



# Barriers to Accessing HIV Treatment from a Community Perspective: Experiences of Orphans and Vulnerable Children in Uganda and Sex Workers in Kenya

RESEARCH REPORT | MAY 2014



INTERNATIONAL TREATMENT  
PREPAREDNESS COALITION

## ABOUT ITPC

The International Treatment Preparedness Coalition (ITPC) is a worldwide network of community activists united by a vision of a longer, healthier, more productive life for people living with HIV. ITPC's mission is to enable communities in need to access HIV treatment. As a grassroots movement, ITPC is the community's response to HIV and is driven, led by, and committed to the human rights of those most impacted by the pandemic. ITPC currently works in nine regional networks in Africa, Asia, the Caribbean, Eastern Europe, Latin America, and the Middle East; over the past decade, it has made over 1,000 grants totalling more than \$10 million to community-based Organisations of people living with HIV in almost 100 countries.

Additional information about ITPC is available at: [www.itpcglobal.org](http://www.itpcglobal.org)

## ABOUT MISSING THE TARGET AND THIS REPORT

ITPC contributes a unique perspective to global health advocacy through its *Missing the Target* (MTT) report series. The MTT reports, along with related advocacy and capacity-building activities, aim to support civil society advocates to monitor the delivery of HIV services in their countries. These advocates hold national governments and global agencies accountable to their commitments to ensure service access for all in need. All ITPC *Missing the Target* reports are available online at [www.itpcglobal.org](http://www.itpcglobal.org).

*Missing the Target 11* is made up of two parts – a research report and subsequent advocacy activities. This report entitled *Barriers to Accessing HIV Treatment from a Community Perspective: Experiences of Orphans and Vulnerable Children in Uganda and Sex Workers in Kenya* is the result of peer-led research conducted in 2013 and forms the basis for the advocacy phase of *Missing the Target 11* (February-December 2014).

The MTT model is unique in empowering communities affected by HIV to understand research methodology and undertake community-led research. Rather than waiting to get the attention of outside researchers or development institutions, the MTT model puts the power in the hands of affected communities to document their issues. As a result, critical gaps in the HIV response are exposed earlier and people empowered to advocate for relevant solutions.

Note on text:

All "\$" figures in this report are U.S. dollar amounts.

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# ABBREVIATIONS AND ACRONYMS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ART</b>	Antiretroviral therapy
<b>ARV</b>	Antiretroviral
<b>COTANET</b>	Community Treatment Access Network
<b>FGD</b>	Focus Group Discussion
<b>HIV</b>	Human Immunodeficiency Virus
<b>IEC</b>	Information, Education and Communication
<b>ITPC</b>	International Treatment Preparedness Coalition
<b>KYP</b>	Kamuli Young Positives
<b>MTT</b>	Missing the Target
<b>OVC</b>	Orphans and Vulnerable Children
<b>STI</b>	Sexually Transmitted Infection
<b>TB</b>	Tuberculosis
<b>UNAIDS</b>	The Joint United Nations Programme on HIV/AIDS
<b>WHO</b>	World Health Organization

## HEALTH FACILITY TERM DEFINITIONS

The following terms are used in Kenya and Uganda and appear throughout this report.

### **KENYA**

**Dispensary:** A small, government-run outpatient health facility, usually managed by a registered nurse or clinical officer. Some dispensaries provide ARVs and other HIV-related services.

**Health centre:** Health centres are medium sized units which are intended to manage more complex health issues than dispensaries.

**District hospital:** In Kenya, each district in the country has a hospital, which is the coordinating and referral centre for the smaller units. They may have the resources to provide comprehensive medical and surgical services, depending on the hospital and other circumstances.

**Private clinic:** Non-government run health clinic that sets its own prices.

### **UGANDA**

**National Referral Hospital:** For the most serious and complex health issues, including surgeries.

**Regional Referral Hospitals:** For serious health issues; they also refer to the National Hospital.

**District Referral Hospitals (Health center IV):** For treating more complex health issues than Health Centre II & II, including overnight wards.

**Health Center III:** Usually located in each sub-county and led by a senior clinical officer, who also runs a general outpatient clinic and a maternity ward. It should also have a functioning laboratory.

**Health Center II:** Typically run by a nurse and providing simple care. Usually also has an out-patient clinic, treating common diseases and offering antenatal care.

# OVERVIEW

## CONTEXT OF MTT11

The International Treatment Preparedness Coalition (ITPC) is a worldwide movement of people living with HIV, treatment activists and their supporters who are committed to expanding access to HIV treatment. ITPC's *Missing the Target (MTT)* series of reports aim to assist civil society advocates to monitor the delivery of HIV services in their countries and hold national governments and other stakeholders accountable to ensuring access for all in need. The MTT process includes the provision of funds for community-level research and advocacy as well as training for participating local organisations. Outputs include MTT research reports and advocacy activities based on the findings that are undertaken by the community organisations.

The MTT process and ITPC's work in general are closely associated with the principles of the Treatment 2.0 initiative, which was launched by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organisation (WHO) in 2010 to rejuvenate efforts to achieve universal access to HIV prevention, treatment and care. Treatment 2.0 provides a framework for further scale-up of antiretroviral therapy (ART) access based on current information and available resources. Mobilizing communities is one of the five pillars of the

Treatment 2.0 initiative. Within that pillar, the framework recognizes the critical importance of scaling up community-based advocacy and service delivery to promote access to care and protect human rights. The MTT process has long played a role in this mobilization approach and effort.

## ABOUT THIS REPORT

With *Missing the Target 11*, ITPC aims to catalyse research and advocacy from a community perspective to expose and address the stigma, discrimination, and human rights abuses that key affected populations face in accessing HIV treatment. ITPC defined key populations at the project's beginning as those who self-identify as any of the following:

- lesbian, gay, bisexual, transgender and intersex (LGBTI),
- orphans affected by HIV,
- people who use drugs,
- sex workers, and/or
- women living with HIV.

At the beginning of the MTT 11 process, ITPC issued an open call for applications from organisations led by and/or supporting key affected populations in Kenya and Uganda. The call also requested Organisations that have the ability to effectively conduct research linked to targeted advocacy

objectives and that have demonstrated advocacy experience. A five-member community review panel selected two projects for funding: one proposed by Kamuli Young Positives (KYP) of Uganda and the other by the Community Treatment Access Network (COTANET) of Kenya. Teams associated with the two organisations conducted research within their communities with the aim of using the results to enact evidence-based advocacy. The research was conducted from August through December 2013.

Through its work with MTT 11 (discussed in Part 1 of this report), KYP assessed and documented the current situation among orphans and vulnerable children (OVC) affected by HIV in Uganda's Buyende District. The Organisation plans to use the information collected for policy advocacy focused on making HIV treatment and care services easily accessible to OVC not only in Buyende but in Uganda overall.

COTANET's research, summarized in Part 2 of this report, focused on sex workers in Nairobi. The goal of the study was to examine the barriers to HIV treatment that sex workers face in one neighborhood in Nairobi to determine the most effective strategies of reaching and providing treatment to them.

# 1

## ACCESS AND UTILIZATION OF HIV CARE AND TREATMENT SERVICES AMONG OVC IN UGANDA'S BUYENDE DISTRICT



The Buyende district of eastern Uganda is primarily rural with poor road infrastructure.

# INTRODUCTION

## 1.1

### BACKGROUND AND CONTEXT

Children under the age of 18 years constitute 57.4% of Uganda's 30.7 million people—more than 17 million of its residents.<sup>1</sup> The OVC Situation Analysis Report identifies critical issues for children in Uganda, including high levels of poverty, HIV and other diseases, inadequacy of support services as well as internal conflicts in some parts of the country. Many OVC end up living on their own in child-headed households or reside with old and usually impoverished grandparents who are themselves in need of external assistance. It is increasingly observed that health care access for OVC and their caregivers and households is a growing challenge.

The OVC situation in Uganda has been exacerbated by the HIV epidemic. According to the Uganda National Household Survey (UNHS) 2009/2010, some 12% of Uganda's children were orphans. Nearly half (48%) of the 2.3 million orphans lost one or both parents due to HIV-related deaths, and about 63% of them were living with caregivers other than a natural parent. While most OVC live with and are cared for by a grandparent or relative, others are forced to assume caregiver and provider roles.

48% of the 2.3 million orphans in Uganda lost one or both parents due to AIDS-related illnesses.

Over 32,130 children between the ages of 10-17 head households. Without adequate protection and care, these OVC are more susceptible to child labour, sexual abuse and other forms of exploitations, denial of basic human rights such as access to HIV treatment care and support, and stigma and discrimination.

The government of Uganda, as a signatory to global and regional frameworks and standards on the rights of the child, is committed to ensuring all children in the country realize their full potential. This commitment is reflected in the formulation of the National Orphans and Other Vulnerable Children Policy and its first operational plan in 2004. In 2011 the government formulated the second National Strategic Programme Plan of Interventions for OVC (NSPPI-2) as a follow-up to the first NSPPI, which was implemented from 2005/6 to 2009/10.

The development of these policies and programmes indicates that as a nation, Uganda has the will and commitment to ensure that OVC are adequately provided for and that their human rights are fully met. Yet although progress has been made over the past five years towards building systems and structures that lay a firm foundation for the national OVC response, much remains to be done to enhance OVC's access to and utilization of basic health services.

NSSPI-2 recognizes the existence of weaknesses in institutional capacity for a national OVC response. For example, the strategic plan states the following:

*“Despite the existence of policies, legislations and institutional frameworks in the country the overall institutional capacity for coordination and implementation of the national OVC interventions is still weak. At lower local government levels...there is an absence of coordination structures and where they exist, they are dysfunctional. Local governments also lack sufficient staff and other resources to ensure a coordinated OVC response and to monitor quality care and support services.”<sup>2</sup>*

<sup>1</sup> Uganda National Household Survey (UNHS) 2009/2010

<sup>2</sup> Ministry of Gender, Labour and Social Development (MGLSD), Government of Uganda (2011): National Strategic Plan of Interventions for OVC 2011/12/2015, p. 15.

## 1.2

### ABOUT KAMULI YOUNG POSITIVES

Kamuli Young Positives (KYP) is an Organisation for and by young people living with HIV in Buyende District in Uganda. It was founded in 2004 and registered in 2006 as a community-based Organisation (CBO). KYP's beginning was championed by a group of young people who had interacted with members of the Uganda Young Positives in Kampala.

The Organisation brings together over 700 young people, including but not limited to OVC (below 30 years of age) living with HIV in Buyende District, to actively participate in HIV prevention, treatment, care and support services in the district. To achieve this, the pertinent issues and crosscutting themes for KYP are protection of human rights of OVC, innovation, evidence-based practices and sustainability as well as gender-related issues in OVC programming.

## 1.3

### STUDY GOALS AND OBJECTIVES

Despite the magnitude and negative consequences of increased numbers of OVC in Buyende (formerly Kamuli) District, insufficient documentation exists to describe key barriers to their ability to access HIV services and strategies for improving their well-being. In an attempt to fill these knowledge gaps, KYP formed a consortium with two other Organisations—Mac and

Mau HIV/AIDS Association and Kidera Orphans and Vulnerable Children's Home—to conduct research. KYP plans to use the information gathered through this research to mobilize a community response to demand support for OVC treatment and care in the district.

The following specific research objectives were identified during a rapid assessment:

- i. Examine and determine the barriers to accessing HIV treatment and care services by OVC in Buyende District,
- ii. Determine the most effective strategies of reaching OVC with regard to HIV treatment and care services in Uganda,
- iii. Obtain evidence-based information to advocate for the creation of an enabling environment for making HIV treatment and care services accessible to OVC in Uganda, and
- iv. Obtain evidence-based information to mobilize a community response to demand support for OVC treatment and care in Uganda.

## 1.4

### STUDY METHODOLOGY

Both qualitative and quantitative data collection methodologies and approaches were used to obtain information on key barriers to accessing HIV treatment and care services. These included structured household interviews that were conducted among OVC caregivers/guardians and OVC 10-17 years old; focus group

discussions (FGDs) held with caregivers and male and female OVC; and key informant interviews conducted with health service providers and health facility personnel, local administrative leaders and government officers in Buyende District.

### Study population and coverage.

The study was conducted among 135 OVC, 126 caregivers, 15 health personnel and 30 local leaders in a total of six sub counties/villages: Kidera, Nkondo, Buyende town council, Buyende rural, Bugaya and Kagulu. The respondents' ages ranged between 10 and 79 years, with the OVC being mainly those aged 10-17 years. The study population also consisted of respondents of different educational backgrounds, from no education attained to secondary school levels. The study focused mainly on five areas, namely demographic characteristics of respondents, barriers to HIV services, factors influencing the barriers, HIV awareness and human rights issues.

**Ethical issues.** KYP took care to adhere to ethical protocol when interviewing children younger than 18 years, seeking permission from the children's caregivers. The lower age bracket of 10 years was chosen because it was considered an age when a child is able to express him/herself independently and discuss issues affecting them. The upper level was chosen based on Ugandan laws recognizing age 18 as the legal age at which a person is considered an adult and hence subject to different laws.

**Limitations.** Current OVC data at district level was not available as desired and hence it was difficult to establish the exact status of OVC in terms of magnitude, numbers and issues affecting them. Not all the targeted sampled respondents were reached due to various reasons, some of which included:

- i. High expectations from caregivers: some said they would only allow their OVC to be interviewed on condition that the researchers promised to support the orphans with scholastic materials, schools fees and transport costs to the health facilities to access treatment.
- ii. Community attitudes towards researchers and past experience: most community leaders thought the researchers were going to use the information for their own financial gain.

The Uganda government defines a vulnerable child as a child who is suffering and/or living in circumstances where he/she is likely to suffer any form of abuse or deprivation and is therefore in need of care and protection. Operationally, vulnerable children are groups of children who experience negative outcomes, such as loss of their education, morbidity and malnutrition at higher rates than do their peers. The loss of a parent through death or desertion is an important aspect of vulnerability. The government further defines an orphan as a child who has lost one or both parents.

- iii. Fear of imprisonment: some caregivers would not allow the orphans to be interviewed or to give appropriate information for fear that they would be imprisoned. Some OVC also thought they would be taken away from their guardians and their community if they mentioned any illegal information about their guardians.
- iv. Difficulty in securing permission from caregivers of all sampled respondents: given that this study targeted legal minors (children less than 18 years of age), permission of caregivers was crucial to the interview process. Many caregivers were not available during the day because of work and as such permission could not be obtained, thus reducing the sample size.

# FINDINGS

## Caregivers

### 1.5 SOCIAL AND DEMOGRAPHIC CHARACTERISTICS OF OVC GUARDIANS/CAREGIVERS

One hundred and twenty six (126) respondents in the category of OVC guardians or caregivers were interviewed using structured household questionnaires.<sup>3</sup> Out of the 126 caregivers interviewed, more than half (N=71) were female: 56.3% of the total. In terms of age distribution, six out of ten of the caregivers (i.e., 62.2%) were in the age range of 25-54 years. Almost 20% of them were 55 years or older; of those, a quarter were 64 years or older.

While almost all (88%) of the caregivers had children of their own, the majority (60%) lived with between 4-10 children, some of whom were orphans (i.e., not their own children). Analysis of the number of orphaned children living with the caregivers showed that the majority of the caregivers (nearly 70%) were living with between 1-3 orphans; for 10% of the caregivers, meanwhile, all the children living with them were orphans. Some 2% had more than 10 OVC to take care of.

<sup>3</sup> The initial plan was to interview 130 caregivers, but 126 were successfully interviewed, representing a response rate of 97%.

**Education.** The majority (nearly 70%) of the caregivers affirmed that the OVC they lived with were attending school at the time of the study, with 63% also stating that they were the ones paying their school fees even though only 21% of the caregivers had a regular source of income. Comparison of OVC school attendance showed an association between the caregivers' own education and school attendance. OVC living with caregivers who had attended some form of school were more likely to also be in school.

Nearly one-third (29%) of the caregivers stated that the OVC living with them were not in school at the time of this study. The main reason was lack of money/school fees (cited by more than half [61%] of the respondents in this category). Other reasons mentioned included that the person paying fees had not sent the money (6%) and the child refused to go to school (6%).

**Relationship of caregiver to OVC.** More than one-third of the caregiver respondents were grandparents, either a grandmother (26.7%) or grandfather (9.2%). Nearly all of the rest were either aunts (21.7%) or uncles (18.3%); less than one percent reported that they were either a friend of the late parent(s) or a neighbour. Almost

80% of the caregivers considered the OVC they were living with to be their sole responsibility.

### 1.6 HIV AWARENESS AND ACCESS TO HEALTH CARE SERVICES

**Knowledge of HIV status.** HIV testing among the caregivers was found to be relatively high, with slightly more than 60% of them stating that they knew their HIV status. Knowledge of HIV status among the caregivers was also found to have a correlation with their age; those aged 24-54 were more likely to know their HIV status than the younger or older caregivers. There was also a positive correlation between knowledge of HIV status and school attendance among the caregivers.

**OVC health status and access to health care services.** Nearly 40% of the caregivers reported they were living with at least one HIV-positive OVC, with nearly one-quarter (24.4%) living with one HIV-positive orphan; 13% with two, and 3% with three HIV-positive orphans.

The majority (85%) of caregivers acknowledged that the orphans they lived with—regardless of their HIV status—had become ill at least once in the last six months. The study also showed that when the children fell sick the majority sought treatment from health centres (reported by

66% of the caregivers with responsibility for OVC who became ill). Only 17% and 9% of the caregivers reported that they sought treatment for the children in private clinics and the district hospital, respectively. This information is presented in Table 1.

Most of the key informants spoken to cited distance to the health facilities as a key barrier to seeking health services. Almost 40% of the caregivers revealed that the health centres they went to were 5 to 10 kilometres (3.1 to 6.2 miles) from their homes. This distance is a problem for many. According to the local council leader from Idhala, "Inadequate transportation means to the health facility is a major barrier." A teacher from Bukamira also noted, "The long distance to a health facility is a major challenge to these children." The main mode of transport to seek treatment in the cited health facilities was either bicycle (60%) or walking (35%).

Nearly 60% of the caregivers said that the children always got the prescribed medication at the health facilities, while 40% said they did not always get every medication needed. Analysis of findings revealed that the children who had been taken to seek treatment from the district hospital were more likely to get all the prescribed medication than those who visited a dispensary, a health centre, a private clinic or a nursing home. The main reasons cited by the caregivers for not obtaining all the prescribed medication was lack of money to purchase the

**Table 1**  
Caregiver respondents: health facility type for OVC treatment

Health facility type	Number of respondents	Where OVC were most recently treated (%)
Health centre	80	66.1
Private clinic	20	16.5
District hospital	11	9.1
Dispensary	5	4.1
Nursing home	1	0.8
Herbalist	1	0.8
Others	3	2.5
<b>TOTAL</b>	<b>126</b>	<b>100.0</b>

medication and stock-outs either at the facility or in private pharmacies in town. At the same time, almost one-third of the caregivers said they usually looked for other ways to ensure the children got their full treatment.

Most (62%) of the caregivers said the health workers generally treated the HIV-positive children well when they went to seek treatment services; however, more than one-third (35.5%) expressed problems or irritations with the health workers. The following three comments were made by caregivers in FGDs:

*"Very little time is given by health workers to patients to listen to them and their needs."*

*"Sometimes it depends on the time and the number of patients they have when they are tired, they tend to be rude and unfriendly."*

*"Some of them are money minded. If you provide some money, they will take care of the child very well."*

When asked about what treatment and support services were available for HIV-positive children at the health facility and in the community, 77% of the caregivers mentioned drugs and medicines; 12% mentioned IEC (information, education and communication) materials; and 7.1% and 1.8% mentioned food supplements and food rations, respectively. Many caregivers in FGDs reported challenges with regard to OVC accessing services, such as:

*"No village or parish in Buyende District has had any sensitization or training for us on how to take care of orphans and vulnerable children."*

*"There are not yet any existing interventions specifically targeting orphans and the caregivers within*

the communities apart from the information we obtain when we go to the health centre.”

“There are no special support services for orphans and vulnerable children in Buyende District.”

Many of the challenges for caregivers with HIV-positive OVC were the same for caregivers who did not know the children’s status, including lack of transportation and lack of regular sources of income. Those caring for HIV-positive OVC noted that in addition to stock-outs of medicines, they often experienced non-functional CD4 testing machines in facilities. Such problems—in addition to the fact that ART is often only available at government health care facilities and there is a lack of nutritional, social and psychosocial support for HIV-positive OVC—make provision of HIV treatment services erratic and unreliable.

A participant in one FGD among caregivers underscored the inadequacy of drug supply: “Many times we/the children are given less doses of medication at the hospital due to the big number of patients who go for HIV treatment services, which is usually the first Wednesday of every month.” Others cited the lack of youth-friendly services at the health facilities, with one noting, “There is no special clinic for children and no paediatrician at the main referral health facility [Kidera Health Centre IV].”

## Orphans and Vulnerable Children

One hundred and thirty-five (135) OVC (aged 10-17 years) were successfully interviewed. The following sub-sections summarize the findings in terms of the OVC’s socio-demographic characteristics; health status and access to health care services; experiences with physical and sexual abuse; and child labour and other forms of abuse such as stigma and discrimination.

### 1.7

#### SOCIAL AND DEMOGRAPHIC CHARACTERISTICS OF THE OVC

Analysis by sex showed that of the 135 OVC interviewed in this study, 64% (N=86) were male, while 36% were female. In terms of age distribution, 73.3% (N=96) were aged 10-14 years, while 26.7% were aged 15-17. More than three-quarters of the OVC interviewed were rural residents, with just 10% and 7% being urban and peri-urban residents, respectively.

**School attendance.** The majority of the OVC respondents (90%) said they had attended some form of school, with about three-quarters (76.4%) of those having attained the basic (or primary) level of education. Only 13% had

attained secondary education. For the few who were not in and/or had never attended school, 5% said they had no one to pay their school fees, 2% said the person they were living with did not allow them to go to school, and another 2% said they personally refused to go to school. Table 2 summarizes the analysis of OVC’s level of school attendance by sex. The analysis clearly shows that school enrolment and progression among female OVC is lower than that of their male counterparts.

Analysis of school attendance by age among the OVC also indicated that the younger ones (10-14 years old) were more likely to be in school than the older ones (15-17 years old).

#### Relationship with caregiver.

OVC respondents were asked to state their relationship to the person they lived with at the time of the study. Some 40% lived with either an aunt or uncle, one-third (31%) lived with a grandparent, and 26% lived with either an elder brother (18.3%) or sister (7.6%). About 2% lived alone in the family house. Of note also is the fact that 10% of the OVC lived with relatives older than 60 years of age, with the

**Table 2**  
Distribution of OVC by current class and sex

Class	Sex		% Total (N=113)
	% Male	% Female	
Junior 1-4	24.8	8.5	41.1
Junior 5-7	15.5	16.3	27.1
Senior 1-4	7.0	11.6	7.0
Senior 5-6 ('A' level)	0.8	0.0	0.8

majority (90%) of the OVC stating that the caregivers/guardians they lived with were not in gainful employment/had no regular income. This corresponds with the findings among the caregivers which also showed that the majority (79%) had no regular income.

More than three-quarters (86%) of the OVC stated that the persons they lived with treated them well. However, close to 15% said they were not being treated well by the caregivers they lived with, citing that they were being frequently shouted at, pinched, beaten, verbally insulted or given a lot of household work.

“Most of the time other drugs (with the exception of ARVs) are out of stock and we are required to buy them ourselves yet our guardians do not even have the money to buy for us [the medicines].”

## 1.8 OVC HEALTH STATUS AND ACCESS TO HEALTH CARE

Questions on OVC health status and access to health care ranged from whether they had experienced any illness in the last three months prior to this study; if they sought treatment; where they sought treatment; mode of

transport; if they got all medications needed to treat their sickness; if they knew their HIV status; and the type of HIV services available in the community and at the health facility.

**HIV knowledge.** The majority (80%) of OVC said that they had heard about HIV and AIDS. In one FGD, an OVC participant noted, “Yes [we know about HIV] because most of us have either lost parents through AIDS or we are personally living with HIV”. In the focus groups they also affirmed their knowledge about mother-to-child transmission of HIV and observed that even children their age could have contracted HIV from their mothers.

Fewer than half of the OVC (49%) knew their HIV status—in other words, had been tested and/or disclosed to by caregivers. Analysis by age revealed that the older OVC (15-17 year olds) tended to know their HIV status more than the younger ones (i.e., the 10-14 year olds).

**Place of health care, access and availability of medication.** As had been reported by the caregivers, OVC respondents said the most likely place for them to seek treatment when they were sick was the health centre (cited by 54.5%), followed by private clinic (15.2%), dispensary (5.3%) and district hospital (3.8%). This is also in agreement with what the caregivers said with regard to where they take the OVC to seek health care (as shown in Table 1 on page 7). The comparable findings underscore the importance of

health facilities having the capacity to respond to children’s needs by providing child/youth friendly services and adequate treatment and care.

As was reported by the guardians/caregivers, findings from the OVC respondents indicated that those who sought treatment at the district hospital were more likely to get all the prescribed medication than those who went to the private clinics, health centre or dispensary.

Many OVC echoed the challenges their caregivers noted in regards to access to medicines and care. For example, one noted in an FGD:

Long waits were cited as a challenge by others, including a local council leader who said the following:

*“[They] don’t get all the treatment because they go and take the whole day waiting for treatment. This also leads to others not going for treatment.”*

Distance to a health facility is a key determinant of access to and uptake of health services in Africa<sup>4</sup>. When asked what the distance was to the facility they normally go to obtain health care, it was apparent that almost one-half of OVC had to travel at least 5 kilometres (3.1 miles) to obtain services. More than 10%

4 See, for example, McLaren, Z et al (2013): Distance as a barrier to health care access in South Africa (retrieved from <http://hdl.handle.net/11090/613>) and Turin, D. R (2010): Health care utilization in the Kenyan health system: challenges and opportunities (retrieved from: [www.studentpulse.com/articles/284](http://www.studentpulse.com/articles/284)).

Overall, it appears that despite the availability of ART, there is a lack of adequate, youth and child friendly treatment literacy that ensures young people understand why they are taking ARV medicines and how they work.

had to travel between 11 and 20 kilometres. Most confirmed their caregivers' reports that the main mode of transport to the health facility was either by bicycle (reported by 59.5%) or walking (cited by 36.6%). The difficulties and challenges associated with transport are clearly a main challenge for OVC to obtain access to quality and consistent health care.

#### **Staff attitude at health facilities.**

Many of the OVC (70%) perceived the health care workers at the health facilities to be friendly. When this question was analysed by type of facility, private clinics ranked highest in treating their patients well (cited by majority of the OVC), followed by health centre, district hospital and dispensary. In one FGD, an OVC participant acknowledged that although s/he usually received treatment whenever going to the health facilities, "the health care workers do not explain in detail why we are

taking ARV and when the illness will get cured".

#### **Availability of HIV treatment and support services.**

OVC respondents were asked to state the kind of HIV treatment and support services available both at the community and health facility levels. The findings correlate closely with the responses from the caregivers (summarized above). Nearly three-quarters (74%) of OVC cited drugs and medicines as the most available, while only 14% mentioned IEC materials. Availability of food supplements and food rations was mentioned by 9.3% and 2%, respectively.

It is also telling that neither the caregivers nor the OVC mentioned counselling services or sex education.

### **1.9**

#### **OVC EXPERIENCES WITH VIOLENCE AND ABUSE**

**Physical abuse.** Eighty-three percent of the OVC reported that the caregiver they lived with generally treated them well. Only 10% reported ill treatment in the hands of their guardians. Further analysis by sex indicated that how well an OVC is treated by the persons they lived with did not vary with the sex of the child. However, when analysed by age, it emerged that the younger OVC were more likely to be mistreated than the older ones.

On whether they had ever experienced physical abuse, nearly 62% (N=82) of the OVC said that they had been physically abused, with higher proportions of male OVC (42%)

compared with female OVC (23%) reporting having ever been physically abused. Those who lived with their grandparents were the most likely to be physically abused. Nearly one-quarter had been abused during the two weeks before this study and one-third within the month before the study. It is important to note that nearly half (52%) of the OVC who had been physically abused did not report the abuse.

**Sexual abuse.** More than 10% (N=16) of the OVC reported having experienced sexual abuse. Of those who said they had been sexually abused, 14 reported having experienced the most recent abuse in the last month before the study. Eleven of those 14 said they had reported the abuse to various people of authority—e.g., the local council leader, a village elder and/or caregiver—and nine of them said action was taken when they reported the sexual abuse.

**Child labour and stigma.** More than 80% of the OVC reported that they perform house chores, with nearly one-quarter adding that their required chores prevented them from going to school. Nearly one-third reported working to make a living. Results of FGDs indicate that female OVC often face more challenges than their male counterparts. As one participant noted:

*"Yes, the girls, much as they are in similar conditions, are involved in quite a number of household activities...some of them end up looking for food for their fellow*

*siblings. They are also responsible for fetching water, which is the biggest problem in the district as most bore holes are as far as 2 kilometres or more away."*

HIV-positive OVC appear to experience significant stigma and discrimination. One respondent, a local council leader in Bukamira, said the following in an FGD: "They suffer discrimination and violation of their rights, such as the right to play with others and denial of medication/medical treatment by the caregivers/guardians...."

HIV-affected OVC also mentioned experiencing stigmatizing behaviour. According to one, "Our fellow children at home make fun of us that we will die soon...this happens usually when we annoy them". Two other respondents reported the following in regards to how they were treated in the community:

The community members are already aware that our parents died of AIDS, so they don't allow their children to associate with us, thinking we shall infect them.

*"My parents died of AIDS but when we were taken and checked they found we were negative, the community members have failed to accept this. They tell us it's not possible for both our parents to die of AIDS and we are negative, that the machines of our health facilities are faulty and we should try other places. This makes us think we are positive and feel out of place."*

# CONCLUSIONS AND RECOMMENDATIONS

## Conclusions

A review of the existing literature—particularly the national-level policies and strategies—revealed that the policy environment is supportive of responding adequately and appropriately to the needs of OVC. Yet while it is encouraging to note that the majority of caregivers surveyed in Buyende ensure that the OVC they take care of access appropriate medicines and care whenever they fall ill, it is also clear that the children face many challenges and barriers that prevent them from living healthy lives. Several conclusions about these barriers can be drawn regarding both community and facility levels:

### Community-level barriers

- i. Long distances that have to be travelled by the OVC to health facilities to seek treatment and other health care services.
- ii. There is inadequate support for community-based HIV programmes and interventions in the district that would increase access to HIV information and care services, including programmes aimed at socio-economic empowerment of OVC caregivers and the OVC themselves.

- iii. Local leaders are not sufficiently empowered and resourced to come up with appropriate and targeted strategies for mobilizing and educating the communities about the need for adequate HIV treatment and care, especially for OVC.
- iv. HIV-related stigma and discrimination targeted at OVC is still common, thereby putting them at risk of not seeking or obtaining needed health care services.
- v. The general poverty in the population has a negative impact on OVC's ability to access quality health care services. For example, most OVC and their caregivers find it difficult to pay for transportation to facilities, and to get the medication they need, with the meagre resources they have.

### Facility-level barriers

It is quite apparent that the government-run health centre is the main facility of choice for HIV treatment for the majority of the population, including OVC in Buyende District. However, the quality of care is compromised due to several factors:

- i. Frequent drug stock-outs and shortage of supplies required for HIV treatment, including malfunctioning of equipment such as CD4 diagnostics.
- ii. Inadequate time spent with patients, which means insufficient dissemination of information about treatment and medication. This is further aggravated by the lack of special counsellors specifically for children and young people. In all the facilities visited the service providers are supported by volunteers who are not well equipped with management of OVC issues.
- iii. Long waiting time for services, a situation that discourages patients from going to facilities.
- iv. Inconvenient timings for provision or dispensing of ART. One health centre was said to have an "ARVs-provision day" once a month on a specific day of the month only.
- v. Lack of youth-friendly HIV treatment and care services in all health care facilities. Among other challenges, OVC are forced to queue for long hours with adults at the health facilities.

## Recommendations

Listed below are some key recommendations that will be used to develop targeted advocacy strategies and concrete plans to change the situation of access to HIV treatment for orphans and vulnerable children in Uganda:

### Community-level recommendations

- i. KYP should advocate for strategies to attract more support for increased community education on HIV and economic empowerment for caregivers to be able to give quality support to the OVC.
- ii. KYP should support and work more with the local leadership for inclusion in community mobilization and education on HIV, including OVC issues.
- iii. KYP should advocate for strategies to help reduce stigma and discrimination levelled at HIV-positive OVC both within the community and in schools.
- iv. KYP should advocate for more health facilities to either be built or for the relocation of existing dispensaries to be closer to the majority of people in need. All facilities should be well equipped to provide HIV treatment services—i.e., in terms of human resources, testing capacity and medication.
- v. KYP should engage in increased community mobilization to keep OVC in school and/or to liaise with

vocational schools to provide them with alternative skills to enable them to earn a living when they are adults.

- vi. KYP should advocate for school-based counselling services and for flexible school schedules for children living with HIV.
- vii. KYP should train guardian-teacher associations in school communities to support and enable OVC to remain in school. KYP will need to work with these associations to support and mobilize communities for anti-stigma campaigns and psychosocial support initiatives for the OVC including identification of children at risk, counselling and effective referrals.

### Facility-level recommendations

- i. KYP should advocate for the establishment of youth-friendly health care services in all the health facilities that are frequented by OVC for treatment.
- ii. KYP should advocate for round-the-clock availability and provision of ART to HIV-positive patients who need them. KYP should monitor and report stock-outs of medicines, test kits and other supplies that are required to provide quality services to OVC in Buyende District.
- iii. KYP should liaise with health service providers to conduct trainings to build the capacity of caregivers on appropriate care of OVC. Issues that should be considered in this

approach include stages of illness, disclosure of HIV status, and treatment literacy (especially so those living with HIV and on ART are aware of why they should take the medicines regularly).

# 2

## ACCESS AND UTILIZATION OF HIV CARE AND TREATMENT SERVICES AMONG SEX WORKERS IN MAJENGO (NAIROBI, KENYA)



The sprawling neighbourhood of Majengo is one of the oldest slums in Nairobi, Kenya with an estimated population of over 500,000 people.

# INTRODUCTION

## 2.1 BACKGROUND AND CONTEXT

In recent years, Kenya has shown great strides against HIV. In 2011, according to government reporting, the rate of new HIV infections had fallen by 40%, 69% of HIV-positive pregnant women received support to prevent vertical transmission, and antiretroviral therapy reached 83% of medically eligible adults.<sup>5</sup> Yet certain populations remain severely affected by HIV, including sex workers. In 2011, 29.3% of sex workers were estimated to be living with HIV in Kenya, with higher percentages in cities like Mombasa.

Data in recent years also suggest that sex workers and their partners account for at least 14% of new HIV infections in Kenya.<sup>6</sup> Sex partners of sex workers also serve as a bridge into the general population, which may increase the spread of HIV and other sexually transmitted infections (STIs) more broadly.

In Kenya, sex workers are vulnerable to HIV for a variety of reasons. While a national survey in

2011 found that 87% of sex workers reported using a condom with their last client, and also demonstrated almost universal awareness of HIV among sex workers, entrenched stigma and discrimination serve as a major barrier to seeking health services. Selling sex is criminalized, and sex workers in Kenya continue to face high levels of violence and abuse from clients and police. In addition, male sex workers in particular report gaps in HIV knowledge; one survey of 425 male sex workers in Mombasa found that 35% were unaware HIV could be transmitted through anal intercourse.

Kenya's national HIV response is also hindered by lack of size estimation of the sex worker population. Sex work-related health programming also does not always accommodate the different forms sex work takes—for example, sex work can be considered as falling along a spectrum ranging from occasional transactional sex for food, shelter or other commodities to working as a sex worker as a full-time occupation. In the former case, sex workers are relatively underground, making it more difficult to identify and provide HIV-related outreach to them.

As the Kenyan government continues to address HIV, the treatment-related needs of sex

workers are of critical importance. More information is needed around whether sex workers are adequately accessing ARVs and any barriers to successful ARV treatment and related-care.

## 2.2 ABOUT COTANET

The Community Treatment Access Network (COTANET) is a project of men and women living with HIV, sex workers and HIV advocates in Majengo, part of Nairobi North District. The Organisation was started in 2008 at a local community forum of HIV-positive advocacy champions in Majengo. The goal of the Organisation is to support improved, effective and sustained quality HIV treatment for women, children, sex workers and people living with HIV. One strategy it focuses on is empowering the community in treatment literacy and advocacy skills in a way that envisions protection of human rights. Some of the current activities that COTANET is involved in include:

- Providing accurate HIV information to the community,
- Sourcing for existing accurate and user-friendly HIV information materials for women and sex workers and distributing in the community,

5 Office of the President, National AIDS Control Council, The Kenya AIDS Epidemic, Update 2011

6 Kenya National AIDS Control Council, Joint United Nations Programme on HIV/AIDS (UNAIDS) and The World Bank HIV/AIDS Program (2009). Kenya HIV Prevention, Response and Modes of Transmission Analysis. Nairobi, Kenya.

- Providing the community with information about current HIV treatment, health and human rights in meetings; and
- Participating in local and national advocacy activities with other Organisations on matters that affect HIV-related care and treatment in the country.

### 2.3

#### STUDY GOALS AND OBJECTIVES

COTANET believes that quality programmes and strategies are based on evidence and that emerging best practices must be monitored and evaluated. These principles guided COTANET's research as the Organisation sought to determine the most effective strategies of reaching and providing treatment to sex workers in Kenya. Specifically, the objectives of the study were:

- i. To examine the barriers to accessing HIV treatment and care services by sex workers in Majengo, Nairobi,

- ii. To determine the most effective strategies of reaching sex workers in Kenya, and
- iii. To obtain evidence-based information to advocate for the creation of an enabling environment for making HIV treatment and care services accessible to sex workers in Kenya.

### 2.4

#### STUDY METHODOLOGY

This study used several data collection methodologies with the aim of obtaining both quantitative and qualitative data. Qualitative data were obtained through focus group discussions (FGDs) conducted with both male and female sex workers and key informant interviews done with health care providers and other personnel at health facilities where sex workers obtain HIV and other related services. In total, eight FGDs (with eight participants per FGD) and four key informant interviews were conducted.

In addition, quantitative data were obtained by administering a structured questionnaire to 54 sex workers (male and female). COTANET estimates the number of sex workers in Majengo to be approximately 90 as per a baseline study the Organisation carried out recently. COTANET used that number as the basis for determining the preferred sample size for the questionnaire. In total, 68 respondents were approached to participate in the research. Responses from 54 were analyzed for the survey (14 questionnaires were not completed fully and accurately). Given that there are approximately 90 active sex workers in the Majengo area of Nairobi, a respondent rate of 54 meant that the study reached 60% of the sex workers operating in the area.

# FINDINGS

## 2.5 SOCIO-DEMOGRAPHIC CHARACTERISTICS

**Sex.** Analysis of the respondents by sex revealed that 76% (N=41) were female and 24% (N=13) male. More than half (52%) of the respondents had been engaged in sex work for more than four years, 40% for 1-3 years and 6% for less than one year.

**Age.** The majority of the respondents (87%) were in the age range of 15-34 years, with 18.5% between the ages of 15 and 19 years; 15% between 20-24 years; 28% 25-29 years; and 26% between and 30-34 years. The remaining 13 percent were below 15 or above 34 years, and were not the focus of this research.

**Marital status and children.** The majority (61%) of respondents were single and had never been married. Of all 54 respondents, 11% of the female and 2% of the male sex workers were in marital unions. The majority (more than 60%) of all informants have had children; of those with children, 11% were male sex workers.

**Education.** All respondents had attended at least some school, with about one-quarter of them indicating that they were still in school/college. A higher proportion of male sex workers (44%) than their female counterparts had attained a

diploma (tertiary) level of education. Most female respondents' (82%) highest level of educational attainment was secondary school.

**Occupation.** Approximately one-third of the respondents reported that they had side jobs other than sex work. They were mainly self-employed in the informal sector.

**Number of regular sex clients.** Table 3 summarizes the findings from questions as to the number of regular clients participants had at the time of the study. It is evident that all the respondents had at least two regular partners. However, the majority (63%) of the female sex workers had at least five regular sex partners.

## 2.6 AVAILABILITY, ACCESS AND UTILIZATION OF HEALTH CARE SERVICES

**Knowledge of HIV status.** It is apparent that HIV testing is a common practice among the sex workers of Majengo. Almost all (nearly 80%) of them reported that they knew their HIV status, with the lowest awareness reported among younger female sex workers. Half the females who were under 15 years old and 10% of the ones aged 15-19 years did not know their HIV status.

**Utilization of services.** Almost all (94%) of the sex workers interviewed had visited a health care clinic or facility at least once in the last three months before the study. On being asked what services they sought during their last clinic visit, more than half (65%) of the respondents had gone for HIV prevention. One-half (50%) also went for STI screening services. An important note is that prevention services here refer only to condoms because none of the

**Table 3**  
Sex worker respondents: number of regular partners

Number of regular partners	Sex		Total %
	Male (% of total respondents)	Female (% of total respondents)	
Two	1.9	Nil	1.9
Three	18.5	1.9	20.4
Four	3.7	11.1	14.8
Five	Nil	31.5	31.5
> 5	Nil	31.5	31.5
<b>TOTAL</b>	<b>24.1</b>	<b>75.9</b>	<b>100</b>

**Table 4****Sex worker respondents: type of services sought in the last 3 months** (Note: respondents could indicate more than one answer)

Service sought	Number of respondents citing	Percent that sought service
Prevention (condoms)	35	64.8
STI screening	27	50.0
Family planning	17	31.5
HIV treatment (ART)	14	25.9
Delivery (maternity)	4	7.4
TB screening	4	7.4
Male circumcision	2	3.7
HIV counselling and testing	2	3.7
Emergency contraception	2	3.7

respondents reported having gone for post-exposure prophylaxis (PEP). Details of the responses are presented in Table 4.

From Table 4, it is apparent that generally the most sought after services are HIV/STI prevention, STI screening, family planning and ART. However, this order changes when the respondents who said they had ever sought HIV-related services were asked to state only the HIV services they sought during their last visit. The results are shown in Table 5.

The results summarized in Table 5 confirm the observation of a service provider from one of the government comprehensive care centres (CCCs), who said, "In general, sex workers do not fear coming for treatment; they only fear being known to be sex workers."

The reasons for high uptake of condoms in both scenarios as shown in Tables 4 and 5 can be inferred from the following

quotations extracted from the various FGDs that were conducted during the study. Of note is that for some, condom use is a response to ongoing HIV information and education programmes and interventions:

*"Yes, nowadays we see everywhere in the media and around us in posters and campaigns that everyone has to negotiate for safer sex to be able to live longer, so we do that."*

*"It is safe and keeps us healthy and away from other diseases like STIs."*

*"Yes, nowadays sex without condoms is unsafe...as we are HIV-positive we do not want to infect others or get re-infected."*

However, some respondents noted that there are occasions when they would agree not to use condoms in exchange for a higher payment:

*"Some people do not like using condoms and occasionally we come across them, but we have no choice, we give them the service but they pay a higher amount of money."*

**Availability of health care services.** For services sought as cited in Table 5, research indicated that the health facilities most frequented by the surveyed sex workers were the district hospital and the dispensary—with about one-third of the respondents stating that they sought services at one or the other (34% for the district

**Table 5****Sex worker respondents: type of HIV services sought during their last visit to a health facility**

(Note: respondents could indicate more than one answer)

Service sought	Number of respondents citing	Percent that sought service
Prevention (condoms)	40	74.1
HIV treatment (ART)	32	59.3
HIV counselling and testing	21	38.9
HIV testing	14	25.9
TB screening	8	14.8
Male circumcision	3	5.6

hospital and 32.2% for the dispensary). The least visited facility types were private clinics (cited by 7.4%) and nursing homes (cited by 3.6%); meanwhile, 15.1% reported having sought services from the health centre during their last visit to a health facility.

It is clear that due to close proximity, HIV prevention (condoms) and treatment (ART) are mostly obtained from the Majengo government via the city council dispensary. As one FGD participant noted, "In Majengo we walk to the [government] dispensary for HIV and TB treatment but when we want other services we have to go to other places away from here." A service provider from Majengo confirmed that services including ART, counselling and male condoms, as well as prevention of mother-to-child transmission (PMTCT) services, are available at the dispensary.

However, sex worker respondents said they still experienced many challenges when they sought HIV treatment and care services, even in Majengo. A common complaint was that the main health facility in Majengo remains open for only eight hours a day, like other government offices, and is closed on the weekends. At one FGD, the following observation was made in relation to the timing of the services:

*"Some private clinics are open 24 hours, while the public one goes for eight hours from Monday to Saturday and remains closed on public holidays...and in case we*

Almost 40% of respondents said they did not get the services they needed during their last visit to a health facility. They gave several reasons, including: the drugs or medication they needed/had been prescribed were not available (28%), the health worker was rude (9.3%), and the service needed was not offered at the facility (7.4%).

*experience violent abuse when it is closed then we have to seek treatment services elsewhere....We suggest that the dispensary should be open 24 hours and on all days of the week including holidays because of emergencies like sexual abuse such as rape and violence."*

Other respondents, including health care service providers surveyed, noted the lack of comprehensive services within Majengo, such as lack of comprehensive family planning services. And although TB treatment is available, access to TB diagnostic services is limited because, according to some respondents, there is no X-ray machine at the local dispensary. Those seeking TB tests are referred to hospitals outside the

area that take a long time to reach, creating a time as well as transport cost barrier, and have lengthy delays due to demand. As one FGD participant noted, "So at times we get services after days or weeks of appointments."

Almost 40% of respondents said they did not get the services they needed during their last visit to a health facility. They gave several reasons, including: the drugs or medication they needed/had been prescribed were not available (28%), the health worker was rude (9.3%), and the service needed was not offered at the facility (7.4%).

The type and scope of challenges were encapsulated in the following comment from one FGD participant:

*"We cannot get treatment for STIs, skin diseases, serious infections or persisting coughs or when you need an operation. We go to Casino in the city centre and Kenyatta Hospital for such problems...The queues at Casino and Kenyatta are heartbreaking and bearing in mind the nature of our work, spending a full day at Casino or Kenyatta means no business for the day at all. So we are forced sometimes to visit private clinics, which are mostly located in Eastleigh—even though they don't give the best quality services because in most cases they are run by unlicensed or unqualified personnel. Again, these clinics do not have certain drugs like Acyclovir and Augmentin."*

In addition, what is available is not always what is desired. According to one FGD

participant, "Another thing is that the services are not based on our needs as sex workers living in Majengo. For example, if only the dispensary could start offering things like lubricants to male sex workers at lower or subsidized prices [so we could] afford them...." One male sex worker said the following in a focus group: "Treatment is not for everyone, even when we are referred, and as we have said before, there is no screening for anal diseases for men and therefore the services are not very good [appropriate]."

The various complications noted above are among the main reasons that only 11.3% of the respondents said they received all of the medications they needed. More than half (54.7%) reported getting only some of the medications they sought and needed, while more than one-third (34.0%) did not get any medication at all. Those who did not get some or all the prescribed medicines mentioned either stock-outs (cited by 45%) or lack of money to purchase (cited by 26%).

All of the health care providers who provide services to the sex workers acknowledged that there are challenges with regard to availability of medications and other supplies. A health service provider at the Majengo dispensary said the following in relation to complaints about the lack of services and products: "We just have to refer patients to other facilities for the services we don't offer and medicines we lack. We cannot do anything about staffing

issues and supplies because those are issues beyond us."

The majority (81.1%) of respondents said they usually visited health facilities that were closest to them (i.e., less than 10 kilometres [6.2 miles] away). Often they feel they have no choice. As noted by one FGD participant: "Not all services are available at Majengo...but for the others that are not offered in Majengo we consider that they are far. The cost of services and transportation to and from the referral service delivery sites is high."

Availability of other support services in the community—e.g., information and education, food supplements, and outreach for STI screening and HIV counselling and testing—can have a positive impact on uptake of health services in a community. It is for this reason that the respondents were asked to state whether there were targeted HIV-related treatment and support services for sex workers in the community. Table 6 shows the HIV treatment and support services that are available for sex workers in Majengo health facilities and the community.

It is clear that IEC materials and contraceptives, sometimes provided by non-governmental Organisations (NGOs), are the most readily available HIV care and treatment support services offered to sex workers in Majengo at the community level. Yet some FGD participants questioned the value of what is

provided by these NGOs, as noted in the following comments:

*"Sometimes people come round talking about HIV and distributing reading materials which some of us cannot read. They also give us condoms but we are ashamed to take them because it is in public."*

*"The condoms are usually of very poor quality."*

*"Female condoms are not given out in the community. Some of us have never seen a female condom with our own eyes."*

All the health care providers interviewed were in agreement that communities have a major role to play in ensuring that sex workers living with HIV access treatment and care services since social support encourages uptake of such services, enhances treatment adherence and reduces stigma. The following are among the comments from health care workers in this regard:

*"Communities should offer alternative [income-generating] opportunities for sex workers since not all of them have chosen to be in the trade."*

*"Provision of family and social support from the community is important to reduce stigma levelled at and experienced by sex workers."*

*"Community members should be sensitized and educated to handle sex workers in a humane way and respect their rights just like they do with the rights of other people."*

**Table 6****Sex worker respondents: types of community-level HIV treatment and support services available to sex workers in Majengo**

(Note: respondents could indicate more than one answer)

Type of service	Percent of respondents citing
IEC materials	90.7%
Family planning methods/contraceptives	75.9%
HIV counselling and testing on demand	37.0%
Food supplements	35.2%
Drugs and medicines	25.9%
STI screening	13.0%

**2.7****QUALITY OF SERVICES**

The way patients are received and handled when they go for health services is a good measure of the quality of services offered at any health care facility. In this study, nearly half of the respondents (45%) felt that patients were not treated well whenever they went for health care services in the health facilities around Majengo and beyond.

Almost all sex worker respondents (94.4%) said that indeed, they had experienced such discrimination at one time or the other. The stigma and discrimination is based either (or both) on HIV status or knowledge that the patient is a sex worker. The following comments were made during FGDs:

*“At Casino there are good medicines but they look down upon us. Some ask you stupid questions, [such as] “where did you get this bad disease.”*

*“They seem to assume that sex workers do not exist and if they do then they do not deserve services.”*

*“At Pumwani, they will help you deliver your baby but they must test for HIV and if you have HIV, you are in trouble. The nurses there and even support staff will know your status and services will not be forthcoming in a good way. You can even be ignored to the extent that you deliver without any help from them. They will ask you why you are giving birth yet you know that you are very sick and can die any time; they ask you who will take care of the baby if by any chance it survives. This is why when we are sick we go to private clinics, though their services are also poor, but we are not humiliated or embarrassed by the people working at the clinics.”*

*“Most health workers are not friendly to us; some demand bribes for services. Some use abusive language towards us and other patients too.”*

However, the health care providers surveyed had different views concerning stigma and discrimination of sex workers. Some providers denied that sex workers are stigmatized, with one

adding, “We treat all patients with the dignity they deserve.” Others claimed that self-stigma among the sex workers was the main problem, as demonstrated in the following health workers’ statements (which blame the sex workers largely or in part for the barriers in service):

*“Most first-time-visit sex workers are a challenge to us because they do not want to be identified, are not open with us service providers and if one is not careful [you] can end up diagnosing a wrong disease. For example a sex worker may tell you she/he has a problem with the stomach whereas the problem is STI-related.”*

*“The majority of the sex workers do not want the nature of their work to be known to service providers in the facility. So it would be hard even to appropriately counsel such a person or even do further tests.”*

Table 7 shows a list of challenges that compromise sex workers’ access to quality health care and treatment services in health facilities situated both in and out of Majengo area.

At the top of the list in Table 7 is lack of medicines/drugs, as mentioned by nearly 90% of the respondents. An FGD participant provided this comment:

*“We can walk to the dispensary in Majengo and we are supposed to get free drugs but the drugs prescribed are in many instances out of stock. We get ARVs but when we need to change the regimen for some reason like*

**Table 7****Sex worker respondents: types of challenges faced at the health facilities by sex workers**

(Note: respondents could indicate more than one answer)

Challenge	Number of respondents citing	Percent of all respondents
Shortage/lack of medication/drugs	47	87.0
Shortage/lack of FP methods	45	83.3
Rude service providers	21	38.9
Lack of privacy	20	37.0
Discrimination by service provider	13	24.5
Lack of confidentiality	11	20.4
Distance to health facility	6	11.1

*adverse side effects, it will take forever. We cannot say the services are acceptable or appropriate because the service providers at the dispensary discriminate and stigmatize us and the drugs are not available."*

Stock-outs affect not only ARVs but a wide range of medicines. According to one sex worker respondent, "Most of the times there are no medicines for other sicknesses like creams for skins and even antibiotics." Often, patients are then directed to go elsewhere, as acknowledged by a health worker at a comprehensive care clinic; "Medications are not available all the time. In such instances we give patients prescriptions to go buy elsewhere."

Sending patients elsewhere is not only a hassle, but can also raise serious quality and access concerns, including when patients feel they have no choice but to go to private pharmacies. One sex worker participant made the following observation: "When we buy some drugs from private

pharmacies around, we buy them expensively and the drugs sold can even be fake also."

Several respondents also mentioned health workers' refusal or inability to ensure confidentiality. According to one sex worker, "Some of the [health] workers do not keep secrets of the patients they attend to, so this can also stop someone from going for treatment."

Overall, nearly half (44.4%) of sex worker respondents rated as "poor" the quality of care they received the last time they visited a health facility to seek treatment and care services. Just 16.7% rated the quality as "excellent".

Both the sex workers and health providers surveyed were in agreement that the quality of health care provision would be greatly improved if services were provided in an integrated and comprehensive manner. Such an approach would ensure the provision of an array of services in one place, including HIV

prevention and treatment; screening for reproductive cancers and TB, along with TB treatment; and family planning, including emergency contraception. A sex worker participant at an FGD summarized and captured the true spirit of integration:

*"The health facilities should be friendly to sex workers and services should be integrated so that one does not keep going from this corner to the other for the required service....I mean that when we go to the facility, we should be able to pick ARVs, condoms, family planning pills and other supplements at one place."*

**Opportunities for More Focus and Resources**

A number of issues or thematic areas, some of them unexpected, arose from this study that may provide new strategic entry points or avenues for further research, attention and resources. Most, including human rights violations, have an impact on sex workers' health and health-seeking behaviour, including their ability to protect themselves from HIV/STI infection.

**Harm reduction.** During the FGDs, one of the discussion points revolved around whether there were any harm reduction interventions targeting sex workers in Majengo—e.g., regarding alcohol and drug/substance abuse. Evidently, no interventions such as needle/syringe exchanges have been put in place for the Majengo sex workers even though most respondents mentioned

substance use as a concern. Comments from survey respondents included:

*“Some of us take drugs and are addicted to it but we have not been helped because the government and stakeholders such as NGOs have neglected our community.”*

*“We just inject ourselves until the needle is not sharp enough and then we dispose and buy another. Occasionally we share with our clients but we normally sterilize the needles by boiling...We have no choice because you cannot buy needles daily.”*

A comment from a participant in another FGD underscored the range of challenges associated with providing appropriate harm reduction in Majengo: “Even if there was such a thing, none of us would want to be identified as abusing drugs because this could land us into more problems with the administration since you will not know who is behind the intervention.” This observation highlights the need to involve sex workers in developing and implementing any harm reduction efforts. They have inherent mistrust of programmes and interventions being initiated and implemented by “outsiders”.

**Human rights violations.** Another key crosscutting theme from FGDs was the violation of sex workers’ human rights and their wish for rights- based approaches to address their health needs across the spectrum— from the individual and community level to programmes and policies to

health care provision. In the FGDs, sex workers revealed how their human rights are constantly violated at the individual level (by their clients); at the community level (by their families, local administration and law enforcement agencies); at the policy and programmes level (through policies and programmes that do not acknowledge or respond to their needs and rights); and at the health care level (because health services are not user-friendly and choices are limited).

Comments from FGDs included:

*“Sex work in Kenya is taken to be an illegal trade, and so there is no respect for our human rights in the eyes of the health workers, police, administrators and community because we are deemed to be carrying out an illegality.”*

*“Everyone in Majengo does not know what human rights are for sex workers except the sex workers themselves.”*

**Acting as champions.** Sex workers see themselves as champions of their own cause, since they are the ones pushing for the provision of user-friendly and improved quality services that are responsive to their needs while also advocating for supportive policies. According to one FGD participant, “We as sex workers should come together and find solutions that suit us best under the circumstances in which we live, so that we can push the government and others to improve access to treatment that benefits us because we have unique needs when it comes to accessing treatment.”

Even health workers’ perceptions about sex workers has been changing, as indicated by the following comments from surveyed individuals from the sector:

*“Sex workers are champions of their own destiny as far as treatment is concerned and they perform better when it comes to adherence and making choices on safer sex. So today’s sex worker who I see in this facility is empowered and knowledgeable; we only need to keep up the momentum and bring others on board.”*

*“I have seen some sex workers who come for services here regularly without fail. To me that means they understand the importance of treatment well.”*

Future research should be considered carefully, and better take into account the past research-related experiences of sex workers. This is because many sex workers in Majengo alluded to “research fatigue.” Many of those surveyed in Majengo felt that they have been “over-studied” or over-researched. This was aptly captured by this quote from a participant in one of the FGDs:

*“When people visit ...we give them all the information that they want...but when they go, we never see anything. Instead, we see another team asking the same questions...promising things. One group asked “Why are you doing sex work?” and my response was “Because I do not have another means to earn a living”. They said they could help us start income-generating activities and that was the end.”*

# CONCLUSIONS AND RECOMMENDATIONS

## Conclusions

This sub-section summarizes some of the conclusions that follow from the findings discussed in Section 6.

**Access and utilization of health services.** Sex workers in Majengo are active users of health care services, especially those that relate to HIV and reproductive health. However, the utilization of these services is riddled with many challenges including shortages and stock-outs in facilities closest to them of vital medications, other supplies and certain procedures and tests. Many therefore are forced to travel to public facilities outside the area or go to private facilities. In both cases, their out-of-pocket expenses are much higher due to travel costs and delays or the need to pay for goods purchased in private facilities. A lack of money to pay for these services was found to be a major challenge and barrier to obtaining health services. Limitations associated with health facility operating hours were also cited as a barrier to access.

**Quality of health services.** The quality of HIV treatment and care services that sex workers in Majengo receive is generally low and compromised by stigma and

discrimination related to HIV status and sex work, inadequately skilled providers, lack of user-friendly services, violations of confidentiality and privacy, and inadequate integration of services. Self-stigma among sex workers was also cited as an obstacle by the health workers surveyed. Respondents from all groups stated that provision of integrated services would be one of the strategies that could be used to effectively address the stigma perpetuated when HIV services are provided separately or in separate sections in a health facility.

**Opportunities for research and programming.** Opportunities exist for more research and programming around HIV treatment and care among sex workers, especially in the areas around harm reduction, human rights violations and training and empowering sex workers to be advocates and champions of their own rights. Many sex worker respondents expressed irritation and disappointment, and in some cases anger, about having been approached and interviewed for numerous surveys and studies over the years. They contend that they have seen few tangible impacts and/or implementation

of the recommendations coming from those studies for the improvement of their welfare—whether in terms of health or general livelihoods.

## Recommendations

Many recommendations can be drawn from the findings of this study. Listed below are some of the key recommendations that will be used as the basis for developing targeted advocacy plans during the second phase of MTT 11:

- i. There is a need to enhance the capacity of health care workers (including sensitizing them) to be able to humanely, skilfully and professionally provide HIV treatment and care services that are both ethically sound and comprehensive, and devoid of stigma and discrimination.
- ii. There is a need to continuously educate, support and work with sex workers to understand that they too have a role to play in advocacy, community education and mobilization for policies, programmes and health care services to be responsive to their needs.

- iii. The need for 24-hour integrated HIV and reproductive health services at the Majengo dispensary cannot be overemphasized as a strategy to enhance quality of services and increase uptake of those services by sex workers on demand and at any time of the day. Provision of integrated round-the-clock treatment and care services would not benefit the sex workers only, but also the entire Majengo community. Such expanded and integrated services would bring services closer to the people of Majengo and environs, promote uptake and help in cutting costs involved in seeking services elsewhere in the city, thus enhancing access to health care.
- iv. There is a need to make use of the opportunities that have been highlighted in this study to put in place other supportive health and social interventions at the community and programmes levels. For example, interventions should be prioritized in the following areas: harm reduction, supporting alternative means of livelihood, and human rights education and advocacy.

# 3

## COMMON FINDINGS, RECOMMENDATIONS AND NEXT STEPS



MTT11 country research teams and ITPC  
Global Staff in Nairobi, Kenya

## COMMON FINDINGS AND RECOMMENDATIONS

The research in both Uganda and Kenya was community-based and community-driven, undertaken by those who closely relate with the HIV treatment issues covered in the studies. And, despite the fact that the studies were undertaken in two very different populations and communities, there were certain common findings as far as barriers to accessing quality HIV services. These commonalities can be used to formulate advocacy messages targeting HIV-related policy and programme formulation as well as implementation and leadership at all levels.

Some key common findings of research regarding OVC (Uganda) and sex workers (Kenya) are noted below. The advocacy messages associated with each are proposed for consideration to the two Organisations, Kamuli Young Positives (Uganda) and the Community Treatment Access Network (COTANET) of Kenya, as well as their allies and colleagues.

**i. Long distances frequently must be travelled to facilities, especially for certain HIV-related procedures and tests.**

These time-consuming and burdensome journeys force patients to incur extra costs to travel and negatively affect all parts of their lives, including their income-generating and caregiving activities.

*Advocacy messages* on this issue should revolve around calling on leaders (policy/decision-makers) to ensure the construction of more facilities closer to the people and ensuring availability of all HIV treatment services in these facilities.

**ii. Limited and insufficient support is provided for community-level HIV programmes and interventions** to address information and knowledge gaps and provide economic empowerment to enhance community-based support services for those affected by HIV.

*Advocacy messages* should target relevant government agencies/leaders, development partners/donors and other stakeholders to support community-level care and support for people living with and affected by HIV.

**iii. The quality of treatment and care services is poor**, as demonstrated by frequent shortages and stock-outs of drugs and supplies; inadequate provider skills and poor dissemination of information about HIV treatment; and lack of targeted user-friendly services.

*Advocacy messages* should target: (a) policy makers, to ensure continuous supply of drugs and medicines in sufficient quantities; (b) decision-makers in public, private and development

sectors to support the establishment and capacity building for the provision of targeted user-friendly HIV and related services in health facilities; and (c) health sector managers to ensure the dissemination of correct information regarding HIV treatment.

### 3.1 NEXT STEPS

The research for and publication of this report constitutes the first phase of the MTT 11 project. For Phase 2, KYP and COTANET will implement and evaluate advocacy efforts aimed at mitigating the barriers to HIV treatment discussed in this report. The second phase will run for one year, through the end of 2014.

Both the research and advocacy components are designed to support and build community mobilization around HIV treatment and care for all in need. Such work is a vital part of the Treatment 2.0 framework, which outlines and justifies a comprehensive strategy for quality, accessible and affordable treatment. Communities and Organisations that work within and for them, such as KYP and COTANET, are essential to the successful achievement of the Treatment 2.0 framework's goals and objectives.



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