequently, the study concludes that unless those observed challenges are addressed at all fronts of the systems, access to and utilization of SRH and HIV care by AWDs remain uncertain. For instance, while some SRH services were available for older adolescents (ages 18-19), the services are typically not disaggregated for AWDs by age, those of younger ages who require such services hence are put at higher risks.

9.4 Lack of data

The unavailability of data on AWDs the SRH and HIV status of AWDs contribute to substandard planning of SRH for the target group. On one hand, the accessible research evidence on SRH was fragmented in multiple voluminous reports and scientific journals that are not convenient to most decision-makers. This situation was further complicated by insufficient technical capacity among policymakers to translate and utilize empirical evidence. Most of prevailing research utilize technical language but even in instances where they have been rendered into user-friendly formats, there had been little efforts to proactively distribute such studies and thus evidence does not reach policy makers and intended users.

9.5 Inequity and inequality

Basic services at the community levels remain inaccessible to AWDs in Siaya County. From the discussion of the findings, the study reiterates that unfair treatment and discrimination against AWDs are major barriers to their access and use of SRH services in Siaya County; and that the barriers are attributable to exclusionary and inadequate SRH policies, poor programing and, inadequate financing, poor infrastructure, and inaccessible points of service delivery. The study found that although the support from partners contributed to expanding

access to services like FP, maternal, child, adolescents and youth services and many non-governmental organizations supported youth-friendly services across the county, such programs were neither equipped for the AWDs' need nor directly targeted AWDs. Moreover the poor design, location and unaffordable costs of services if not addressed will continue to alienate vulnerable groups especially AWDs from accessing services.

9.5 Utility of CBHC in SRH delivery for AWDs

Overall the study concludes that although CBHC approach provided an appropriate avenue for the health system to deliver sustainable SRH and HIV services for AWDs, an integrated and multi-sectoral approach and direct public investment in health system development and strengthening across the building blocks especially at the community level are required. And, that such must elicit meaningful participation of AWDs, organizations of PWDs, community members, CBHC/ non-state actors, County and national governments department to leverage every available resource. Application of comprehensive model of primary health care therefore remains the most appropriate form of CBHC approach to deliver an integrated care that address wholistic needs of vulnerable groups in particular, AWDs. Moreover the study strongly concludes that although addressing the health system weaknesses in particular the individual components (building blocks), this alone would not improve the utility of CBHC approach without also addressing the demand factors at all levels of the SEM.

CHAPTER TEN

RECOMMENDATIONS

This study set to analyse the community based health care approach as an alternative means to the delivery of sexual reproductive health and HIV services for adolescents with disabilities in Siaya County, rural Kenya. The study has observed significant capacity and strengths in community based health care (CBHC) approach to the delivery of Kenya essential health package (KEPH) as envisaged in the community health strategy framework (2006). Conversely however, as demonstrated by this study, glaring gaps persist across the health system building blocks and, attributes within and beyond the formal system consequently hindering effective delivery of and access to SRH and HIV services for AWD through CBHC approach. Although systemic weaknesses persist in the overall health system in the county, with sufficient attention to the prevailing challenges, the community based approach remains it's most realistic and practical mechanism through which households and communities' role in sustainable health and health-related development programs can be realized for AWDs. I here recommend the following as guided by the multidimensional issues that are identified to adversely mediate against community health systems responsiveness to AWDs' care needs:

1. Policy environment: The county government should domesticate critical policies related to disabilities to facilitate access to services and social safeguards. Currently, despite the numerous policies and legislation in Kenya, in support of international human rights instruments especially those linked to SRH, disability and child right issues, Siaya county health care system has not adequately aligned. AWDs continue to face exclusion from SRH and HIV services due to ineffective and non- responsive healthcare systems including CBHC initiatives.

2. Leadership and Governance: Specifically, this should include strengthening the leadership capacity and technical skills of the community based health providers in particular the community volunteers and the link facilities staff on how to assess disabilities, communicate through sign language, manage stigma and reporting of violation of all forms including sexual and gender based violence meted on children. This will required strengthening the judicial systems and aligning them to community structures that upgrade access to justice and protection of individual rights in the context of morally sound cultural imperative

3. Partnerships: That the county government and its partners including the community should invest in strengthening CBHC and public system-linkages through formal synergistic arrangements. Therefore, continued strengthening of the capacity of the communities and creating new avenues for acquiring new knowledge and skills to effectively engage in solving essential health needs such as SRH and HIV, in particular for most vulnerable members like AWDs should be of a priority. In this regard, continuous assessment and analysis of practical and strategic needs of AWDs must constitute regular agenda in community dialogue meetings to surmount negative socio-cultural barriers that continue to inhibit full enjoyment of SRH rights by AWDs. This will foster an influence for inclusive planning that ensures that indeed 'no one is left behind' as per the SDGs mantra goes.

4. Systems strengthening: The individual health system building blocks that are outlined in community strategy including, the type of services to be delivered at level 1, the mix of human resources especially those that are adequately trained on special needs required for level 1 services delivery, the minimum commodity kits required, the community health information system and the leadership and management structures to be used, will go a long way in ensuring access and use of essential health services including SRH and HIV care for wholistic development of AWDs to be effective participants in the countries socio-economic developed.

5. Sector wide approach: I believe the forgoing will require effective support from the public systems through sector wide approaches that seamlessly account for the multidimensionality of health and health related development needs of vulnerable children not only living with disabilities (AWDs) but also in difficult circumstances. It will be necessary therefore for the county and national governments to review and elaborate on responsive policy frameworks with in-built, efficient and practical reinforcement mechanisms that quickly address and punish any form of violation against AWDs; with respect to their rights to dignity and inclusion in social life alongside the rest of the society.

6. The justice system: Related to the above recommendation (5), the lack of judicial role under the county government was affecting the efficiency of turning around cases that had cultural underpinnings like SGBV against minors living with disabilities. The government should explore and establish a community based legal mechanisms of devolved judicial system to expeditiously handle such cases. Moreover there is a need to establish county based judicial systems with full powers to adjudicate on cases that are county-related in nature.

7. Health financing: Inadequate financing is a challenge to both the county system and the community based health programmes. There is urgent need for the county government to consider adequate allocation of funds to the sub-county health management teams (SCHMTs) across the county for enhanced supportive supervision; and sufficient supplies of health commodities especially for unmet SRH as per the annual work plans (AWPs) to the link health facilities.

8. Moreover, the National and County government should partner with non-state actors to expand the financial capacity of the CBHC initiatives that are inclusive of households with children with disabilities towards universal health coverage. This may include expansion of and working with community based health insurance

schemes for families that are not directly covered under the national health insurance schemes. Adequate public investment in comprehensive primary health care is highly recommended for improved quality of community health services.

9. Research Fund: The County government, development partners and persons with disability organizations should collaborate to establish county based research fund for disability studies to build repository of data on disability related issues. Currently there is perennial inadequacy of data on AWDs has serious implications for access to care by this target group.

10. Research on local sign language: Academic institutions of higher learning, including special education units in Siaya County should research on and incorporate dominant local sign languages used by households hosting children with speech and hearing impairments.

11. Inclusive Data: The omission of disability indicators on critical community health services captured from the household to the district health information system (DHIS) is a major setback to equity in access to SRH and HIV services for AWDs in Siaya County. The household data that include disability issues should be entrenched in the county and ultimately national health and development information systems to ensure visibility and inclusion of AWDs in planning and participation in socio-economic activities as bonafide citizens.

12. Creation of County-based Disability Fund: The county government should identify and strengthen partnership with non-state actors with the organizations for persons with disabilities to create a county community based disability health Fund (CCBDHF) for basic health needs of AWDs. The current poor resource allocation for primary health care is limiting access to SRH and HIV services and information both

at the public and community based health care systems. Moreover the fund should be structured to bridge the credit facility gaps for AWDs who may need capital to start up small businesses.

13. Further research: As at the time of this study, women (main) caregivers, were completely entangled with the lifelong care of their AWDs with less support from the society that stereotyped a disabled child as a curse and asexual. This had made access to SRH care through the family rather difficult as mothers contend with other family care needs. Further research is needed that targets low income households to find out the best approach to support home based caregivers of AWDs especially with respect mental health, how to improve micro-economies including household incomes.

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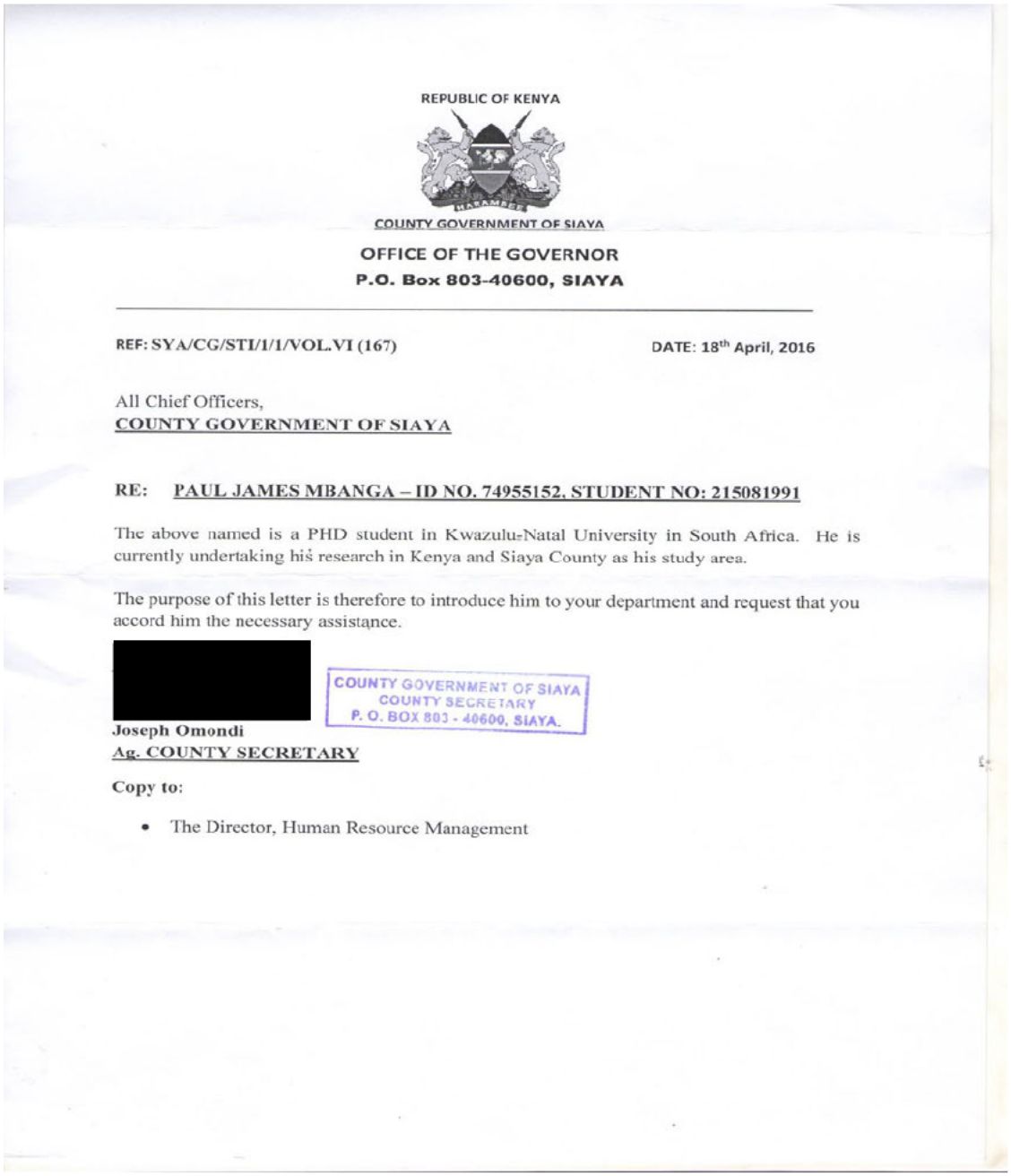
APPENDICES

APPENDIX 1: GATEKEEPERS

(i) OFFICE OF THE GOVERNER



REPUBLIC OF KENYA

COUNTY GOVERNMENT OF SIAYA

OFFICE OF THE GOVERNOR
P.O. Box 803-40600, SIAYA

REF: SYA/CG/STI/1/1/VOL.VI (167) DATE: 18th April, 2016

All Chief Officers,
COUNTY GOVERNMENT OF SIAYA

RE: PAUL JAMES MBANGA – ID NO. 74955152, STUDENT NO: 215081991

The above named is a PHD student in Kwazulu-Natal University in South Africa. He is currently undertaking his research in Kenya and Siaya County as his study area.

The purpose of this letter is therefore to introduce him to your department and request that you accord him the necessary assistance.

[redacted]

COUNTY GOVERNMENT OF SIAYA
COUNTY SECRETARY
P. O. BOX 803 - 40600, SIAYA.

Joseph Omondi
Ag. COUNTY SECRETARY

Copy to:

- The Director, Human Resource Management

Approval later from Department of Health Siaya County

COUNTY GOVERNMENT OF SIAYA

MINISTRY OF HEALTH

E-mail: siayachd@gmail.com
PHONE:
KNUT BUILDING
SIAYA TOWN

COUNTY HEALTH HEADQUATERS
SIAYA COUNTY
P O BOX 597
SIAYA

Our Ref: SYA/CHD/RESEARCH/VOL.I (59) 18TH APRIL, 2016

- The Medical Superintendent

SIAYA COUNTY

Dear Sir,

RE: RESEARCH APPROVAL: ADOLESCENT REPRODUCTIVE HEALTH FOR PERSONS WITH DISABILITIES IN SIAYA

The bearer of this letter, Mr. Paul James Mbanga a student at the University of Kwa Zulu Natal (UKZN) in South Africa intends to carry out the above research in Siaya County. He has been granted approval and permission from the undersigned.

This is to introduce him to you and request that you accord him all necessary assistance.

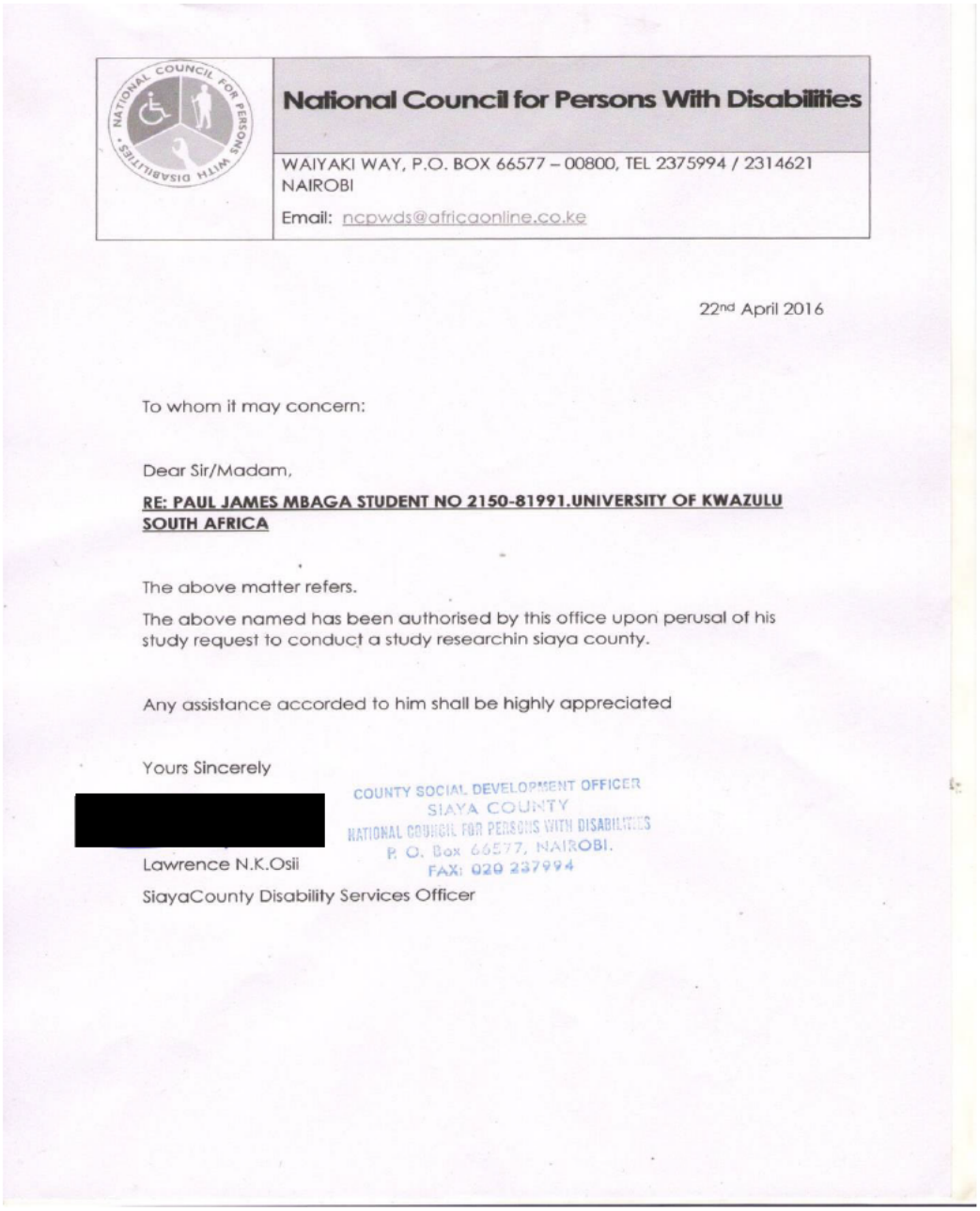
Yours [redacted]

DIRECTOR
COUNTY HEALTH SERVICES
SIAYA
DATE:.....

DR. OMONDI OWINO MBchB, MPH, Dip. (HSM)
COUNTY DIRECTOR OF HEALTH – SIAYA

Copy to: Mr. Paul James Mbanga

(ii) ***Approval letter from the National Council of Persons With Disability In Kenya***



National Council for Persons With Disabilities

WAIYAKI WAY, P.O. BOX 66577 – 00800, TEL 2375994 / 2314621
NAIROBI
Email: ncpwds@africaonline.co.ke

22nd April 2016

To whom it may concern:

Dear Sir/Madam,

RE: PAUL JAMES MBAGA STUDENT NO 2150-81991.UNIVERSITY OF KWAZULU SOUTH AFRICA

The above matter refers.

The above named has been authorised by this office upon perusal of his study request to conduct a study researchin siaya county.

Any assistance accorded to him shall be highly appreciated

Yours Sincerely

[redacted]

COUNTY SOCIAL DEVELOPMENT OFFICER
SIAYA COUNTY
NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES
P. O. Box 66577, NAIROBI.
FAX: 020 237994

Lawrence N.K.Osii
SiayaCounty Disability Services Officer

Approval from the Association of persons with physical disabilities in Kenya (APDK)

Paul James Mbanga,

Student Number: 215081991

ID NO. 7495152

University of KwaZulu- Natal SA

P.O.BOX 48846- 00100, NAIROBI KENYA

21st APRIL, 2016

APDK SIAYA BRANCH
P. O. Box 144 - 50626 SIAYA
RECEIVED
22 APR 2016
TEL: 0702 717 812
Email: apdsiaya@yahoo.com

County Co-ordinator,

Association Of Persons With Disability-Kenya,

County of Siaya.

SIAYA

Dear Sir,

REF: REQUEST FOR AUTHORITY

Greetings!

I am Paul James Mbanga from Siaya County. Currently I am pursuing PhD Studies at the University of KwaZulu Natal (UKZN) in South Africa. As a requirement for my study, I will need to undertake a field research on my topic area, which is 'Community Based Approach to Adolescent Reproductive Health for Persons with Disabilities in Siaya County, Kenya'.

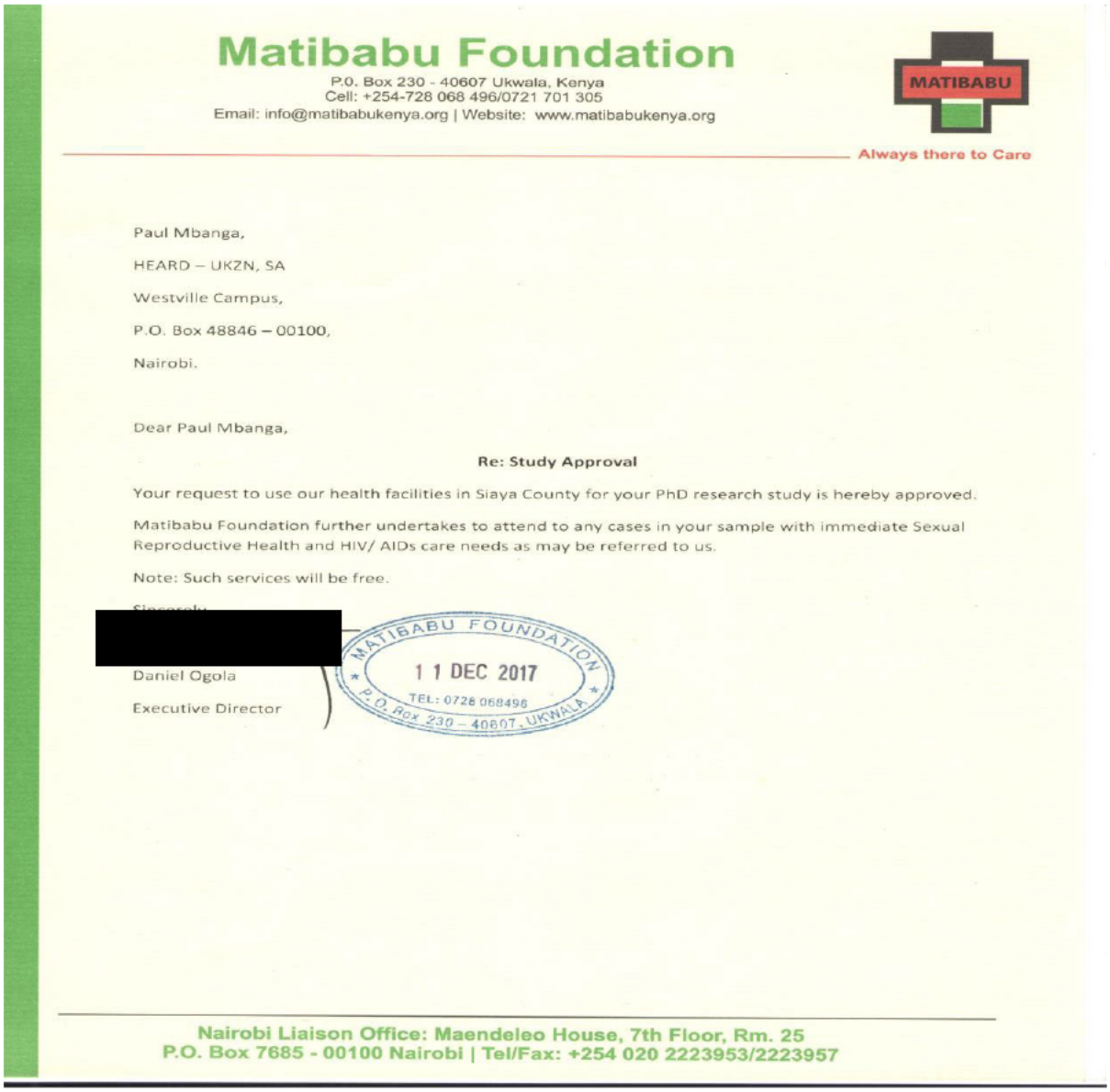
As per the foregoing I am kindly requesting for a letter of authority in support of my need to interact with community members and relevant government departments under your jurisdiction. Your support in this matter is highly appreciated.

With Kind regards,

[redacted]

Paul Mbanga, MCHD, MOL, PhD (IP) UKZN,

Approval and Commitment to Provide Psychosocial Support to Participants who may be in need during the interviews



Matibabu Foundation

P.0. Box 230 - 40607 Ukwala, Kenya
Cell: +254-728 068 496/0721 701 305
Email: info@matibabukenya.org | Website: www.matibabukenya.org

MATIBABU

Always there to Care

Paul Mbanga,

HEARD – UKZN, SA

Westville Campus,

P.O. Box 48846 – 00100,

Nairobi.

Dear Paul Mbanga,

Re: Study Approval

Your request to use our health facilities in Siaya County for your PhD research study is hereby approved.

Matibabu Foundation further undertakes to attend to any cases in your sample with immediate Sexual Reproductive Health and HIV/ AIDs care needs as may be referred to us.

Note: Such services will be free.

Sincerely,

[redacted]

Daniel Ogola

Executive Director

MATIBABU FOUNDATION
11 DEC 2017
TEL: 0728 068496
P.O. Box 230 – 40607, UKWALA

Nairobi Liaison Office: Maendeleo House, 7th Floor, Rm. 25
P.O. Box 7685 - 00100 Nairobi | Tel/Fax: +254 020 2223953/2223957

APPENDIX 2: ETHICAL APPROVALS

(a) UKZN Protocol HSS/1883/017D

10 January 2018

Mr Paul James Mbanga (215081991)
School of Applied Human Sciences – Psychology
Howard College Campus

Dear Mr Mbanga,

Protocol reference number: HSS/1883/017D
Project title: Delivery of Integrated Sexual, Reproductive Health & HIV services for adolescents with Disabilities : An analysis of community based health approaches in Kenya

Approval Notification – Full Committee Reviewed Protocol

With regards to your response received on 17 December 2017 and 19 December 2017 to our letter of In response to your application received on 13 October 2017, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

[redacted]

Dr Shamila Naidoo (Deputy Chair)

/ms

cc Supervisor: Dr Kaymarlin Govender
cc Academic Leader Research: Dr Jean Steyn
cc School Administrator: Ms Ayanda Ntuli

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 3587/8350/4557 Facsimile: +27 (0) 31 2604609 Email: singhsh@ukzn.ac.za / snyamane@ukzn.ac.za / mchunu@ukzn.ac.za
Website: www.ukzn.ac.za

1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: Edgewood, Howard College, Medical School, Pietermaritzburg, Westville

(b) ETHICAL APPROVAL IN KENYA: AMREF- ESRC P358/2017

amref health africa

Amref Health Africa in Kenya

REF: AMREF – ESRC P358/2017 July 21, 2017

Paul James Mbanga,
University of KwaZulu Natal,
West Ville Campus, Private BagX54001,
Durban 4000, South Africa
Tel. No. +254 724 33 1919
Email: pmbanga@yahoo.com

Dear Mr. Mbaga,

RESEARCH PROTOCOL: AN ANALYSIS OF COMMUNITY BASED HEALTH APPROACHES TO THE DELIVERY OF INTEGRATED SEXUAL, REPRODUCTIVE HEALTH AND HIV SERVICES FOR ADOLESCENTS WITH DISABILITIES IN SIAYA COUNTY, KENYA

Thank you for submitting your protocol to the Amref Ethics and Scientific Review Committee (ESRC).

This is to inform you that the ESRC has approved your protocol. The approval period is from July 21, 2017 to July 20, 2018 and is subject to compliance with the following requirements:

a) Only approved documents (informed consents, study instruments, advertising materials etc.) will be used.
b) All changes (amendments, deviations, violations etc.) are submitted for review and approval by Amref ESRC before implementation.
c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the ESRC immediately.
d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to Amref ESRC immediately.
e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period (attach a comprehensive progress report to support the renewal).
f) Clearance for export of biological specimen or any form of data must be obtained from Amref ESRC, NACOSTI and Ministry of Health for each batch of shipment/export.
g) Submission of an executive summary report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

Please do not hesitate to contact the ESRC Secretariat (esrc.kenya@amref.org) for any clarification or query.

Yours sincerely,

[redacted]

Prof. Mohamed Ka[redacted]
Chair, Amref ESRC

AMREF - ESRC
21 JUL 17
P.O Box 30125 - 00100, NAIROBI

CC: Dr. George Kimathi, Director, Institute of Capacity Development, Amref Health Africa and Vice Chair Amref ESRC
Samuel Muhula, Monitoring & Evaluation and Research Manager, Amref Kenya

APPENDIX 3: CONSENT AND INFORMATION FORMS

(1) Children Information Sheet and Consent and assent to Participate in the PhD Research (Over 18)

A. Information Sheet

Date: _____

Good Morning/Good Afternoon,

My name is Paul James Mbanga. I am studying PhD in Psychology at the University of KwaZulu Natal, School of humanities, Durban, South Africa. I am collecting data for a research project implemented by me. My telephone numbers are +254 724 33 1919 while in Kenya and +27 62087154 while in South Africa.

You are kindly invited to consider participating in a study that involves research on the capacity and appropriateness of Community based approach to delivery of Adolescent Sexual and Reproductive Health (ASRH) for Persons with Disability (PWD) in Siaya County, Kenya. The aim and purpose of this research is to explore and understand several factors interacting and influencing effectiveness and sustainability of community based approach to access and utilization of ASRH services by PWD in Siaya County.

The study is expected to include participants from the national, county, sub-county and community levels. In the above arrangement, 90 PWD in need of ASRH and HIV services from community based health facilities/programs (CHBC)- (30 people from each of the 3 sub-counties). In addition, community members from community units, 12 health care workers (From CBHC/CU facilities/programs), 6 CHVs, 9 health administrators/managers, 3 opinion leaders, 4 County based disability organization officials, 3 county executives and thee relevant national leaders (Ministry of health, commission of human rights and Council for people with disabilities) among other critical sources that might emerge in the course of this study.

You are selected by (name of CHU leader/community health assistant) for your rich knowledge and experience on disabilities, and limited access to sexual and reproductive health services by young people and ways of coping with them. We believe your experiences can be very useful for this study in understanding contexts and factors related to, and affecting community based health approach to access and utilization of ASRH services by persons with disabilities. The duration of your participation if you choose to enroll and remain in the study is expected to be about 60 minutes. This research doesn't have any external funding and very small grant from the University of KwaZulu-Natal covers travel and logistics related expenses.

Again, you do not have to give us permission to interview you and refusing permission will not affect your involvement in community activities you may be part of. Furthermore, if you give us this permission, be assured that nothing that you tell me will be mentioned to your parent/guardian.

Some of the risks and discomforts of participating in this discussion may be that it takes some of your time out of your plan and some of the questions may trigger your emotions towards past experiences. In addition, some questions might be related to your private experiences and practices or feelings and may cause discomforts. However, there are no other physical risks expected. I hope that the study will create the following benefits: At the end of study, the findings will be presented to county health department and the Government of Kenya ministry of health for the purpose of informing policies, programming and further research that hopefully may improve access to and utilization of ASRH services by PWD in Kenya. Your participation does not involve any instrumentation and is only a group discussion type.

However, at your discretion, I would like to record audio of the discussion which will help me catch all points raised by you. The audio recordings will be destroyed after transcription of the interview and will not be used for anything else, except for the research purposes. No real names will be used, but you may choose a pseudonym.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee and AMREF (approval number_____). In addition, permission letters have been obtained from Siaya County government, County Director of Health, National council of persons with disability in Kenya and Siaya Disabled persons Organization (DPO).

In the event of any problems or concerns/questions you may contact me with Tel. +254- 724331919 or +27 62087154 or e-mail pmbanga@yahoo.com. If you wish to contact the UKZN Biomedical Research Ethics Committee, contact details are as follows:

HUMANITIES & SOCIAL SCIENCE RESEARCH ETHICS COMMITEE

Research Office, Westville Campus

Govan Mbeki Building,

Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: +27 31 2603587/8350/4557 - Fax: +27 31 2604609

Email: ximbap@ukzn.ac.za, snymanm@ukzn.ac.za, mohunp@ukzn.ac.za

Your participation in this research is voluntary and that you may withdraw participation at any point, and that in the event of refusal/withdrawal of participation you will not incur any penalty or loss of treatment or other benefit to which you are normally entitled. However, your participation is vital to the success of this study and will contribute to improvement of ASRH and HIV for PWD services. Please tell me at any point if you wish to quit including specific reservations on information collected till then. When the information collected is sufficient or not suitable for the study objectives, I may terminate the interview any time.

I highly appreciate you for the time you spend on this interview. As I had explained to you before the interview, no additional payments will be made to you.

All the information you provide will be kept between you and me, and will not be transferred to third party unless ordered to do so by law. You will not be held liable to any information you provide. None of your identifying information will be collected during the interview or transcripts. This informed consent will be detached from the questionnaire and will be kept in locked cabinet. Audio document will be destroyed after transcription while other research data will be destroyed after five years. Databases will be password locked and secured until then.

B. Consent Form

I (_____Name_____) have been informed about the study entitled "Effectiveness and sustainability of community based health programs in provision of adolescent sexual and reproductive health services for persons with disabilities" by Mr. Paul James Mbanga.

I understand the purpose and procedures of the study (to explore and understand several factors interacting and influencing effectiveness and sustainability of community health approach to delivery of adolescent sexual and reproductive health and HIV services for persons with disabilities.)

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I declare that I have been informed about recording of my voice during the discussion and I permitted to do so for the use in this research.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at Tel +254 724331919 or +27 62087154, e-mail: pmbanga@yahoo.com).

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCE RESEARCH ETHICS COMMITEE

Research Office, Westville Campus

Govan Mbeki Building,

Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: +27 31 2603587/8350/4557 - Fax: +27 31 2604609

Email: ximbap@ukzn.ac.za, snymanm@ukzn.ac.za, mohunp@ukzn.ac.za

_____ _____

Signature of Participant **Date**

_____ _____

Signature of Witness **Date**

(Where applicable)

(II) Parents/ Guardians (With assent of AWDs underage or on behalf of severely disabled children who may not assent to the interviews): Information Sheet and Consent to participate in the PhD Research

Information Sheet

Date: _____

Good Morning/Good Afternoon,

My name is Paul James Mbanga. I am studying PhD in Psychology at the University of KwaZulu Natal, School of humanities, Durban, South Africa. I am collecting data for a research project implemented by me. My telephone numbers are +254 724 33 1919 while in Kenya and +27 62087154 while in South Africa.

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You are selected by (name of CHU leader/community health assistant) for your rich knowledge and experience on community problems (disabilities, and limited access to sexual and reproductive health services by young people) and ways of addressing them. We believe your experiences can be very useful for this study in understanding contexts and factors related to, and affecting community based health approach to access and utilization of ASRH services by persons with disabilities. The duration of your participation if you choose to enrol and remain in the study is expected to be about 60 minutes. This research doesn't have any external funding and very small grant from the University of KwaZulu-Natal covers travel and logistics related expenses.

In addition, I would like to interview your adolescent child (*name –as obtained from Community health Units records*). Again, you do not have to give us permission to interview your child and refusing permission will not affect your involvement or that of your adolescent child's involvement in project activities. Furthermore, if you give us this permission, be assured that nothing that you tell me will be mentioned to this child and also I will not mention anything he/she tells me to you.

Some of the risks and discomforts of participating in this discussion may be that it takes some of your time out of your plan and some of the questions may trigger your emotions towards past experiences. In addition, some questions might be related to your private experiences and practices or feelings and may cause discomforts. However, there are no other physical risks expected. I hope that the study will create the following benefits: At the end of study, the findings will be presented to county

health department and the Government of Kenya ministry of health for the purpose of informing policies, programming and further research that hopefully may improve access to and utilization of ASRH services by PWD in Kenya. Your participation does not involve any instrumentation and is only a group discussion type.

However, at your discretion, I would like to record audio of the discussion which will help me catch all points raised by you. The audio recordings will be destroyed after transcription of the interview and will not be used for anything else, except for the research purposes. No real names will be used, but you may choose a pseudonym.

This study has been ethically reviewed and approved by the **UKZN Humanities & Social Science Research Ethics Committee** (approval number_____). In addition, permission letters have been obtained from Siaya County government, County Director of Health, National council of persons with disability in Kenya and Siaya Disabled persons Organization (DPO).

In the event of any problems or concerns/questions you may contact me with Tel. +254- 724331919 or +27 62087154 or e-mail pmbanga@yahoo.com. If you wish to contact the UKZN Biomedical Research Ethics Committee, contact details are as follows:

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Research Office, Westville Campus

Govan Mbeki Building,

Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: +27 31 2603587/8350/4557 - Fax: +27 31 2604609

Email: ximbap@ukzn.ac.za, snymanm@ukzn.ac.za, mohunp@ukzn.ac.za

_____ _____

Signature of Participant **Date**

_____ _____

Your participation in this research is voluntary and that you may withdraw participation at any point, and that in the event of refusal/withdrawal of participation you will not incur any penalty or loss of treatment or other benefit to which you are normally entitled. However, your participation is vital to the success of this study and will contribute to improvement of ASRH and HIV for PWD services. Please tell me at any point if you wish to quit including specific reservations on information collected till then. When the information collected is sufficient or not suitable for the study objectives, I may terminate the interview any time.

I highly appreciate you for the time you spend on this interview. As I had explained to you before the interview, no additional payments will be made to you.

All the information you provide will be kept between you and me, and will not be transferred to third party unless ordered to do so by law. You will not be held liable to any information you provide. None of your identifying information will be collected during the interview or transcripts. This informed consent will be detached from the questionnaire and will be kept in locked cabinet. Audio document will be destroyed after transcription while other research data will be destroyed after five years. Databases will be password locked and secured until then.

Consent Form

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I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I declare that I have been informed about recording of my voice during the discussion and I permitted to do so for the use in this research.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at Tel +254 724331919 or +27 62087154, e-mail: pmbanga@yahoo.com).

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

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Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: +27 31 2603587/8350/4557 - Fax: +27 31 2604609

Email: ximbap@ukzn.ac.za, snymanm@ukzn.ac.za, mohunp@ukzn.ac.za

_____ _____

Signature of Participant **Date**

_____ _____

Signature of Witness **Date**

(Where applicable)

(III) Service Providers: Information Sheet And Consent To Participate In The PhD Research

(a) Information Sheet

Date: _____

Good Morning/Good Afternoon,

My name is Paul James Mbanga. I am studying PhD in Psychology at the University of KwaZulu Natal, School of humanities, Durban, South Africa. I am collecting data for a research project implemented by me. My telephone numbers are +254 724 33 1919 while in Kenya and +27 62087154 while in South Africa.

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You are selected by (name of CHU leader/community health assistant) for your rich knowledge and experience on community problems (disabilities, and limited access to sexual and reproductive health services by young people) and ways of addressing them. We believe your experiences can be very useful for this study in understanding contexts and factors related to, and affecting community based health approach to access and utilization of ASRH services by persons with disabilities. The duration of your participation if you choose to enrol and remain in the study is expected to be about 60 minutes. This research doesn't have any external funding and very small grant from the University of KwaZulu-Natal covers travel and logistics related expenses.

Some of the risks and discomforts of participating in this discussion may be that it takes some of your time out of your plan and some of the questions may trigger your emotions towards past experiences. In addition, some questions might be related to your private experiences and practices or feelings and may cause discomforts. However, there are no other physical risks expected. I hope that the study will create the following benefits: At the end of study, the findings will be presented to county health department and the Government of Kenya ministry of health for the purpose of informing policies, programming and further research that hopefully may improve access to and utilization of ASRH services by PWD in Kenya. Your participation does not involve any instrumentation and is only a group discussion type.

However, at your discretion, I would like to record audio of the discussion which will help me catch all points raised by you. The audio recordings will be destroyed after transcription of the interview and will not be used for anything else, except for the research purposes. No real names will be used, but you may choose a pseudonym.

This study has been ethically reviewed and approved by the UKZN Humanities & Social Science Research Ethics Committee (approval

number_____). In addition, permission letters have been obtained from Siaya County government, County Director of Health, National council of persons with disability in Kenya and Siaya Disabled persons Organization (DPO).

In the event of any problems or concerns/questions you may contact me with Tel. +254- 724331919 or +27 62087154 or e-mail pmbanga@yahoo.com. If you wish to contact the UKZN Biomedical Research Ethics Committee, contact details are as follows:

HUMANITIES & SOCIAL SCIENCE RESEARCH ETHICS COMMITTEE

Research Office, Westville Campus

Govan Mbeki Building,

Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: +27 31 2603587/8350/4557 - Fax: +27 31 2604609

Email: ximbap@ukzn.ac.za, snymanm@ukzn.ac.za, mohunp@ukzn.ac.za

Your participation in this research is voluntary and that you may withdraw participation at any point, and that in the event of refusal/withdrawal of participation you will not incur any penalty or loss of treatment or other benefit to which you are normally entitled. However, your participation is vital to the success of this study and will contribute to improvement of ASRH and HIV for PWD services. Please tell me at any point if you wish to quit including specific reservations on information collected till then. When the information collected is sufficient or not suitable for the study objectives, I may terminate the interview any time.

I highly appreciate you for the time you spend on this interview. As I had explained to you before the interview, no additional payments will be made to you.

All the information you provide will be kept between you and me, and will not be transferred to third party unless ordered to do so by law. You will not be held liable to any information you provide. None of your identifying information will be collected during the interview or transcripts. This informed consent will be detached from the questionnaire and will be kept in locked cabinet. Audio document will be destroyed after transcription while other research data will be destroyed after five years. Databases will be password locked and secured until then.

(b) Consent Form

I (_____Name_____) have been informed about the study entitled "Effectiveness and sustainability of community based health programs in provision of adolescent sexual and reproductive health services for persons with disabilities" by Mr. Paul James Mbanga.

I understand the purpose and procedures of the study (to explore and understand several factors interacting and influencing effectiveness and sustainability of community health approach to delivery of adolescent sexual and reproductive health and HIV services for persons with disabilities.)

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I declare that I have been informed about recording of my voice during the discussion and I permitted to do so for the use in this research.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at Tel +254 724331919 or +27 62087154, e-mail: pmbanga@yahoo.com).

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCE RESEARCH ETHICS COMMITTEE

Research Office, Westville Campus

Govan Mbeki Building,

Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: +27 31 2603587/8350/4557 - Fax: +27 31 2604609

Email: ximbap@ukzn.ac.za, snymanm@ukzn.ac.za, mohunp@ukzn.ac.za

_____ _____

Signature of Participant **Date**

_____ _____

Signature of Witness **Date**

(Where applicable)

APPENDIX 4: DATA COLLECTION TOOLS AND ANALYSIS FRAME

(A) FACILITY CHECKLIST

Health Services Checklist: Sub-county Code....Health Facility Level...

The following checklist assesses if your health services more accessible and disability friendly. Please answer yes/no/not sure if your facility as designed is an accessible and disability friendly manner. Please tick the last column "things I can change/influence" if you feel that you can influence or change these aspects.

Issues:	**Check/comment**
Does the facility have the following? 1. Ramps to access your buildings and outside areas 2. Crucial services on the ground floors 3. Doors that fit a wheelchair and open easily 4. Wheelchair accessible toilet 5. Railings along the corridors or outside areas **6.** Directions on key areas in Braille (e.g. lifts, signposts) 7. Simplified information for 8. people with intellectual 9. disabilities related to counseling 10. Simplified information for people with disabilities related to treatment 11. Simplified information for 12. people with disabilities related to abuse 13. Medication boxes with symbols, pictures or Braille to accommodate special needs **14.** Staff who have a disability 15. Disability desk at the entrance area 16. Preferable treatment so people with disabilities don't have to stand in long cues 17. Sign language interpretation and information in pictures for the deaf 18. Information in Braille or in audio format 19. Beds that accommodate physical disabilities through height adjustments particularly in the maternity **Have your staff been exposed to the following:** 20. Anti-stigma training focusing on disability and HIV 21. Training on sign language interpretation and Braille 22. Training course focusing on the interrelationship of disability and HIV (sensitization) 23. Training on health rights of people with disabilities	

24. Training to screen for disability including mental health in general services such as ART 25. Referral systems to rehabilitation including Community Based 26. Rehabilitation 27. Staff who have a disability **Are your health services linked to the following:** 28. Back to work programs for people who acquired disability 29. Food security programs that include people with disabilities 30. Sheltered employment 31. Referral system from disability services to reproductive health services and VCT 32. Screening tools to identify disability including mental health problems in your 33. ART program people with disabilities **Are your health services linked to the following**: 34. Home Based Care 35. Community Based Rehabilitation 36. Food security programs 37. Livelihood programs that 38. focus on adolescents with 39. disabilities 40. Disabled Peoples Organisations	

INTERVIEWING GUIDES

I. Focus Group Discussion Guide for Community Health Volunteers (CHVs)

Sub-county

CHU

Place of interview

Name of Interviewer

Date of Interview

Introduction

Community health volunteers are the main providers of community health services at level 1. The function is therefore critical for the community health system within which much of preventive and promotive health care services are delivered.

Instructions

Description	This key informant interview guide is a tool to enable the interviewer collect and record qualitative information on the role and performance of the CHVs within the community health system including delivering ASRH and HIV services for AWD**.**
Information to be collected?	Should provide insight on community health services needed to strengthen community based health system and linkages to include AWD.
Time frame	The interview will take about 45 minutes to one hour.

Health situation and social determinants of health

1. What are the most common health problems in your community?
2. What are the key social determinants that affect health and health behaviour of AWD in your community?
3. What are you a community health volunteer doing to address these factors that affect health and health behaviour of AWD in your community?
4. What are some of the challenges the following groups experience in accessing community health services in your area?

Group	Challenges to accessing services	Suggestion on how to overcome challenges
Persons with disabilities		
Adolescent youths		
Orphaned and vulnerable children		
Poor households		
Women		

Role and functions of CHVs

5. In your view, who is community health volunteer?
6. What is the role and function of a CHV?
7. To whom does a CHV report?
8. Who supervises the work of CHVs?
9. How often is the supervision carried out?
10. Who assesses your performance as a community health volunteer?
11. When was your performance last assessed?
12. How does the CHV work in relation to the following structures and stakeholders:

Community health structures	Work relationship
Link health facility	
Community Health Committee	
Community/local leaders NGOs/implementing partners	
Faith based organizations/providers/CBHC	
Community groups	
Alternative health service providers	
Households	

13. What are the challenges CHVs face in executing their duties in particular providing ASRH and HIV services for PWD?

14. Suggest ways the role of CHVs can be strengthened to be effective in providing ASRH and HIV care services to PWD.

Community Health Volunteer services

15. What range of services do CHVs offer? (list the services offered, probe ASRH/HIV if not mentioned)

16. Do your clients appreciate or compensate you for the services offered?

1. Yes 2. No

17. If yes, how do they show their gratitude for your services? (list how the gratitude is demonstrated in cash or kind)
18. If no, what motivates you to continue offering services without compensation?
19. How do the community health volunteers work with the link health facility?
20. Under what circumstances do you refer clients to your link health facility?
21. What basic skills should a community health volunteer have to effectively refer clients to the link health facility?
22. Would you say that there is currently an effective working relationship between the community health volunteers and the health facility? (probe whether public or private facility)
23. What are the main challenges in the relationships between the Community health volunteers and the health facility?
24. Suggest ways the relationship can be strengthened and streamlined.

Training and capacity

25. When did you become community health volunteer?
26. How does one become a community health volunteer?
27. What is the minimum academic qualification that a person should have to be enrolled as a CHV?
28. What qualities should a good community health volunteer have?
29. What training does one go through before becoming a CHV? And how long is the training?

    Who conducts the training and what does the training involve?
30. How prepared are you to handle sexual and reproductive health care needs of adolescents with disabilities? Please share your experiences on this and how this should be done differently.
31. In your view what are the issues surrounding access and utilization of ASRH and HIV services in the community by AWDs? What should be the role of CBHC programs and with what support?
32. Have you undergone a refresher course since you became a community health volunteer?

1. Yes 2. No

33. If yes, how many times have you gone through training?_____

Compensation

In your view, how best should the efforts of the community health volunteers be rewarded in a sustainable manner?

Role of the community health units

34. In your view what is the role or function of a Community Health Unit in relation to a CBHC program?
35. What challenges do you face in working within the community health unit and CBHC?
36. In your assessment, how effective is the community health unit in addressing the prevailing community health problems including ASRH for PWD in the context of CBHC?
37. In your assessment, how effective is the linkage between the CBHC programs, community health unit and the link health facility?
38. What are the challenges that the CBHC programs, Community Health Units and link facilities are experiencing in their individual and joint operations to deliver ASRH & HIV services for AWDs?
39. Suggest ways that Community Health Units can be strengthened.

Role and functions of CHAs

40. In your view what is the role and function of a CHA?
41. What support do you receive from the CHA?
42. What are the challenges do you face in working with CHAs?
43. Suggest ways the working relationship between CHVs and CHAs can be strengthened to effectively deliver community health services including ASRH for PWD?

Community Health Committees

44. In your view, what is the role and function of a community health committee?
45. What leadership qualities should members of community health committees possess?
46. In your assessment, do you think your community health committee is operating effectively as should be expected?

1. Yes 2. No

47. What are the challenges that the community health committees are experiencing in their operations?
48. Suggest ways that Community Health Committees can be strengthened.

Infrastructure and supply chain

49. Do you receive any equipment and supplies for your work as a CHV?

1. Yes 2. No

50. If yes what equipments and supplies do you receive and from who?

51. How regularly do you receive the supplies?

52. What you do often do when there is stock out?

53. How often do you experience stock outs?

54. Would you say that your community health unit is adequately equipped with the necessary infrastructure and supplies to function effectively?

1. Yes 2. No

55. What infrastructure does the community health unit need most to function effectively?
56. What should be done to strengthen the community health supply chain in particular with respect to ASRH and HIV services for PWD?
57. What should be done to strengthen the community health commodity security to ensure regular access by clients?

Standards and quality assurance

58. Are you using any guidelines in your work?

1. Yes 2. No

59. What should the ideal standards for community health services constitute?

60. Suggest ways of ensuring that there is sustained quality of community health services for persons with disabilities.

Community Health information systems

61. How frequently do you produce the reports?
62. Where do you send the reports?
63. What improvements would you like to see in how community health information is managed?

THANK YOU

I. FGD Guide For Community Members

Sub-county

CHU

Category of Group

Name of interview

Date of Interview

Time if interview:

Introduction

Instructions

Description	This FGD guide is a tool to enable the interviewer collect and record qualitative information on access to community health services, the role and performance of the CH structures and the community expectations**.**
Information to be collected?	Should provide insight on community health services needed to ensure equitable access to quality CHSs in particular ASRH and HIV by PWDs and strengthen CH structures.
Who is targeted?	• Community Groups – Parents/Guardians of AWDs • Community groups – Support groups/ DPOs • Community groups – Local leaders • Community groups – alternative health service providers
Time frame	The interview will take about 45 minutes to one hour.

Health situation

1. What are the common health problems in the community in relation to the following?

a) Maternal and child health

b) Adolescent sexual reproductive health

c) Communicable diseases

d) Non-communicable diseases Hygiene and sanitation

e) Healthy lifestyle (health diet and physical health)

f) Alcohol and drug abuse

g) Mental health

h) Disaster and emergency response

i) Occupation health and safety

j) Nutrition

2. What are the major cases of sexual gender based violence common in the community?
3. How are cases of sexual gender-based violence normally dealt with in the community?

Access and utilization of community health services (level1)

4. Who are the main health care providers in the community?

5. What are the shortcomings of each of the health care provider listed?

6. What are some of the challenges the following groups experience in accessing health care in the community?

a) Adolescents and the youth with disabilities

b) Women

c) PLWHIV

d) Orphaned and vulnerable children

e) Poor households

7. Suggest way the above groups' access to health care can be enhanced.

Role of alternative health care providers

8. Apart from the health facilities and CHVs, are there other health care providers in the community?If yes, List them.
9. Are these alternative health care providers currently working with the community health unit and the nearest health facility in any way?
10. Is there a referral mechanism between alternative health care providers and the Community Health Unit and health facilities?
11. Under what circumstances do they refer their clients to the CHV or the health facility?
12. Suggest ways linkage between the alternative health care providers and the CHU and health facilities can be strengthened?

Health rights

13. In the community who provides information or education on health rights especially to people with disabilities?
14. If these rights are not fulfilled where do you seek redress?

Role and functions of CHVs

15. What is the role and function of a CHV?
16. What health services are the community health volunteers providing in the community?
17. What are the challenges CHVs face in executing their duties?
18. Suggest ways the role of CHVs can be strengthened in the community?
19. Under what situations do the community health volunteers make referrals to the nearest health facility?
20. What are the main challenges that exist in managing referral between the CHVs and the nearest health facility?
21. Suggest ways the linkages between the CHVs and health facilities can be strengthened and streamlined.

22. In your opinion, do the CHVs have the necessary equipment and supplies they need to offer quality services?
23. What equipment and supplies do they normally lack to provide quality services?
24. In general what does a community health volunteer need to have to work effectively?
25. Do the CHVs charge for the services they offer?
26. If yes, what do they charge for the services (specify the services and what is charged for each service)?

Health financing

27. In your opinion who are main funders of community based health care activities? List them

28. How adequate is the government currently investing in community health for effective delivery of level 1 services?

29. What would you recommend in relation government funding for community based health care?

30. How do most members of the community finance their health care? Explore on the health insurance schemes (e.g. NHIF, community based health insurance etc.)?

31. How about adolescents with disabilities?

32. What challenges do they face in meeting the costs of health care? Probe on coping mechanisms and limitations

Role and functions of Community Health Assistants (CHAs)

33. What is the role and function of a CHA?
34. What health services do CHAs provide in the community?
35. What are the challenges CHAs face in executing their duties?
36. Suggest ways the role of CHAs can be strengthened?

Community Health Units

37. How are the Community Health Units operating currently?
38. What kind of benefits are you obtaining from Community Health Units if any?
39. What kind of leadership is required for the Community Health Units to operate and function more effectively?
40. What kind of infrastructure does a Community Health Unit need to function effectively?
41. What are the challenges that the Community Health Units are experiencing in their operations?
42. How are the community currently contributing in supporting the functions of the community health services?
43. Suggest ways on how Community Health Units can be strengthened and sustained.

Community Health Committees

44. What is the state of functionality of the community health committees?
45. What leadership qualities should members of community health committees possess?
46. What are the challenges that the community health committees are experiencing in their operations?
47. Suggest ways that Community Health Committees can be strengthened.

II. In-depth Interview Guide for Adolescents With Disability (Over 18)

Sex
Age
Marital status
Education level
Type of impairment
Sub-county
Community Unit

Let's discuss disability and SRH & HIV needs and experiences with health care services for Adolescents with disabilities in the community

1. To start us off in this discussion kindly tell me about yourself, who you are and what you are currently involved
2. What is your understanding and experience of living with disability? Probe on self-stigma, discrimination, exclusion from social participation and services
3. In your view what are the pressing SRH & HIV needs you experience a young person with disability? Probe on individual, family, societal and organizational factors related to the needs and in what ways?
4. How should the needs be addressed at the community level and by who, which organizations? (Probe on knowledge and experience with any of the community based organizations)
5. What is your view and experience with programmatic characteristics of the place where you get health services (SRH & HIV). Probe on the lines suggested below

(1) AWDs are involved in program design.
(2) Persons with disabilities are included the design
(3) Both boys and girls are welcomed and served.
(4) Unmarried clients are welcomed and served.
(5) Group discussions are available (sign-language?)
(6) Parental involvement is encouraged but not required.
(7) Affordable fees are available.
(8) A good range of services is offered or necessary referrals are available.
(9) An adequate supply of SRH/HIV commodities is available.
(10) AWDs clients are welcome, and appointments are arranged rapidly.
(11) Waiting times are not long.
(12) Information material is available on-site in appropriate language and form for AWDs
(13) Services are well promoted in areas where youth and adolescents gather.
(14) Services are linked are with schools, youth clubs, and other youth-friendly institutions.
(15) Alternative ways to access information, counselling, and services are provided.

6. Kindly share your views and experiences with respect to service provider characteristics at the family, CBHC/CU/link facility listed below.

- Staff are trained in adolescent issues (including ASRH and HIV)
- Staff are trained in disability concerns of adolescents
- Respect is shown to young people with disabilities.
- Privacy and confidentiality are maintained.
- Adequate time is given for client-provider interaction in appropriate language.
- Peer counsellors are available.

7. What would say regarding CBHC and health facility characteristics in terms of:

- flexible hours
- Convenient venues
- Adequate space
- Sufficient confidential
- Comfortable environment
- Disability friendliness

8. What are your perceptions of the program with respect to the following qualities?

- Privacy is maintained at the facility.
- Confidentiality is honoured.
- Youth are welcome regardless of disability status.
- Youth and adolescents are welcome.
- Service providers are to my needs.

9. What do you think should be done to make adolescents with disabilities to fully participate, access and utilize health services including ASRH & HIV? Probe on roles AWDs can play in CBHC interventions to improve their inclusion.

III. In-depth Interview Guide for Community Health Assistants (CHAs)

Sub-county

Health facility

Community health unit

Place of interview

Name of Interviewer

Date of Interview

Introduction

The community health assistants are the technical link persons between the CUs and health facilities. They work with CHVs to ensure quality of CHS at level one.

Instructions

Description	This key informant interview guide is a tool to enable the interviewer collect and record qualitative information on community health services and the performance of the CHAs within the county health system**.**
Information to be collected?	Information collected should provide insight on standards for community health services needed to strengthen the community based health system and linkages.
Time frame	The interview will take about 45 minutes to one hour.

Health situation and social determinants of health

1. What are the leading health problem s affecting the community?
2. What are the key social determinants of health in the community?
3. How is the health system currently responding to these determinants?
4. Suggest ways the health system should best address or respond to these social determinants of health and their effects on SRH&HIV for AWDs?

Access to community health services

5. What are the main community health services available in the community and who are the providers of the services?

6. What should the minimum package of the following community health related services consist of in your county?

7. What are some of the challenges the AWDs experience in accessing community health services:

Role and functions of CHAs

8. What is the role and function of a CHA?
9. To whom is a CHA responsible within the health system?
10. How does the CHA work in relation to service provision with the other structures and stakeholders:
11. What are the challenges CHAs face in executing their duties?

Role of the community health units

12. What is the role or function of a Community Health Unit?
13. What support do you provide to the community units?
14. What challenges do you face in working with the community health unit?
15. In your assessment, how effective is the community health unit in addressing the prevailing community health problems?
16. In your assessment, how effective is the linkage between the community health unit and the link health facility?
17. What are the main challenges in the relationship between the community health unit and the link health facility?
18. What are the main challenges that the community health unit experience in its operations?
19. Suggest ways the challenges can be overcome

Community health volunteers

20. What is the role of community health volunteers?
21. What challenges do you face in working with the community health volunteers?
22. In your assessment, how effective are the community health volunteers in addressing the prevailing community health problems?
23. How effective is the referral system between the community CHVs and the health facility?
24. What basic skills should a community health volunteer have to work within the referral system?
25. What are the main challenges that the community health volunteers experience in their work?
26. Suggest ways the challenges can be overcome

Standards and quality assurance

27. Are you using any guidelines in your work?

1. Yes 2. No

28. What problems do you face in applying the guidelines?
29. How would you assess the current community health based services with respect to expected quality? Please explain.
30. What should the ideal standards for community health services constitute? Suggest ways of ensuring that there is sustained quality of community health services.

Infrastructure and supply chain

31. Who currently supplies the community health units with necessary equipment and kits in providing ASRH and HIV services for PWD?

32. What does the community health unit kit typically consist of with respect to ASRH and HIV care services for PWD?
33. How adequate is the Community Health Unit kits?
34. What improvements need to be introduced to the kits to adequately meet ASRH care needs of PWD?
35. How regular are the supply of the equipment and kits? How adequately are the kits equipped with the necessary infrastructure and supplies to function effectively?
36. What infrastructure do the community health units need most to function effectively?
37. What should be done to strengthen the community health supply chain?
38. What should be done to strengthen the community health commodity security for ASRH and HIV services for AWD?

Human resources

39. What human resources are currently available in your community health unit?
40. what would be the ideal personnel establishment for a community health unit and CBHC programs to ensure effective delivery of ASRH services for PWD?
41. How should the efforts of the community health volunteers and members of the community health committees be sustainably rewarded within the health system?

Health financing

42. Do you have budget for community based health activities?

1. Yes 2. No

43. Which are the main sources of funding for the community health programs/units/services?
44. Is there a development budget line for community health services in your county health budget?

1. Yes 2. No

45. How can community health financing be made sustainable for continued improvement of ASRH for PWD?

Organization, governance and health system

46. Who is currently responsible for overseeing the functions of the Community Health structures i.e. CHUs and CHCs?
47. What leadership qualities should members of the Community Health Committees have?
48. What are the challenges that the community health structures (CHUs and CHCs) are experiencing in their operations?
49. Suggest ways that Community health structures can be strengthened.

Regulation

50. Who is currently responsible for regulation of community health services within the county?
51. What should be done to strengthen the regulation of community health services within the county system?

Community Health information systems

52. Is there a well function community based health information system in place in your area?

1. Yes 2. No

53. If there is a functioning community based health information system, how does it link with the health facility information system?

1. Yes 2. No

54. How adequate is the CBHIS in capturing disability related data?
55. What are the challenges in the functionality of the community based health information systems?
56. What improvements would you like to see in how community health information system is managed?
57. Overall, what would you say about CBHC intervensions with respect to alignment with Community Health strategy in delverying the ASRH & HIV package?

Thanks for your time, please give any comment you may have

IV. In-depth Interview Guide For Link Health Facilities In-Charges

Sub-county

Health facility and Level

Place of interview

Name of Interviewer

Date of Interview

Introduction

Community health strategy and KEPH envisage effective interaction between level one and other levels as links for continuum of care. In this respect referral back and forth from one level to the other is expected for quality and efficient services delivery as may be needed by the client.

Instructions

Description	This key informant interview guide is a tool to enable the interviewer collect and record qualitative information on community–health facility interface and linkages within county health system**.**
Information to be collected?	Should provide insight on standards for community health services needed to strengthen the referral system and the community health facility linkages.
Time frame	The interview would take about 45 minutes to one hour.

Health situation and social determinants of health

1. What are the leading conditions that the health facility mostly handle?

2. What are the key social determinants of health in the community?

3. How is the health facility currently responding to these determinants?

4. Suggest ways the health facility should best address or respond to these social determinants of health with respect to ASRH and HIV for PWD?

Role of the community health units

5. What is the role or function of Community Health Units with respect to health care for PWD?

6. In your assessment, how effective is the linkage between the community health unit and the health facility?
7. What are the main challenges in the relationship between the community health unit and the health facility in response to ASRH and HIV care needs of PWD?
8. Suggest ways the linkages can be strengthened and streamlined.

Community health volunteers and health facilities

9. How do the Community health volunteers work with the health facility?

10. What conditions with respect to ASRH and HIV for PWD do they deal with without being required to refer to the health facility?
11. What ASRH and HIV services for PWD do the community health volunteers often refer to the health facility?
12. How effective is the referral system between the community CHVs and the health facility ?

Community health assistants and health facility linkages

13. What is the role of community health assistants (CHAs)?

a) Facility based CHA
b) Community based CHA

14. How do the CHAs work with the health facility?
15. Would you say that there is currently an effective functional relationship between the community health assistant and the health facility with respect to refferral of PWD for ASRH and HIV services? If yes please share your experience.
16. What are the main challenges in the relationships between the CHAs and the health facility?
17. Suggest ways the relationships can be strengthened and streamlined.

Infrastructure and supply chain

18. Do you supply the community health units with kits?

1. Yes 2. No

19. What does the kit consist of?
20. How adequate is the Community Health Unit kits with respect to SRH and HIV commodities and equipment?
21. What improvements need to be introduced to the kits to effectively meed ASRH and HIV care needs of PWD?
22. Would you say that the community health units are adequately equipped with the necessary infrastructure and supplies to function effectively in serving PWD?

1. Yes 2. No

23. What kind of infrastructure do they need most to function effectively ?
24. What should be done to strengthen the supply chain and commodity security for community health units to make them AWDS- friendly?

25. Would you say that the current community based ASRH and HIV services are of the highest quality as would be expected by PWD?

1. Yes 2. No

26. If yes, explain.

27. If no, in your opinion what are the existing quality gaps in the community health services being provided?

Human resources

28. What human resources are currently available in your link community health unit?

29. Would you say that the community health units linked with your facility have the ideal establishment in terms of personnel to ensure effective delivery of ASRH and HIV for PWD as would be expected of community health services?

1. Yes 2. No (explain)

30. How should the efforts of the community health volunteers and members of the community health committees be rewarded within the health system to ensure continuity of CS?

31. In your opinion should there be a standard community health volunteers'compensation policy guideline?

1. Yes 2. No

Health financing

32. Does you facility budget include some community based health activities?

1. Yes 2. No

33. If yes, what tier one activities are currently financed through HSSF?

34. Do you think the current community health financing situation/arrangement is sustainable?

1. Yes 2. No

35. How can community health financing be made sustainable to deliver continuied ASRH and HIV services for PWD?

Organization, governance and health system

36. Who is currently responsible for overseeing the functions of the Community Health structures i.e. CHUs and CHCs?

37. What leadership qualities should members of the Community Health Committees have?

38. Do you think the community health structures are operating effectively as should be expected?

1. Yes No

39. If no, what are the challenges that the community health structures (CHUs and CHCs) are experiencing in their operations?

40. Suggest ways that Community health structures can be strengthened to effectively address care needs of AWD.

Stakeholder coordination and health system integration

51. How are the various community health stakeholders currently coordinated within facility catchment area ?

52. Would you say that the manner community health stakeholders are coordinated within the area is effective?

1. Yes 2. No

53. If no, how should the stakeholder coordination be strengthened in community health in the your facility catchment area to benefit AWDS?

Regulation

54. Who is currently responsible for regulation of community health services within the county?
55. What should be done to strengthen the regulation of community health services within the county system to benefit AWDS?

Community Health information systems (CBHS)

56. Is there a well functioning community based health information system in place in your catchment area?

1. Yes 2. No

57. Does CBHIS in your catchment arearel capture segregated data on activities related to PWD?

1. Yes 2. No 3. I don't know

58. If there is a functioning community based health information system, how does it link with the health facility information system?
59. What are the challenges in the functionality of the community based health information systems?
60. What improvements would you like to see in how community health information system is managed?

THANK YOU

(C). GUIDELINE FOR QUALITY ADOLESCENT AND YOUTH FRIENDLY SERVICES (ASSESSMENT TOOL)

No	Characteristics And Definitions	Details	Observation With Respect To Adolescent With Disabilities (in brief what is working, challenges & coping mechanisms)
1	**Equitable** All adolescents and youth, without Discrimination, are able to obtain the health services they need.	i. All adolescents and youth including those living with HIV, those living with disability, sexually active, exploited adolescents, key populations, hard to reach adolescents and youth including those in emergencies/ humanitarian situations, resource constrained and those with any other characteristics that may put them at a disadvantage will receive the full range of health services they require.	

2	**Accessible** All adolescents and youth are able to obtain the health services that are provided.	ii. All adolescents and youth should be able to receive health services free of charge or are able to afford any charges that might be in place. iii. Health services should be available to all adolescents and youth during convenient hours, after school or work hours, during weekend and holidays where applicable. iv. The physical infrastructure should be user-friendly. v. Adolescents and youth should be aware of what health services are being provided, where they are provided and how to obtain them. vi. The location of the facility should be such that young people find it easily and feel free to get there	

3	**Acceptable** Health services are provided in ways that meet the diverse expectations of adolescents and youth clients.	a. vii. Policies and procedures should be in places that maintain adolescents and youth privacy and confidentiality at all times except where staff are obliged by legal and medical requirements with consultation with the adolescent and / or youth. viii. At the point of service, policies and procedures will address registration, consultation, record-keeping, and disclosure of information a. ix. Service providers should be non-judgemental, considerate, and easy to relate to. x. Adolescents and youth should be able to consult within short notice, whether or not they have a formal appointment. xi. Referrals should take place within a short and reasonable time frame. xii. Information that is relevant to the health of adolescents and youth should be available in a variety of channels and in different formats. xiii. Materials should be presented in a familiar language, easy to understand, eye catching and responsive to different disabilities and other needs. xiv. Options for delaying pelvic examinations and blood tests until the adolescent and youth are psychologically prepared should be created. xv. Adolescents and youth should be given	

4	**Appropriate** Health services that adolescents and youth need are provided.	xvi.	The health needs and issues of all adolescents and youth will be addressed by the health service package provided at the point of health service delivery or through effective referral linkages and networks.	
		xvii.	The services provided should meet the special needs of marginalized groups of adolescents and youth and those of the majority.	
5	**Effective** The right health services are provided in the right way and make a positive contribution to the health of adolescents and youth		.	
		xviii.	The points of service delivery should incorporate appropriate innovative strategies to deliver the required health services.	
		xix.	Health-care providers should have the required competencies to work with adolescents and youth and provide them with the required health services.	
		xx.	Health service provision should be based on protocols and guidelines that are technically sound and of proven usefulness.	

(D) THEMATIC ANALYSIS TABLE

1. Health system's Building Blocks	Codes	Themes	Meaning Summary
Leadership and Governance ATRIBUTES: -SRH policy -strategies -management -Inclusivity -Equity - Justice on SGBV	- No SRH policy - No supervision of primary facilities - Poor SRH planning for AWDs - Inactive community health committees planning - Conflict between SCHMT and CHMT - No waiver policies for AWDs - Inequality - Discrimination - Exclusion of AWDs - Policies not disseminated - Poor responses to SGBV	- Poor Health management team - semi optimal community health units - weak health system -Inadequate justice for SGBV - irresponsive policy	There was poor coordination of AWDs related health services, inadequate policies and weak community health structures to AWDs' access to SRH including justice for SGBV.
Human Resources for health -training -numbers -attitude	- inadequate staff - No sign language - Negative attitude - Not motivated - Delayed allowances - Not trained on SRH and AWDs - Stigma - Staff strikes - Unsupervised staff - CHV dropout	Inadequate and poorly trained staff on SRH for AWDs Poorly motivated staff Poor attitudes towards AWDs	CBHC and public health staff were inadequate, unmotivated and ill prepared to handle SRH needs of AWDs, moreover, they stigmatized AWDs

Health Financing -sources - adequacy -sustainability allocation	- Inadequate funding - External funding - No budget for AWDs services - User fee payment - Out-of-pocket - National health insurance scheme - Community health financing - Donor driven - Health cover	Inadequate financing Lack of financing for SRH for AWDs Overburdening of AWDs households Lack of health cover for AWDS	Community health systems were inadequately resourced to deliver SRH for AWDs who were generally poor and without cover to afford services
Commodities and Technology -SRH commodities -stocking -acquisition and distribution	- Stock-outs - Only condom - Ordered through KEMSA - Restocking not guarantee - Inadequate HIV test kits - Adults getting FP services	Inadequate supplies Lack of FP services for AWDs Limited choices of SRH services for AWDs	Lack of wide range and frequent stock-outs of SRH commodities at the community level affected access to services by AWDs
Health information -inclusion of disability data	- -DHIS at sub-county - -no data segregated by disability - inappropriate tools for data collection - -lost data from household - Community whiteboard not updated - Poor data use	Lack of disability and age desegregated data. Poor disability data management	There was generally poor management of disability related data that affected planning for AWDs related SRH and HIV services

Service delivery -quality/AWDs disability friendliness - target -referral - SGBV	- SRH services not available for AWDs - Discrimination of AWDs - Not affordable - Not physically accessible - Covering a few people - Negative attitude from providers - Through CBHC - Not sustainable - Inappropriate SGBV - No ramps - No Braille - No voice direction -	Poor environment for AWDs services Unaffordable services for poor AWDs Weak referral system Poor quality of SRH services for appropriate to AWDs needs	The environment of services delivery was generally inaccessible physically and financially with weak referral systems that made access to SRH and HIV services including access to justice for SGBV cumbersome for AWDs.
2. Socio-Ecological Attributes	**Codes**	**Themes**	**Meaning Summary**
Individual (microsystem) - -age - Gender - Disability - Education - -attitude	- Poor AWDs - Girls most affected - Experienced SGBV - Not educated - Lacks awareness - Self stigma - Low self esteem - Married off at young age - Unplanned pregnancy - HIV positive	- At risk of SGBV - Inadequate self-efficacy	- The AWDs was inadequately prepared to access services due to poverty, low education levels that also made them prone to SGBV, HIV infection and early marriages

Interpersonal (meso) - Family - Peers - school	- Lack of parental care - Peer discrimination - Ridicule - Stigma - Isolation - Low socio-economics	- Lack of acceptance and support - Inadequate resources to afford care for AWDs	- The AWDs suffered isolation from family and peers that was also compounded by lack of supportive socio-economic environment for growth
Community - Culture - SGBV - View of SRH - View disability	- Poor health care services - SGBV tolerated - Disability is unaccepted - Stigma - Lack of appropriate services for AWDs	- Disability was negatively perceived - AWDs restricted from services and events - No justice for AWDs	- Community concept of disability had made AWDs less prioritized in the community that mad access to care difficult
Society (Macro) - Social policies - Culture - Justice for SGBV - Police investigation of SGBV	- Inadequate SRH policies - Poor implementation of legal protection mechanisms - inadequate justice system for AWDs	- Inadequate policies and legal frame works on SRH -	Inadequate policy environment was making the life of AWDs with respect to access to SRH and rights
Time (chrono) - Duration of events - Onset - changes	Onset of disability Length of parental care Length of interaction with care	Experience of disability and duration of interaction with care and support system	The length of time AWDs had lived with disability and interacted with care systems mediated their efficacy to access care