

**SEX WORKERS' ACCESS TO HEALTH CARE IN  
LILONGWE, MALAWI**

by

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# Approval

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## **Abstract**

Research indicates that sex workers have a high disease burden, especially in terms of HIV and AIDS, which necessitates preventative care and timely treatment. In Lilongwe, Malawi sex workers encounter barriers that limit their access to these services, which affects not only their health but also the health of their clients. To date, however, information about these barriers and how to address them has been lacking. Through interviews with sex workers and representatives from government, non-governmental organizations (NGOs), and other non-state agencies, this project identified both structural and social barriers to health care. Accordingly, the research proposes five comprehensive policy options: creating a sex worker network, providing *mHealth*, introducing a peer-mentoring scheme, training and sensitizing health professionals, and utilizing a health voucher system for private care. It underscores that all stakeholders, including sex workers, government, and NGOs, should be involved in creating better access to health services for sex workers.

**Keywords:** sex work; health care access; Malawi; Southern Africa; HIV and AIDS; stigma

## **Executive Summary**

This study uses qualitative methods to assess the barriers sex workers face when accessing health care services in Lilongwe, Malawi. In this study, access refers to: availability, quality, costs, and adequate information. Sex workers have a high disease burden, evidenced by high rates of STIs and HIV (70% prevalence), which requires access to health services. Even though government has put some interventions in place, many sex workers still suffer from poor health. They encounter barriers that limit their access to health services, which affects not only their own health but also the health of their clients. To date, however, research in Lilongwe and Malawi on these barriers and how to best address them is limited.

This study proposes a theoretical framework, based on the literature, that separates the barriers to health access into two broad categories: structural and social. Structural barriers refer to the social determinants of health (SDH), which broadly influence health outcomes, and structural violence, which are institutional factors that disproportionately disadvantage the poor. Social barriers refer to various types of stigma. The framework suggests that sex workers experience stigma related to the perception of sex, gender, and HIV. Stigma related to sex is further analysed in terms of widespread Christianity, conservative cultural norms, traditional cultural practices and beliefs, prevalence of multiple concurrent partnerships, and the influence of normalized transactional sex.

Data was collected through interviews performed with sex workers ( $n=7$ ) and other stakeholders ( $n=20$ ). Through the lens of the theoretical framework, the key issues revealed were:

## **Structural**

- The ambiguous climate in government related to sex work. Respondents detailed the government's motivation for change and a description of an interdepartmental working group on sex work.
- The possible influence of the proposed HIV Bill and an analysis of the implications of mandatory testing on sex workers.
- The low capacity and corruption of the public health system and how it negatively affects sex workers.
- The use of alternative and traditional health practices and the order in which sex workers seek health advice and treatment.

## **Cultural and Social**

- The types of stigma sex workers experience from the general population, which included sex, gender, and HIV status.
- The underlying reasons women and men become sex workers, many of which are linked to poverty.
- Self-imposed barriers, which connect motivation to seek health services with self-stigma.
- Provider-imposed barriers, which translate to verbal and physical abuse, deterring sex workers from seeking health services.

Following an analysis of the data, the study proposes five policy options. Each option is based on the literature and the analysis of the data.

1. **Sex Workers as Stakeholders:** a network of sex worker organizations would be established between NGOs, other community-based organizations, and health providers. The network would engage various levels of government including policy makers by way of an executive board.
2. *mHealth* – Mobile Phone Counselling and Information Service: this program would connect sex workers to counsellors who would provide preventative health and information on available treatment options.

3. Peer Education: this policy option builds upon existing programs that are already in place by NGOs in Lilongwe. Peer educators would be sex workers connected to community health centres across the city. They would train their peers in preventative health measures.
4. Training of Health Care Workers: training would be incorporated into on-going professional development. Sessions would be run through the collaboration of government, NGOs and sex workers. All health care workers would be sensitized to the specific health needs of sex workers in order to create an environment more conducive to effective treatment.
5. Vouchers for Private Clinics: this program models other programs that have been successful with sex workers in other low-income countries. NGOs would distribute vouchers to sex workers who could use vouchers at private health clinics across the city.

An analysis of the policy options revealed that all but the voucher program should be implemented due to its high cost and administrative complexity. The study recommends that the government working group on sex work build on the status quo and implement the *mHealth* and Peer Education options in the short term and Training of Health Care Workers and Sex Workers as Stakeholders options in the long term. This action would improve the overall health of sex workers, their clients, and the population in general. Currently in Malawi, current events, optimal politics, and engaged stakeholders have created a strong opportunity for action to be taken to give sex workers better access to health services. Government should seize this chance and continue to build its reputation as a health leader in Southern Africa.

## **Dedication**

*To the participants and staff at Theatre for a Change, Malawi.*

*You set an example of humanity to which I aspire.*

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## Glossary of Acronyms

ABC	Alliance for Behaviour Change ( <i>TfaC Program</i> )
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral Drug
AU	African Union
CBO	Community Based Organization
CHRR	Centre for Human Rights and Rehabilitation ( <i>Malawian NGO</i> )
DHO	District Health Office
EQUINET	Regional Network on Equity in Health in Southern Africa ( <i>NGO</i> )
FPAM	Family Planning Association of Malawi ( <i>Malawian NGO</i> )
HIV	Human Immunodeficiency Virus
IDU	Intravenous Drug User
MANET+	Malawi Network of People Living with HIV/AIDS ( <i>Malawian NGO</i> )
MCP	Multiple Concurrent Partnerships
MHEN	Malawi Health Equity Network
MSF	Médecins Sans Frontières ( <i>International NGO</i> )
MSM	Men who have Sex with Men
NAC	National AIDS Commission [of Malawi]
NGO	Non-Governmental Organization
ODA	Official Development Assistance
PIH	Partners in Health ( <i>International NGO</i> )
PLHIV	Person Living with HIV
REACH	Research for Equity and Community Health Trust ( <i>Malawian NGO</i> )
SDH	Social Determinants of Health
STI	Sexually Transmitted Infection
SWEAT	Sex Worker Education and Advocacy Taskforce ( <i>South African NGO</i> )
TfaC	Theatre for a Change ( <i>British/Malawian NGO</i> )
UN	United Nations
UNAIDS	The Joint UN Programme on HIV and AIDS
UNFPA	UN Population Fund
YONECO	YouthNet Counselling Service ( <i>Malawian NGO</i> )

# **1: Background**

## **1.1 Introduction and Policy Problem**

Sex work is a high-risk occupation. Apart from the environmental hazards of soliciting sex, the sub-population is at risk for diseases that threaten their health. For sex workers worldwide, this translates into high rates of human immunodeficiency virus (HIV)<sup>1</sup> and other sexually transmitted infections (STIs) (Day & Ward, 1997). Without treatment, including prevention and intervention initiatives, these illnesses can negatively affect sex workers' long-term health outcomes and increase the risk that they will pass a range of infections on to their clients.

In the country of Malawi, sex work poses substantial health risks. The National AIDS Commission (NAC) (2009) recognizes sex workers as one of the nation's most vulnerable populations and a key group to target programs designed to encourage behaviour change, provide preventative resources (e.g. condoms), and ensure access to antiretroviral (ARV)<sup>2</sup> treatment. Sex workers in Malawi have an HIV prevalence rate of 70% (NAC, 2009): HIV prevention and treatment are vital for sex workers. However, the implementation of policies and programs for sex workers has been sparse. Apart from some increased access to ARV treatment, programs that target sex workers are provided mostly through the determination of non-governmental organizations (NGOs).

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<sup>1</sup> The human immunodeficiency virus (HIV) is the precursor to the acquired immunodeficiency syndrome (AIDS). AIDS is diagnosed when the viral load in the body exceeds a threshold, defined by health systems in each country.

<sup>2</sup> ARVs are the drugs used to slow the progression of HIV in the body. More than one ARV is generally taken concurrently and as such, the drugs are generally referred to in the plural.

The health of sex workers is not solely determined by their HIV status: sex workers have other health needs that require adequate access to preventative and treatment services. This acknowledgement is lacking in much of the services health services and care that should be available to sex workers (Kamtengei [int.], 2010). In addition, barriers exist that prevent sex workers from acquiring health care. These factors include underlying stigma, social factors, such as poverty – a strong driver for women and men to enter into sex work in Malawi (Ndovie [int.], 2010) – and lack of education (WHO, 2010b). When these barriers intersect, they lead to further proliferation of not only HIV, but also other STIs.

In Lilongwe, Malawi international NGOs provide measures to reduce these barriers. However, the NGOs do not have the capacity to ensure that sex workers can adequately access proper health services. Therefore, the policy problem addressed in this study is that sex workers in Lilongwe do not have enough access to health services to mitigate the effects of a high disease burden. In this problem statement, Lilongwe includes the urban areas of the capital city of Malawi. Health services refer to preventative and treatment services administered by health care workers at clinics, hospitals, and in the community within the public health system.

This research draws on the following UNAIDS definition of sex workers: “female, male and transgender adults and young people who receive money or goods in exchange for sexual services, either regularly or occasionally” (UNAIDS, 2002). Sex work does not include transactional sex (regular sex with the same partner undertaken for food or money) that is prevalent in some rural areas of Malawi (see section 1.4.2.2). This study will focus on adults specifically, although if appropriately adapted, some of the options may be applicable to youth. Sex workers are a priority for this research because they have the highest rates of HIV in the population, there are significant knowledge gaps in understanding their health experiences, and the health sector has not responded adequately to their needs.



The research uses a comprehensive definition of access from a UK study by Goddard and Smith (2001) examining equity and access to health. Goddard and Smith (2001) identify four elements that overall make for good access: availability (are the services available?), quality (is treatment appropriate?), costs (are there financial or other costs associated with care?), and information (is there health information and knowledge of services available?). They explain that if any of these components are not satisfied, it could potentially lead to the “inappropriate use of health care services,” “dissatisfaction [that could] deter compliance,” and ultimately poor health outcomes (Goddard & Smith, 2001, Section 1).

### **1.1.1 Study layout**

The background section (1.2) provides context for the research including a brief history of Malawi and the socio-political environment in which sex workers operate in Lilongwe. A theoretical framework (1.4) is then proposed and explored in the Malawian context to outline the barriers experienced by sex workers. The findings section (3.0) presents the evidence collected about these barriers and details the nuances that exist when sex workers try to access services. Next, the policy options section (4.0) outlines possible actions that can be taken based on the evidence collected. This is followed by an evaluation of the options (5.0) and recommendation for policy action (6.0). The study ends with some brief concluding remarks (7.0), which include some reflections on future research priorities in this policy area.

## **1.2 Context**

### **1.2.1 Malawi Geopolitics**

Malawi is a small, land-locked country in the heart of Southern Africa. It is bordered by Mozambique to the south, Tanzania to the north, and Zambia to the east. Most of the western border lies along the shores of Lake Malawi. The capital city, Lilongwe, is in the centre of the country (see Figure 1). Historically, under British rule, it evolved through different forms and

names. For most of the official colonial period (1891-1964) it was named Nyasaland but ten years before decolonization, it united with Rhodesia to form the Central African Federation (Brelsford, 1960). In 1965, Malawi declared its independence from Britain, following a trend of decolonization taking place in Africa at the time.

Although the people democratically elected its first government, the new Prime Minister, Dr. Hastings Banda, installed himself as permanent ruler. He governed the country with the Malawi Congress Party and the support of the country's élites for 30 years (Kaspin, 1995). The legacy of his autocratic rule was an increase in infrastructure, entrenchment of social conservatism, and focus on rural development, discouraging people from moving to cities. As of 2010, only 19% of the population live in urban areas, compared to a regional African average of 37% (WHO, 2010a).

Without the mass urban migration that other African countries experienced, there is now considerably less urban poverty and slums, like those found in Kampala, Uganda or Nairobi, Kenya (UN Stats, 2010).

Banda's dictatorship ended in 1994 and since then, Malawi has benefited from a reasonably well-functioning parliamentary democracy. This official national system is complemented by traditional authorities, which continue to be a respected component of the Malawian political identity. Although these leaders are found more often in rural areas, even Malawians who have immigrated to urban centres value their chief's opinions and decisions (Kaspin, 1995).

Figure 1 — Map of Malawi



Source: CIA, 2011

### **1.2.2 Socio-Economics of Malawi**

Malawi is one of the poorest countries in the world. With a population of just over 15 million, the GNI per capita (2009 US\$) is \$280 per annum (WHO, 2010a). Almost 50% of the population lives on \$2 per day (adjusted PPP) (WB, 2011). Similar to other countries in the area, while human development indicators – such as life expectancy, infant mortality, and primary school completion – are rising, relative to other developing countries, they generally remain low (UNDP, 2010b). Malawi is ranked 153 of 169 countries on the United Nations Development Program's (UNDP) Human Development Index (UNDP, 2010a).

One of the most far-reaching indicators is the literacy rate, which affects day-to-day life in Malawi. While 98% of the population has attended some primary school, challenges, such as large class sizes and additional school fees for uniforms and books, lead to high attrition and failure rates (WB, 2011). According to the UNDP (2010a), less than 7% of students attend high school. The result is low levels of educational attainment nationally, evidenced by the current adult literacy rate, which is 49% for females and 76% for males (UNDP, 2010a). As is well known in the literature, a lack of education and literacy has far reaching implications for health. Education is considered one of the most important components to determine a person's eventual health outcomes (WHO, 2010b). Those who are not equipped with education find it more difficult to respond to basic health concerns, as they do not have health-seeking behaviours usually learned in school, and cannot read and follow directions for public health improvements or on medicines (Kickbusch, 2001).

Beyond education, Malawi's status as a low-income country has implications for health-related policy development and implementation. In brief, the country faces many policy problems, such as food security, economic growth, lack of infrastructure, gender inequalities, and environmental biodiversity, to name a few (Mutharika, 2010). These problems can be challenging to prioritize and the country does not have adequate local resources to implement the policies

necessary to ensure the best outcomes for its citizens. As a result, health competes with numerous other important policy priorities.

To compensate for the financial shortages, Malawi relies on Official Development Assistance (ODA) from higher-income countries. In 2008, the nation received \$912-million in this type of aid (WB, 2011). There is literature that suggests that aid corrupts government in the long term and results in a loss of accountability to its citizens and reluctance to take important policy action (Moyo, 2009), however, in the short term, the reality of low-income countries is that financing implementation of social policy relies on external sources of revenue. In addition to ODA, funding is attained in the form of alternative government funding (non-official government to government transfers, such as PEPFAR<sup>3</sup>), large-scale private contributions (from organizations such as the Bill and Melinda Gates Foundation), or through implementing partners (NGOs that contribute to the government agenda by helping to implement) (Cohen, 2006). In all of its forms, this aid usually comes with so-called ‘strings attached’ requiring the government to spend it on certain projects. This often results in policy frameworks that meet the objectives of donors, when in reality these priorities may not line up with the actual needs of the country. Furthermore, in some cases, donors only fund the development of policy and not implementation, which results in good planning with no action.

In the context of health, having multi-sourced funding has specific implications for effective development and implementation of policy and services. It can be counterproductive to have a *mêlée* of official and non-state actors working independently towards the same objective, especially when each has a slightly separate agenda and desired outcome (Cohen, 2006). Often, there is little collaboration between these programs, leading to programmatic overlaps or conversely to the abandonment of geographic areas or specific populations. As some of these programs favour targeted approaches in which some societal groups are treated more favourably

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<sup>3</sup> President’s Emergency Plan for AIDS Relief (PEPFAR): the US Program set up by George W. Bush.

than others, some populations receive special attention, such as children or expectant mothers leaving out other populations, like sex workers (Lynch, 2009).

Despite these challenges, international aid has not been without its successes. One of the more successful global health interventions has been related to HIV and AIDS. This field has benefited from funding, since it has had strong political and celebrity advocates pushing the international community to recognize it as a pressing concern. This has led to numerous international, national, and local coordinating bodies that have worked to secure large-scale funding to implement effective programs (Merson, 2006). Evidence of the impact in Malawi of HIV funding is discussed in section 1.2.3.1. Targeting specific diseases, however, like funding certain populations, can ultimately come at the expense of funds directed to general health care (Ravishankar et al., 2009). In the end, this adds to inequities in health delivery in the public health care system to those people who do not suffer from HIV.

### **1.2.3 Health care in Malawi**

Health care provision in Malawi takes four forms: public, private, NGO-administered, and traditional. The public system provides and funds about 60% of all health services (WB, 2011): donors fund over two-thirds of that amount and the balance is from employer contributions and taxes (The Global Fund, 2008). Health care is administered by the Ministry of Health but decentralized into health districts across the country managed by District Health Offices (DHO). The Lilongwe DHO administers the health care within the Lilongwe city limits. The public system allows Malawians to access health centres and hospitals across the country without formal charges, provided they present a health passport.<sup>4</sup>

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<sup>4</sup> A health passport is similar to a health card. It contains a basic medical record and entitles the bearer to public treatment.

The private system operates on a business model, providing services for user fees. Private care accounts for approximately 2% of health services and used by wealthier citizens. The NGO sector administers the third segment of health delivery accounting for about 37%. This category includes faith-based institutions as well as those delivered by international and local NGOs. Even though separate from government, the DHOs have a mandate to monitor private and NGO-administered facilities to ensure standards of care for the practice of medicine in Malawi. Finally traditional medical practitioners contribute to the delivery of health. Although the Ministry of Health does not know how many traditional healers practice at a national level, these healers contribute to the overall health of Malawians. Traditional medicine is often used in conjunction with medical health services.

Structurally, in urban centres like Lilongwe, the health system is broken into primary and tertiary care. Primary care is delivered at the community level through clinics and small medical centres (Daire & Khalil, 2010). The three large central hospitals comprise the health system's tertiary facilities. In Lilongwe, Kamuzu Central Hospital is the only public tertiary institution. Unless the patient has an emergency, access to the health system is mediated through primary health providers at the local clinics; patients are not permitted to change clinics (Daire & Khalil, 2010). When required, primary health care workers (doctors, nurses, or clinicians) provide referrals to tertiary services at the central hospitals.

According to the Constitution of the Republic of Malawi, government has been given the broad task "to provide adequate health care, commensurate with the health needs of Malawian society and international standards of health care" (Malawi Constitution, Article 13(c)). Thus, this article lays the foundation for a universal health care system, providing health care for all Malawians. To demonstrate their commitment to the rights enshrined in the constitution, the government, in collaboration with the Malawi Health Equity Network (MHEN), produced the Malawian Patients' Rights Charter in 2003 (see Appendix D). The Charter outlines a progressive

list of rights each Malawian should have when accessing health services in Malawi. However, due to the lack of leadership required from the Ministry of Health to guide it through the legislative process, the implementation has all but ceased since the Charter's submission to parliament (London, 2007).

These rights are difficult to uphold because, not unlike other low-income countries, Malawi's health system is under constraint with shortages in human resources and infrastructure. In the standard measures of health human resources, Malawi's prevalence of physicians and nurses/midwives per 10,000 people are 0.2 and 2.8 respectively. This is nearly 12 times below the African average for physicians and 4 times below for nurses/midwives (WHO, 2010a). According to a study at the University of Malawi College of Medicine in 2006, the explanations for the shortages were: retirement of existing health professionals, mortality (many denote deaths due to HIV), and international migration to South Africa and other higher-income countries (Muula, 2006). This leaves Malawi with a dwindling supply of health care professionals. In terms of infrastructure, in 2008, there were 7.3 hospital beds per 10,000 people, which is very low (WB, 2011). Coupled with the human resource shortage, an inadequate quantity of facilities leaves Malawians waiting for treatment that ultimately can be insufficient.

### **1.2.3.1 Response to HIV**

Since 1985, HIV has added a considerable strain to Malawi's health system (UNAIDS, 2004). The virus has raged through lower-income countries such as Malawi; almost 95% of global HIV cases are found in the global South (TeachAIDS, 2010). In these countries, the epidemic of HIV is generalized throughout the population. In contrast, the HIV epidemic in high-income countries is concentrated, primarily affecting individuals who engage in high-risk behaviour, such as men who have sex with men (MSM), injection-drug users (IDU), and sex workers (UNICEF, 2008)..

Table 1 – HIV Prevalence by Age

	15-19	20-24	25-29	30+	Total
Females	3.7%	13.2%	15.5%	17.0%	13.3%
Males	0.4%	3.9%	9.8%	17.5%	10.2%

Source: NAC, 2009

In Malawi, HIV prevalence is 12% for people aged 15-49, see Table 1 (NAC, 2009). With one in eight people seropositive<sup>5</sup> for the virus, Malawi has struggled to standardize care and address the needs of a disease-burdened population. At the government level, NAC was established in 2001 to provide leadership and coordinate the Malawian HIV and AIDS response (NAC Malawi, 2011). NAC works with the Ministry of Health to integrate treatment schemes into a broader response. In 2005, Malawi entered a financial collaboration with the Global Fund to Fight AIDS, Tuberculosis, and Malaria, to introduce a free ARV program, providing life-saving drugs to patients diagnosed with AIDS. The program has proved successful in decreasing the rate of transmission decreasing prevalence of HIV from 15% in 2003 and is keeping people alive that would otherwise have died (The Global Fund, 2010). The ARV program was one of the first of its kind in Southern Africa making Malawi a forerunner in HIV and AIDS treatment.

Despite its huge successes, the program is not without its challenges. Based on rough estimates, there are one million Malawians who are living with HIV and of those more than 300 000 have cases that have progressed to AIDS<sup>6</sup> (MSF, 2009). As of 2010, only 198 000 people were receiving ARVs (The Global Fund, 2010): just under two-thirds of the population in need.

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<sup>5</sup> Serostatus is the biomedical term to describe being positive or negative for a disease; seropositive for HIV indicates that viral antibodies have been found in the patient's blood.

<sup>6</sup> In Malawi, AIDS is constituted by a CD4 count of less than 250.



## **1.2.4 Sex Work in Malawi**

### **1.2.4.1 History and Context**

Although sex work has probably existed in Malawi for some time, there was little documentation of the occupation until the advent of HIV and AIDS in 1985 (UNAIDS, 2004). In the early years of independent Malawi, sex work is suspected to have remained largely underground (Ndovie [int.], 2010). According to one source, it was considered even more taboo and inappropriate to discuss sex work in public than today. Due to restrictions, the news media did not allow itself to be used as a medium for open discourse or present a venue through which sex workers could make their voice heard publicly.

Sex work in Malawi is still generally undocumented. Moreover, while there are some HIV prevention projects that have been initiated by the government, but programs tend to be on a small scale and not well implemented (Chikaphupha, Nkhonjera, Namakhoma, & Loewenson, 2009). The literature is silent on much of the previous action taken by government pertaining to sex work in Malawi, presumably due to lack of research. However, one historic policy, designed to combat STIs before the onslaught of HIV has been acknowledged by several anecdotal sources at the Ministry of Gender and several NGOs (Ndovie [int.], 2010; Kamtengei [int.], 2010). According to these individuals, the Ministry of Health required proprietors of pubs and bars to enforce STI testing for sex workers who frequented their establishments. Sex workers would have to produce a doctor's certificate to the bar, which indicated their health status: those who were healthy would be allowed to continue to work, but if they were found to have contracted an STI, the owner had an obligation to prevent the sex worker from soliciting further. This policy forced sex work further underground as sex workers became apprehensive about accessing health care or refused to be tested.

#### **1.2.4.2 Status under the law**

Malawian law does not criminalize sex work outright, unlike the laws of many countries in southern Africa (UNAIDS, 2011a). The law draws a distinct line between an individual earning money from sex work, which is legal, and money earned through a sex worker by way of employment or bondage, which is illegal. As a result, the law prohibits, organized sex work, including the operation of brothels or the employment of pimps (Bureau of Democracy, Human Rights, and Labor, 2010). Although not officially illegal, sex workers operating independently are not free from harassment from the police. There are other sections of the law that, in practice, limit sex work and lead to *de facto* criminalization. For instance, sex workers are often arrested or fined under the pretence of the “rogue and vagabond” provision of the penal code, a vestige law left from the British colonial times (Majawa, 2002).

This uncertainty also has implications on public perception for sex workers in Malawi. Until recently, the media published under the assumption that sex work in Malawi is illegal (Ndovie [int.], 2010). However, a September 2010 article in *The Nyasa Times* was one of the first to clearly emphasize that sex work is legal with the connotation that this would not otherwise be known. This could indicate that a slow change in the understanding of sex work in Malawi is underway.

#### **1.2.4.3 HIV and Sex Work**

In terms of occupation, sex workers have the highest prevalence rate for HIV in Malawi. This is more than double the prevalence of the next highest occupation (see Table 2). As mentioned earlier, sex workers are identified by NAC as one of the country’s most vulnerable groups and in need of assured access to ARVs (NAC, 2009). As part of greater strategies to reduce the spread of HIV, sex workers have been the targets of some national education and prevention campaigns.

Table 2 — Rates of HIV by Occupation, top eight

Occupation	HIV Prevalence (%)
1. Female sex workers	70.7
2. Police Officers	
Male	23.7
Female	32.8
3. Primary school teachers	
Male	23.5
Female	22.1
4. Female border traders	23.2
5. Estate Workers	
Male	19.9
Female	17.5
6. Secondary School Teachers	
Male	17.4
Female	16.1
7. Fishermen	16.6
8. Truck Drivers	14.2

Source: NAC, 2009

### 1.3 Previous Research

Currently, there is little research encompassing both sex workers and access to health in Malawi. Malawian sex work research has concentrated on the uptake of preventative health measures for sex workers, including the use of condoms and various methods of behaviour change to slow the spread of HIV (Swidler & Watkins, 2007). Other research has explored the cultural practice of transactional sex in rural Malawi, described in section 1.4.2.2 (Walden, 1999; Forster, 2000). These studies are more explanatory in nature, focusing on the social impact of sex work in the population rather than the implications on the sex workers themselves.

There are two studies that have deviated from this trend. First is a study conducted by the Centre for Human Rights and Rehabilitation (CHRR) in 1998 on adolescents entering sex work in Mzuzu and Salima (cities in Malawi). The mixed-methods study examined push and pull issues that influence young people to become sex workers. The study provided recommendations to government to mitigate these factors, such as incentives to keep children in school and early sexual education. Second is a recently published study by the Regional Network on Equity in

Health in Southern Africa (EQUINET) and the Research for Equity and Community Health (REACH) Trust (2009) examining the interactions between sex workers in Area 25 (a district in Lilongwe) and the clinic in their community. The study revealed that the negative attitudes of health workers deterred many of the sex workers from accessing health services. Although a useful source for literature on the attitudes of health workers, the research only examines the health system as it relates to sex workers who are seropositive for HIV.

This study departs from the literature on sex work in Malawi and similar countries, which conflates sex work with HIV. The previous section has shown that many sex workers in Malawi are seropositive for HIV. However, there are a broader set of reasons sex workers would seek out health care services. This research will provide a comprehensive examination of the barriers to health faced by sex workers, which to date, remain largely overlooked.

## **1.4 Sex Workers' Barriers to Health Care Access: A Theoretical Framework**

A review of the literature on sex workers and health service access indicates that Malawi could follow similar trends to other low-income countries. Other studies have identified factors that limit the access of health services for sex workers such as stigma (Makoae et al., 2008), self-stigma (Tomura, 2009), and lack of equity in health delivery (Kalipeni, 2000; Novogrodsky, 2009). These factors can be broadly categorized as structural barriers or social barriers. These two 'meta' barriers thus comprise the theoretical framework for this study. This section describes the theory and its applicability to Malawi.

### **1.4.1 Structural**

In the literature, the structural component to health access is connected to the social determinants of health (SDH). SDH are those 'upstream' factors that influence the individual's health outcomes. As the literature on the social determinants of health shows, globally, poor

people generally have poor health outcomes (WHO, 2010b). Poor health outcomes, in turn, necessitate an increased reliance on the health care system. This can be challenging since the poor may not have the resources to travel to clinics, the time to wait for services creating a significant opportunity cost or the education to recognize the symptoms of disease (Kagee et al., 2010). Due to their socioeconomic standing, low literacy rates, and general lack of voice in government, they have little recourse of action for any negative experiences they encounter (Gwatkin, Bhuiya, & Victora, 2004). This can result in programs and services designed without attending to the needs of this population causing further suffering.

This kind of oppression is termed structural violence. Coined originally by Johan Galtung in the 1960s, it refers to the condition where a governmental institution or structure causes harm to people by limiting their access to basic needs (Galtung, 1969). The term has more recently been associated with Dr. Paul Farmer (Farmer, 2009). In many of his works, he describes situations where the poor attempt to access health, which is often hindered by barriers caused by the intrinsic structures embedded in the system. Farmer et al. (2006) point out that structural violence is closely linked with the social determinants of health and social injustice. In his experience, Farmer points out that people getting sick are most often at a disadvantage in terms of gender, geography, socioeconomic status, education, and race.

Since many sex workers in low-income countries enter sex work due to poverty, they are affected by structural violence (Scambler & Paoli, 2008). If low literacy rates are prevalent, sex workers' health literacy is also very low and can contribute to the absence of health-seeking behaviours (Rekart, 2006). This means that when they are feeling ill sex workers may not seek medical services. Therefore, it is not until symptoms become worse that they might obtain medical attention. This latter form of health intervention can end up taking more resources from an already strained system, since it requires more resources to bring the patient back to full health.

## **1.4.2 Social**

Stigma is a crosscutting theme impacting entrenched systems and structures as well as personal social relationships. While stigma could also be framed as a component of structural violence, in this research it is framed socially to capture the sex workers' personal clinical experiences. Sex workers experience a great deal of social stigma (Tomura, 2009). It influences how the public and, by extension, service providers perceive them. Stigma can manifest itself in discriminatory language, actions, and violence leading to social exclusion and isolation (Fick, 2005). Stigma not only affects how people treat sex workers, but also how sex workers see themselves. In Malawi, sex work is not the only factor that could be stigmatizing for the sex worker: they also could be subject to stigma related to sex, gender, and HIV and AIDS (Fick, 2005). Following an examination of stigma, the subsequent sections propose each of these as a further source of stigma in the Malawian context.

### **1.4.2.1 Stigma**

Psychologist Erving Goffman (1963) explains that people stigmatize when “something unusual or bad about the moral status of the signifier [the stigmatized person]” is identified. This identification renders the stigmatized person sub-human, giving licence to discriminate. Further, stigmatization can lead to stereotyping, when members of the same population are characterized in the same way. For sex workers, stigma leaves them stereotyped as undesirable, dangerous, and to be avoided (Tomura, 2009).

According to the literature, the very use of the word prostitute or sex worker conjures images of bad practice and behaviour among individuals, usually female (Falk, 2001). In her research, Tomura (2009) traces the origins of the word, which itself carries is the source of intrinsic stigma. The definition implies that sex workers are members of a profession that is “sexually, morally, and socially inappropriate and not worthy of human dignity” (Tomura, 2009).

Although English has not been spoken in Malawi until recently, *hule*, the word for sex worker in the Malawian language Chichewa, carries with it similar associations (Ndovie [int.], 2010).

Falk (2001) points out that with the associations with poor morality, sex work creates a ‘negative audience’, of which sex workers themselves are a part. This is self-stigma. Wilkinson (2005) indicates that self-stigma can lead to self-despoliation and ambivalence about their health choices, leading to poor health outcomes. Self-stigma not only affects physical health, but mental health as well. There is a certain amount of stress associated with ‘giving yourself away,’ which can translate into increase psychological trauma (Goffman, 1963). This is particularly applicable to sex workers in a health setting as it may be more challenging to hide in relative to other settings.

#### **1.4.2.2 Sex**

In Malawi, sex is a source of stigma in itself. The literature reveals that there are three competing streams that influence the Malawian perceptions of sex: religion, traditional practices, and normalized promiscuity. The three overlap to make stigma related to sex complex to decode. To start with, the prevalent conservative form of Christianity can partially explain this stigma. Malawi is 80% Christian, one-quarter of which is Catholic reference. The literature identifies the church as the bearer of the moral framework in Malawi, identifying not only what should not be possible, but should not be conceivable (Englund, 2000). As people feel compelled to comply with beliefs that condone premarital and extramarital sex, the sex that sex workers engage in is viewed as outside the tolerable moral realm. Malawian culture strengthens these interpretations as it is rooted in ideas of individual privacy and modesty. Cultural norms dictate that sex should be taboo, inappropriate for open discussion, especially if it is sex outside of marriage (One Love, 2008). This reinforces a “culture of silence”, restricting flows of information about safe sex and limits acceptance for those who participate in sex outside marriage, such as sex workers (TfaC, Kachingwe, & Chidalengwa, 2009).

Contrary to these religious and cultural beliefs, Malawians do engage in extramarital sex. Muula and Mfutso-Bengoare (2004) identify that there are cultural practices and traditions that are carried out throughout the country that promote non-monogamous sex between men and women who are not married to each other. Practices include sexual initiation rites for boys and girls (*kuchotsa fumbi*), use of a surrogate male to produce children (*fisi*), wife swapping (*chimwana maye*), funeral sexual cleansing (*kupita kufa*), and wife inheritance (*chokolo*). They are common throughout the country and entrenched in Malawian tradition. These practices are coupled with beliefs that specify unless they are performed, bad fortune will come to the family. Muula and Mfutso-Bengoare note that there have been attempts to eradicate these practices, by and large because they put people at risk for HIV, but these attempts have generally failed.

In addition to traditional forms of extramarital sex, Malawian social culture accepts multiple, concurrent partnerships (MCP). UNAIDS identifies that it is not uncommon to find men and women in Southern Africa having more than one sexual partner, overlapping for months or years at a time (UNAIDS, 2011b). Societal norms are such that men, and women to a lesser extent, may participate in MCP (One Love, 2008). The literature indicates that although MCP may be accepted socially, sex workers are seen as different and still subject to stigma.

Finally, similar to many other countries in the region, some Malawians engage in normalized transactional sex (Poulin, 2007). Unlike the Euro-American framing of transactional sex as prostitution, the cultural context in Malawi allows for courtship and money to be conventionally entwined. Forester (2000) identifies that these kinds of relationships preclude an exchange of money or other goods for sex but are different from commercial sex work because the relationship is with the same partner and does not include solicitation.

Contradicting attitudes about sex have clear implications for sex workers. While multiple partners may be conventionally tolerated, this type of practice conflicts with factors that



encourage monogamy, such as religion. The disjuncture between the two cultural standards can leave sex workers caught in a moral limbo and subject to blame and stigma.

### **1.4.2.3 Gender**

Gender further contributes to the other forms of stigma sex workers experience. In Southern Africa, there is pervasive gender inequality that affects the way in which people access health care. Women in particular face barriers due to higher rates of poverty, socially ascribed responsibility for house work and child rearing, restricted mobility, and economic dependence on men (Kagee et al., 2010). Being female in the region also has an impact on a diminished social location, status, and hierarchy, which can make negotiating safe sexual practices challenging (Baylies & Bujra, 2000). Moreover, biologically, women are at higher risk for HIV and other STIs (Baylies & Bujra, 2000). In many cases, by engaging in sex work, women challenge societal norms that would stipulate that they be passive, innocent, and submissive (UNFPA, 2004). This can further marginalize and stigmatize female sex workers and can make them vulnerable to gender-based violence (Andersson, Cockcroft, & Shea, 2008).

Men, on the other hand, have different barriers that can both impact poor health outcomes and lead to additional stigma. The literature identifies that men in Southern Africa face issues of emasculation when accessing health services as illness is sometimes construed as a form of weakness (Kagee et al., 2010). This can cause delays in treatment and worsen health outcomes. Specifically related to male sex workers, however, stigma can be expressed through negative public perception. As a recent article in Malawi's news media suggests, until recently, the public has not been aware of male sex workers and that when they are, they are socially rejected (Munthali, 2010). This could manifest itself in stigma towards male sex workers in Malawi.

#### **1.4.2.4 HIV and AIDS**

Stigma related to HIV is a global phenomenon. Stigmatizing perceptions of HIV in Malawi and Southern Africa are linked to the myths about the modes of transmission, a lack of understanding of the disease, and the lack of access to appropriate treatment (Rankin, Brennan, Schell, Laviwa, & Rankin, 2005). People living with HIV (PLHIVs) have experienced disease-related stigma since the virus first became prevalent in the region. Recently, while there has been a shift in public perception, especially since ARVs have become widely available in Malawi and other countries, discrimination still exists for people who are positive for HIV (Kohi et al., 2006). For many people, HIV is still viewed through the lens of blame: people who are HIV positive are seen as having done something wrong and as a consequence, have contracted the virus.

### **1.5 The Opportunity for Change**

Currently in Malawi, there is opportunity to instigate structural and cultural change through the favourable confluence of social and political factors. This creates a policy window that decision makers should take advantage of to allow sex workers better access to health. The following section details these important factors at play.

#### **1.5.1 Current Events**

In 2010, several events transpired that allowed for a more open dialogue about sex and sex workers to take place. First, in late 2009, breaking with legal, social and cultural norms, two men held an engagement party in Blantyre (Malawi's largest city) (BBC News, 2009). They were arrested and held in custody until they were put to trial in May 2010. Both men were sentenced to fourteen years of hard labour. After being in jail for only two weeks, however, they received a full presidential pardon following international pressure coinciding with a visit from the United Nations Secretary General, Ban Ki-Moon (Lesser, 2010). While there is not a direct link between this news story and sex workers, it opened a dialogue in public discussion and in the news media

in Malawi about the rights of persons in the country who are unfairly labelled as ‘sexual deviants’.

During the same time, the government of Malawi was devising a bill, which among other things would criminalize the spread of HIV (BBC News, 2010). The policy included provision for mandatory testing for sex workers, housekeepers, pregnant women and their husbands, similar to the historic sex worker policy described earlier, in the name of public health. The draft of the bill was only circulated internally and to a few key stakeholders for critical review. However, the local media reported that government officials were on record saying that by “making the transmission of HIV/AIDS a criminal offence would help in preventing new HIV/AIDS infections and thereby slow down the progress of the AIDS epidemic” (Nyasa Times, 2010).

Both these events induced a flurry of media discussion and mobilization of forces supporting or opposing the issues. The Malawian news media ran numerous stories following this case and the public engaged in discussions about how homosexuals and sex workers fit into the social makeup of Malawi. While the media was of the opinion that Malawi was not ready to engage in talks about legalizing sex work, it became clear that literate Malawians who read and interacted with the newspaper were gaining a better grasp and slightly more positive attitude on the issues surrounding sex work (Munthali, 2010). While the public may not accept broad policy changes, incrementally introducing policy on sex work could be possible while the public is still considering their stance on sexual minorities.

### **1.5.2 Optimal Politics**

Presently in Malawi there are two political conditions that make it an optimal time to introduce policy change on sex work. First, is that the current party in power holds a sizable majority in the legislature (CIA, 2011). Policy changes on controversial issues such as sex work

require new, often controversial, legislation. With the political will, a majority government could allow for any necessary legislation to be passed more easily into law.

Second, the government has shown increasing and positive interest in sex workers. A working group has been established to devise a health and social strategy for sex workers, which includes the Ministries of Gender and Health with the input of the UN Population Fund (UNFPA) and the Joint UN Programme on HIV/AIDS (UNAIDS) (Kamtengei [int.], 2010). The strategy is based on the UN's five thematic areas for sex work: laws, clients, provision of economic alternatives, gender, and human rights (MoH [int.], 2010). This direction shows that government recognizes the necessity of a comprehensive approach to sex work. Although this group has been working for two years, there has been little subsequent action and no implementation of these programs. The opportunity is present to provide direction for this group to address the specific health needs of sex workers in Malawi. If programs that include health as its foundation are established, other effective programming could be built around them.

### **1.5.3 Engaged Stakeholders**

There are NGOs in Lilongwe that are already doing extensive work with sex workers. However, each NGO has only a targeted area in which they work. Because they do not reach every sex worker in Lilongwe, many sex workers have no formal support systems in place. Due to the limitations of government resources, NGOs have come to play a principle role in the organization and service delivery of some social services in Malawi. It is important to consider that NGOs have and will continue to play an important role in providing education, service, and networking for sex workers. They bring first-hand experience in working with sex workers and have build trust with them. These NGOs are therefore essential to developing any effective large-scale service delivery programming. Below are the key stakeholders in Lilongwe that are involved with sex work. For any policy change, it will be integral to guarantee their support and participation.

### **1.5.3.1 Theatre for a Change**

Theatre for a Change (TfaC) uses interactive theatre techniques and experiential learning to provide participants with the knowledge, attitudes, and behaviours to protect themselves from HIV infection and become advocates for their gender and sexual rights (TfaC, 2011). TfaC engages sex workers through the Alliance for Behaviour Change (ABC) Program. The program operates near Mchesi (an area in Lilongwe), where many of the participants are from Mchesi, although there are other participants recruited from Kawale and Biwi as well. Facilitators, who are former sex workers, recruit participants and explore with them knowledge, attitudes, and behaviour change specifically related to the spread of HIV. After the training, some of these women and men become facilitators themselves.

TfaC has been involved at the political level as well. In a recent program, the “Legislative Theatre Project,” sex workers performed interactive theatre for decision and policy makers in Lilongwe depicting and portraying some of the challenges they face on a regular basis. The objective of the project is to compel these decision makers to consider sex workers when making policy. TfaC has also been involved in advocacy. In March 2010, the organization planned a ‘Big March’ of sex workers to demand rights and express their opposition for the proposed HIV Bill. The march progressed through Lilongwe and terminated at the Ministry of Gender building on Capital Hill.

### **1.5.3.2 Other Organizations**

There are two other major organizations in Lilongwe that provide services and support for sex workers. The Family Planning Association of Malawi (FPAM) has a mission to deliver sexual reproductive health and protection of reproductive rights for Malawians (FPAM, 2010). Specifically, the organization works with young people and sex workers. FPAM has been a leader in peer education in southern Lilongwe and has been involved with the provision of targeted health services for sex workers. The Centre for the Development of People (CEDEP) is a human

rights organization with the mission to improve the lives of ‘neglected minorities’ in Malawi (CEDEP, 2010). CEDEP runs a program for peer education of sex workers and MSM in Lilongwe. The organization also engages in research about these neglected minorities.

## **2: Methodology**

The methodology of this study was designed to examine the following research question: what are the barriers for sex workers to access health care in Lilongwe? The methods in this study were chosen to uncover and understand these barriers in the urban Malawian context. The urban population was examined due to its feasibility in a short research timescale and due to the identification of best practices established by NGOs in urban areas. Following this study, further research should explore sex workers elsewhere in Malawi. The previous section illustrated that there are research gaps in how barriers to health are realized in Malawi and Southern Africa. The literature indicates that barriers are multidimensional, intersectoral, and under the purview of more than one department of government. Thus, the data in this study was gathered not only from sex workers, but also from NGOs that work with sex workers, government officials who are connected to the policy-making process, and UN agencies that both collaborate on program delivery and advise policy-makers.

Purposefully, each stakeholder contributed differently to the research. Sex workers provided valuable insights into their experiences. Through their perspective, a better understanding was reached about first-hand health care access. The NGOs provided additional insight to the interviews from sex workers, corroborating the results and contributing a generalized perspective on issues of access. NGOs that deal with analogous issues, such as PLHIVs were included to better ascertain best practices and common challenges. Through the government interviews, further information was obtained on sex work under the law. These interviews were also used to ascertain government interventions and the general attitude of government representatives on sex work. Finally, the UN agency representatives were consulted

about their opinions on the actions of the Malawian government as well as benefit from their broad, international perspectives.

## **2.1 Data Collection**

Data was collected for this study in two ways. First, qualitative data was obtained from Theatre for a Change (TfaC). The data consisted of interviews with sex workers (17%  $n=5$ ), focus groups with sex workers (7 %  $n=2$ ), and interviews with other stakeholders (59%  $n=17$ ). A TfaC volunteer conducted the interviews and focus groups in the language of Chichewa and a TfaC intern completed the interviews with other stakeholders in English. A secondary data analysis was performed on this data. Primary data was gathered from additional interviews with sex workers in the same sample (7 %  $n=2$ ) and other stakeholders (10%  $n=3$ ) in a similar style to the previously collected data.

In total, there were two focus groups (7%), seven interviews with sex workers (24%), and twenty interviews with other stakeholders (69%). Other stakeholders included (see Appendix A for complete list):

- NGOs working with sex workers (15%  $n=3$ )
- other NGOs (5%  $n=1$ )
- public health system (25%  $n=5$ )
- human rights-based organizations (10%  $n=2$ )
- PLHIV organizations (10%  $n=2$ )
- government (25%  $n=5$ ), and
- UN agencies (10%  $n=2$ ).

## **2.2 Sample and Location**

### **2.2.1 Sex Workers**

The sex workers in both the primary and secondary data were drawn from participants in TfaC's ABC program. Interview participants were former sex workers who are now facilitators at



TfaC. They had worked for varying periods of time with the organization (to a maximum of two years) and therefore their exposure to the TfaC methodology and instruction varied. Interview and focus group participants were selected at random from the attendance list, which included both female and male participants. Those who participated in the first focus group were not invited to participate in the second to diversify the responses and to reduce influence from the previous group. All the interviews and focus groups were conducted and recorded by the same interviewer in a secluded area of the program centre at TfaC, to ensure privacy, and lasted from thirty minutes to one hour. Most of the sex workers were unable to speak English and had low literacy skills.

### **2.2.2 Other Informants**

The other key informants in this study were drawn from organizations in the international, governmental, or civil community. TfaC identified stakeholders initially as agents contributing to the landscape of sex work in Lilongwe. Subsequent interviewees were found through ‘snowball recruitment’, further research, and personal networking. Each of the stakeholders was linked to either sex workers, the health sector, and/or to HIV and AIDS.

Most of the stakeholders worked in the Lilongwe area. While many were Malawian, the interviewees in the international NGOs and in UN organizations were, for the most part, expatriots. Interviews generally lasted one hour, most were recorded, and where possible, were held at the interviewees’ place of work. There were some exceptions for stakeholders who did not have an office or the researcher was unable to meet with in person. In these cases, a quiet area was found or the interview took place over the phone. All the key informants spoke English.

## **2.3 Research Tools**

### **2.3.1 Sex Worker Interviews and Focus Groups**

The focus groups were designed to obtain information about the attitudes of the broader population of sex workers. They were held prior to any of the interviews. The interviews were

performed in a semi-structured or conversational style. In TfaC's monitoring and evaluation, they have found that semi-structured interviews give respondents the opportunity to have a broader conversational dialogue with the interviewer. Many of the participants had limited experience with interviews and this style reduced some of the formalities caused by a highly structured style (TfaC, Kachingwe, & Chidalengwa, 2009). The interviewer used a set of standard probe questions but then would ask follow-up questions based on the respondent's answer. The interview schedule was based on the literature, previous program evaluation exercises conducted by TfaC (TfaC, Kachingwe, & Chidalengwa, 2009), and on the results obtained during the focus groups. The questions focused on understanding of health, identifying the attitudes that prevent them from adopting health-seeking behaviours, personal experiences in accessing services, stigma of health workers, and other barriers encountered when interacting with the health system (see Appendix B). Both the primary and secondary data collection used the same interview schedule.

### **2.3.2 Other Interviews**

The interviews with the other key informants served a dual purpose: first to collect information about the organization and second, to collect data on the topic of health for sex workers, to identify structural and attitudinal barriers. Depending on the organization, the interviewees were asked different context questions (see Appendix C). The primary and secondary data collection used similar interview schedules.

## **2.4 Limitations**

There are several aspects of his research that limit the data. . The major limitations include the sample bias, inconsistencies in interview locations, complications with the instrument, and the interpretation of the data by the investigator. There were attempts to mitigate the impact of these limitations, but they are present and could have affected the overall analysis.

### **2.4.1 Self Selection**

Overs (2002) points out in her analysis of research on sex work that “sampling [...] is often biased and non-random.” In this study, while subjects were chosen randomly, the sample was already biased and not representative of sex workers across Lilongwe. Since all of the sex workers were members of the TfaC program, there was a significant selection bias in the sample. The participants have already self-selected to become members of the program and therefore could be more proactive about their personal well-being. Furthermore, since the TfaC curriculum instructs sex workers about human rights and builds a support community for them, the lens through which they reflect on their experiences in accessing health care could be altered from when they were practicing sex work. This limitation was mitigated by asking sex workers about their experiences when they were working and by asking NGOs to recount experiences of other sex workers.

### **2.4.2 Location**

For the sex workers, the location of the interviews was uniform and therefore consistent. Other interviews, however, were not consistently held in a specific location. This could have influenced how the informant answered each answer, especially if they were uncomfortable with the location and concerned with who might be listening. To mitigate this limitation, private interview locations were found at the digression of the interviewee.

### **2.4.3 Instrument**

The instrument used to capture the data could have been a source of error. Since many of the sex workers had little education, they were not exposed to research or the research process, which was implicitly understood by the interviewers, who had a Euro-American education (Moravcsik, 1964). Many had never been interviewed before. This could mean that they were nervous or did not give accurate or complete information since they were asked to artificially

recall experiences. Furthermore, they could have been intimidated by the presence of a voice recorder. These factors could have impacted the openness of the views expressed by sex workers or the detail in which they described their experiences. There was an attempt to address this limitation by using a semi-structured interview style, more like a conversation, to make the interviewee at ease.

With the other key informants, the instrument could have been perceived as a criticism of the organization the interviewee represented, especially in the case of government. To mitigate these concerns, the interview schedule was structured to begin with general, factual questions leading to neutrally worded opinion questions.

#### **2.4.4 Interpretation by a Canadian Researcher**

The interpretation of the data by the principal investigator could be a further limitation to this research. First, nuances may have been lost in the translated transcripts. Not all words and phrases translate easily to other languages as connotation shifts and words take on different meaning. In the a study on translation in nursing, Twinn (1996) explains that the accuracy and authenticity of translated data depends on the translator's knowledge of both languages. The translator for this study was a Malawian who was completely fluent in English and Chichewa. Her intrinsic knowledge of Malawian language and culture helped to mitigate the potential pitfalls of translation in this research project.

Interpretation could have also been affected by a different value system. The values that persist in a Euro-American context are not necessarily shared with Malawians, which could cause misinterpretation in priorities. Furthermore, due to the limited time spent exposed to Malawian culture, the interpretation could have missed references or implicit norms to which the interviewees referred. These issues were addressed in part by further researching Malawi and Malawian institutions, culture, and people and by sharing ideas with the TfaC staff.

### **3: Data Findings and Analysis**

After collecting the data and reading the transcripts several times, a thematic analysis was undertaken.. In each transcript, themes were coded then combined into a master document. When categorized on a broad level they matched the predicted results: sex workers have reduced access to health services through prevailing health system structures and through culture and societal challenges. The findings resonated with the theoretical framework outlined in previous sections, which is grounded in research globally on sex work and health care. Sex workers and other stakeholders described the nuances of each of these barriers, identifying where the barrier was common to many Malawians and distinguishing where it was unique to sex workers. This section examines and deconstructs each of these principal barriers to identify the key issues within each.

In general, sex workers, or those who work with sex workers regularly, identified similar challenges and causes to reduced access. They concurred that with more health needs than the average Malawian, services should be altered to cater more to sex workers. Overall, there tended to be unified and overlapping responses from these two groups.

On the other hand, representatives from government were varied in their responses and attitudes towards sex work. Those who were connected in some way to TfaC answered the questions with a similar attitude as the NGOs, easily recognizing the challenges sex workers face. The government officials not connected with TfaC, however, earnestly defended the systems in which they work and trivialized the problem of access for sex workers. These officials tended to be at a higher rank. The Ministry of Gender representative explained: “those that are supposed to assist become a bit defensive, so you may not get the support you want to get. Even high-level officials...they are so much on the defensive part rather than seeing how they can help change the environment.”

The human rights associations framed the problem of access to health as an issue of the human right to health. This diverged from other organizations, which approached the problem in terms of health risk to the sex workers and the clients. With the HIV bill fresh in their minds at the time of the interview, the human rights organizations called for sex workers as a group to take collective action against the bill's inequitable provisions.

Finally, the medical respondents condemned their peers for creating a stigmatizing environment for sex workers. All the health care workers interviewed understood the issues around sex work. As they were closest to the health system, they could describe the problems that existed in detail. They also provided valuable insights into possible solutions to the status quo. The exception to this trend was the District Health Officer, a doctor-turned-bureaucrat, whose answers were similar to the high-ranking government officials. As is evident here, but was clear in all the interviews, when interviewees had past experience with sex workers their responses were closer to the responses of the sex workers, indicating that interactions lead to better understanding of the situation of the sex worker population. .

### **3.1 Structural Framework**

The prevalent structural framework of the health system, laws, policies, and social institutions shapes how sex workers access health services in Malawi. The framework further mediates how NGOs, community organizations, and UN agencies must work in Malawi. This section outlines the ways in which stakeholders perceive existing structures affecting sex workers' interaction with health services.

#### **3.1.1 Current Climate in Government**

Many of the informants, who were not sex workers, maintained that the government has taken some role in addressing sex work. For example, the Malawi Health Equity Network (MHEN) spokesperson explained, "it's been a deliberate attempt by government to make sure that

these people are not left out by virtue of having several sexual partners and they are one of the groups that is very vulnerable.” However, one of the former sex workers countered such an assertion by stating that, “I’ve never heard of any campaigns done by government to reach out to sex workers.” Other sex workers echoed this sentiment. The representative from Partners in Health (PIH) indicated that he is consistently surprised that the government, and particularly NAC, shows little interest in implementing sex worker-related programming.

There was some confusion about whether sex work was legal in Malawi. The representatives from many of the NGOs seemed to be clear about the legal status of sex work, however, in some instances, some government employees were unsure. The representatives from NAC cited that the legal status of sex workers acts as a barrier to provide appropriate programming. The YONECO representative explained that because the legal framework is not widely known, it means that adequate services are not provided nor sought after.

Many respondents emphasized a need for a more deliberate shift in policy and government action toward sex workers with a targeted, programmatic approach. They indicated, however, that without appropriate data about the prevalence of sex work, their disease burden, and other concurrent issues they face, there is little hope for change. The representative from UNAIDS supported this in saying:

We don’t have, for example, the population size estimations for sex workers, we don’t have a national study on HIV-sero prevalence among sex workers, we have some projections, some data, but what commonly people say here is that, like all the countries in the region, people engage in sex work for economic reasons; poverty. Poverty is the major factor, as of lately, poverty is the most fully reason for engagement in sex work. But we must define it exactly. Maybe it’s another discussion.

Other stakeholders emphasized that the problem is not the policy but the lack of policy implementation. The MHEN representative recognized that, “we are one country that has lots of beautiful policies but I think our enforcement mechanism [is weak].” She went on to say that

because government is dependant on donors foreign governments dictate how money is spent: they would rather fund policy formation rather than implementation.

Some respondents pointed to effective organizations, such as TfaC, as a model for how to have a positive impact in the lives of sex workers. They explained that these organizations were reaching out to sex workers and through education and behaviour change, were giving them the tools to better maintain their health. One former sex worker expressed that TfaC, “changed my life and prevented me from [acquiring] things like HIV.” Most sex workers felt that programs like TfaC should be broader in geographical scope. The DHO nurse agreed, mentioning, “the challenge is TfaC is not reaching out to a lot of lives. [...] I feel if the program could be scaled up so that a lot of people could be reached, that could assist [with realizing large-scale behaviour change].”

Finally, the NGOs, UN agencies, and human rights organizations indicated that to address health access for sex workers, the government should emphasize the intersection between human rights and public health. They indicated that until now, the government has taken an approach to sex work, especially in HIV policy, to protect the public from diseases passed from sex worker to client. The YouthNet Counselling Service (YONECO) representative indicated that government officials know about the human rights approach but have yet to create policy that merge it to the existing strategy. The Ministry of Gender agent demonstrated this division: “there’s a debate from the HIV perspective as to whether it should go in the Ministry of Gender or should go in the Ministry of Health as a public health issue, so that debate has not been resolved, or maybe it will be a joint between the two ministries, but the idea is that we don’t create a conflict among ourselves.” This representative, as well as those from the UN agencies and the Ministry of Health, referenced the work plan for developing intersectoral action to address the specific needs of sex workers. The plan includes laws, clients, provision for economic



alternatives, gender, and human rights. They indicated, however, that this is not a solution but a worthwhile starting point.

### **3.1.1.1 HIV Bill**

Most of the informants referred to the draft HIV bill as an indicator of the government's attitude toward HIV and sex work. Overall, most concurred that some components of the bill formally address issues that until now have not been in the government HIV discourse. Many were pleased that it includes a greater provision of rights for PLHIVs and assures better-integrated responses to HIV responses; although the details are unclear, a central feature of the bill is that it requires breaking down department silos and working interdepartmentally.

Most stakeholders, however, agreed that provision under the bill for mandatory testing of specific populations is problematic for sex workers. The UN and NGO representatives were certain that mandatory testing would push sex work further underground, which according to the YONECO representative would mean that “they don't access services, they can't use condoms, and it becomes more dangerous.” The UNAIDS agent concurred arguing that “mandatory testing would be exceptionally detrimental to sex workers...criminalizing of [any] PLHIVs is unacceptable.”

Representatives from human rights organizations emphasized that mandatory testing infringes on a person's basic rights. They argued that under this policy, “many groups will be victimized” and could induce a “witch hunt” for sex workers, perceived to be spreading HIV. This would set up even more explicit social hierarchies between sex workers and non-sex workers. If a sex worker decided not to disclose her or his status, the law would demonise them and take away their means to make an income. The respondent from the Centre for Human Rights and Rehabilitation (CHRR) indicated, speaking from the perspective of a sex worker, “I want to be part and parcel to national affairs...as a human being whether I am HIV-positive or not, but I

don't want to be discriminated and I don't want to be sacrificed.” The NGOs and human rights organizations felt that any progress that has been made to this point will become meaningless if this bill were passed.

Those stakeholders with an international perspective pointed out that the move towards criminalizing the transmission of HIV and mandatory testing are not phenomena unique to Malawi. Other countries such as South Africa have also moved in this direction; Botswana already has mandatory testing (Mail Foreign Service, 2009). The representative from the UN Population Fund (UNFPA) stated that, “in as far as [the] bill is concerned, these are areas of concern and from evidence [in other UN jurisdictions], it doesn't work.” These stakeholders explained that because the region follows the policy direction of South Africa, if that country did not implement a mandatory testing policy, it could influence other countries in the region to do the same. The stakeholders who consulted with the government on the bill indicated that the drafters felt that mandatory testing is a response to the wishes of the general population rather than based on research evidence. The representative from UNAIDS reported that at some meetings with government, the officials repeatedly say that, “it's not us, the government, but it's the people [who want mandatory testing].” Of the stakeholders that were interviewed, none of the ones that work directly with sex workers were consulted during the drafting of the bill. This indicates that the government may not have comprehensively assessed the impact the bill could have on sex workers.

### **3.1.2 Health Provision and Programming**

Whereas government attitudes and action influence how policy and programs respond to sex work, the delivery of the services also influences how sex workers access health. Health provision in Malawi is divided into public and private care. This section examines some of the direct structural challenges faced by sex workers when accessing the public health system. It also includes the alternatives they use and their experiences with ART.

### **3.1.2.1 Capacity of the public health system**

All respondents, including those from the Ministry of Health, indicated that the public health system lacks capacity to address the needs of the Malawian population. The representative from the HIV Unit of the Ministry of Health plainly stated, “we don’t have enough capacity to meet the demands of patients.” He indicated that this was both in terms of human resources and infrastructure. Many stakeholders gave examples to support the fact that the health system is neither uniform nor equally accessible. The Ministry of Health representative continued, “[Malawians are] supposed to access those services for free without any discrimination or favour. But there is inequity.” He referenced the disparities between the public and private system, producing inequality in terms of resources and also that some groups have reduced access, like those in rural Malawi who face the challenge of distance to health centres.

The informants identified that several factors contribute to limited system capacity. Most often, they indicated that geographical access to clinics and hospitals impeded the provision of adequate health care. They cited that the Ministry of Health is supposed to provide clinics every ten kilometres, especially in urban areas, which is a very long distance when transportation is not readily available. A nurse, whose job required her to travel between clinics explained, “[a] big challenge is the distance; in the whole of Lilongwe district [...] almost each and every facility is far from the others, about 10km or more.” The representative from the HIV unit indicated that he was aware of the challenges explaining, “some people will travel longer distances to get the service and sometimes during the rainy season some of the roads may be impassable.”

Some respondents reported that even though clinics may be within a reasonable distance to the patient’s home, it might be responsible for too many people with not enough health workers. This causes long queues, requiring some people to wait all day for service. One former sex worker said that after waiting for much of the day, “sometimes I would return home without receiving help at all.” While this may be common to other Malawians, the social challenges

outlined in the next section would make waiting for services difficult. Also, opening times for clinics can pose an issue with respect to when sex workers are available. There were different interpretations of this theme. Some stakeholders pointed to the fact that care is available at all times in certain locations, others mentioned that sex workers' schedules do not coincide with the opening hours of regular clinics. One nurse explained "you know sex workers are always out in the night, and during the day, it is their time to rest."

In addition to the physical locations of the clinics that serve Lilongwe, many of the respondents revealed that not all clinics are equipped to provide appropriate treatment and care. When a service is not available, the patient is referred to another clinic or the central hospital. Extra travel results in both monetary and opportunity costs for the patient. Some government officials, including the District Health Officer, did not seem to be aware of the burden this caused. According to him, "the facilities have the required initial basic medication to assist." The representative from the HIV unit concurred, stating, "for the STI program, each and every health centre does offer services, for HTC<sup>7</sup>, each and every health facility offers HTC." Sex workers, NGOs, and UN agencies did not concur, suggesting that it might be the intention of the government to provide these services, but it is not the reality. The agent for the Malawi Network of People Living with HIV (MANET+) said directly that in their experience, not all health facilities have the capacity to deal with HIV.

Finally, many of the sex workers expressed frustration with the method of accessing the health system. Since they have to go through their community clinics first, sometimes they have to go back and forth between facilities, which is an expensive venture. One said, "in our community there's a community clinic, when we go there they refer us to the central hospital and when we go to the central hospital we are sent back and told that we should go to the community clinic."

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<sup>7</sup> HIV testing and counseling (HTC)

An economic analysis of the evidence from this section reveals that there are costs, monetary and otherwise, the structure of the system forces the patient to incur. First, there can be a high monetary cost associated with going for treatment. The patient may require transportation and food while waiting. Second, there are opportunity costs that impede patients from going to the clinic. For sex workers, these could include household work, childcare, sleep, or secondary employment. As long distances and lines are time consuming, these costs are high.

Coupled with these high economic costs is a absence of health literacy. An American doctor working with Baylor Paediatric AIDS Initiative described, “there is a lack of education about the signs and symptoms of severe illness [...and a] lack of education about the services that are available, because despite the limitations of the medical system in Malawi, there are definitely certain things that could be done and are available and people did not avail themselves of those early enough.” The DHO nurse explained what that would lead to: “they only come whenever they are having complications. They may have a minor condition this time, but that minor condition progresses to a very big complication, that's when they make themselves available to the health facility.” When faced with such trade offs and lack of information, sex workers may decide not to access health services until their ‘cost’ of their illness outweighs the ‘benefit’ of not getting treated.

### **3.1.2.2 Corruption**

Unlike other respondents, the sex workers reported that corruption in the clinics was a key barrier to health access. Many indicated that when they were in public hospitals, they experienced doctors who have practices in both public and private facilities. A nurse working at the Central Hospital corroborated the claim indicating “there are a lot of them here in Malawi.” While this behaviour is not illegal, some physicians refer the patients to their private clinics while treating them in the public clinic. This can mean that patients need to incur the additional cost of travelling to another clinic as well as pay the requisite user fees. A sex worker described another

way in which this corruption can affect quality of treatment: “when they have received calls from their clinics and they are rushing to go attend to their patients there” instead of staying in the public ones.

Furthermore, most of the sex workers revealed that having connections with a health worker in the clinic achieved better and timelier patient care. Many said that the workers “help people who they know and the well to do” and “if there is someone you know, things go smoothly for you.” One sex worker clarified in an example during which he went to the hospital for diarrhoea and the nurse knew he was a sex worker. She told him, “well since I know you, I’m going to treat you, but if I didn’t know you, I wouldn’t have treated you.” Many of the other sex workers had similar stories.

Moreover, sex workers agreed that bribing health workers for treatment happened on occasion, but in their experience, not often. Some had never heard of it. For the respondents, bribing took the form of money or sex. During a focus group, one participant said a doctor, “maybe asking you to date them, so that when you say yes, you should be sleeping with them and you’ll be getting free and quick help when you go to the hospital.”

Structural inequities that already exist in the health system become further pronounced with corruption. Those with more social status or money can access services faster and more readily. Sex workers, who are poor, socially unconnected, or may be unwilling to provide sexual services to the health care workers, may not get treated promptly or at all.

### **3.1.2.3 ART**

Antiretroviral therapy (ART) is in a separate section because it is funded differently than other health services, even though the Ministry of Health manages it. The funding structure influences the service and quality of care received by sex workers on ARVs. Most stakeholders agreed that the ART program had more capacity than the rest of the health system. Some of the

respondents indicated that there are “services everywhere.” All of the sex workers agreed: “the hospitals that are very helpful here in Malawi are the ones for those that are HIV positive” and “those that are HIV positive are better off in terms of receiving treatment than the rest of us.”

The stakeholders who had worked in Malawi before the introduction of free ARVs in 2004 expressed astonishment with the influence that it has had. One respondent indicated: “we commend the government for introducing free ARVs.” Another said, “it’s so surprising, it’s so amazing the magic that ARV brought.” He attributed ART to a significant reduction in the instance of stigma on PLHIVs.

Stakeholders mentioned some drawbacks to the program, however. Some of the government-level respondents expressed concerns that too much of the program is donor-driven and without meaningful commitments from donor countries, could collapse at any time. A further challenge, reiterated in the background, is that it does not yet reach all the PLHIVs (see section 1.2.3.1). The representative from MANET+ explained that once people’s treatment “start[s] then that will be fine, but the challenge is to start.”

The same stakeholders recognized that ARVs are sometimes not available at the clinics. They indicated that ‘stock-outs’ are not only an inconvenience, but they can potentially affect the rate at which the body develops resistance to the drugs. This can lower the confidence that people have in the health care system to provide services when required could lead to trepidation about going for HIV testing.

The attitudes about ART show that this is not as much of an issue for sex workers as general health access. While it is devastating to contract HIV, if a patient is admitted into the ART program, they will be treated with minimal barriers. On the whole, all the stakeholders recognized that even though there are limitations to the ART program, the barriers to accessing ART were due to capacity: sex workers were not affected disproportionately. The stakeholders recognized that pressing need is to ensure equality of access in the general health system.

#### 3.1.2.4 Alternatives

To cope with the inadequacies of the public health system, most of the stakeholders indicated that where possible, sex workers and other Malawians prefer to access alternative, usually private, care. Sex workers indicated that the social challenges described in the next section increased their willingness to access private care. Many of the sex workers, as evidenced by the following quote, were impressed by their experiences at private clinics: “[you get] better treatment when you go to the private clinic and you are even given expensive drugs.” They admitted, however, that for the most part sex workers can rarely afford to use private clinics.

Health workers argued that while sex workers may perceive positive aspects of the private system, they have concerns that because private clinics are profit-driven enterprises, the quality of care is often compromised. One nurse was, “scared in private hospitals: most of the times they are doing shortcuts because they would want to utilize their resources.” Another nurse understood that some private clinics are prone to over-diagnosis or people are “misdiagnosed at a private hospital, depending on where, so I always advise people to go to a government hospital.”

From an administrative point of view, the District Health Officer explained that the DHO is responsible for monitoring these clinics but he indicated, “we are supposed to visit [them], at times due to a lot of workload, that is not done.” He concluded that his office usually investigates and closes facilities only when a patient launches a significant complaint. The Officer did not divulge how complaints were made and there was no indication what threshold of concern would constitute closure.

The stakeholders that worked with PLHIVs indicated that to avoid issues of crowding and poor quality in the public health system, some PLHIVs would move closer to a clinic that would treat them “more humanly” where financially possible. The representative from the National Association of People Living with HIV and AIDS in Malawi (NAPHAM) mentioned that she had encountered several instances where PLHIVs had moved to Chilradzulu and Thyolo



(cities in southern Malawi) where they could access better services provided by Médecins Sans Frontières (MSF)<sup>8</sup>. In all, limitations in the health care system were shown to affect sex workers and the general population. Seeking alternative treatment is commonplace if the requisite financial resources were available.

### **3.1.3 Engaging with the system**

Engagement with the health system refers to the ability to engage decision makers to bring about positive change. Most respondents agreed that government overlooks sex workers as a stakeholder group when developing policy. None of the sex workers expressed any confidence in being able to give feedback to government without organizations like TfaC. One sex worker indicated, “for those outside organizations [like TfaC], they have no access [to policy makers].” The UNFPA representative asserted, “they [sex workers] don’t know where to go with their issues and stuff like that.”

Even though sex workers felt that by being part of an organization like TfaC, they were closer to government, one of the only government-engagement activities that many of the respondents could think of was TfaC’s Big March (see 1.5.3.1). One respondent reflected on the Big March, indicating that the Minister of Gender was not pleased with it. As a result, it received negative media attention. She contrasted it to a similar activity organized earlier in the year by a Swedish NGO petitioning the Minister of Gender for better rights of female rural workers. They were “received with open arms,” indicating that perhaps these responses are mediated by underlying stigma. Respondents from TfaC indicated that there are other organizations that mobilize sex workers to engage with government, but they are few and do not do as much as TfaC does.

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<sup>8</sup> MSF was integral to the development of the Malawian health system during the 1990s and 2000s. Furthermore, they acted as a lead player in the establishment of the current free ARV regime. The public perception of MSF is very positive in Malawi (MSF, 2009).

Most of the stakeholders agreed that in terms of consultation around issues of HIV, the government was selectively receptive to input. Those stakeholders working directly with PLHIVs, specifically NAPHAM and MANET+, indicated that they were regularly contacted for stakeholder engagement sessions in which some of their opinions were taken into account. As organizations, they were able to further engage the media and direct some of the public response to the governmental issues. MANET+ also organizes their own policy dialogue sessions, but indicated that when the government is not hosting, “sometimes they are reluctant to come to these policy dialogues or either to take our issues into consideration.”

Some informants cited that high levels of government use ‘helicopter engagement,’ or checklist engagement. These refer to consulting with an organization but not taking any information. The advocacy organizations believe that it is used only as a measure of good faith to the stakeholders. Government has consulted YONECO in this way. The representative asked rhetorically, “if you do your helicopter thing, do you understand them?” The human rights organizations argued that in these cases, instead of seeking informed consensus with all the key stakeholders, decisions are made, sometimes politically motivate, based on the limited expertise of politicians instead of experts or those who are affected.

Informants situated within the health system expressed that policy is not easy to change. One community nurse explained that she regularly prepares reports about the challenges she experiences, but the items she identifies are not adequately reflected in future planning and policy. At a higher level, the District Health Officer explained that he was a member of a policy review board but “policy in every place takes long to change” and when it does, it is downloaded to his office from the Ministry of Health. This means that government decision-makers are not adequately using the resources at their disposal, their own employees with invaluable information, to inform positive policy change.

Engagement with the health system in general, as evident from this section, is very limited. The HIV organizations appear to have the government's attention more than others. This only occurs, however, when the government chooses to take their advice and insights. Sex workers rarely have the opportunity to engage with government.

### **3.1.3.1 Lack of a formal complaint mechanism**

The challenges in the engagement process are compounded with the few options for recourse when patients experience problems interacting with the health system. When sex workers were asked what they would do if they had a bad experience with a health worker, all replied, "we do nothing." To combat this, some of the NGOs have internal mechanisms for reporting grievances. NAPHAM accepts complaints from its members and will respond appropriately, following up with the police if the situations requires, because, as the representative asserted, "formal channels aren't there!" With the exception of two interviewees, government representatives were not aware of any mechanisms that patients could use to address personal treatment at clinics or hospitals.

The District Health Officer and one of the hospital nurses were the only stakeholders able to give a definitive answer to this question. The Officer cited the *Charter on Patients' Rights*, which claims that every patient has the right to complain (see Appendix D). He explained that to do this, the patient should come physically to a district health office or submit it in writing. He maintained that the office would "tackle it anonymously and report appropriately." A nurse in the Central Hospital explained that, "we have got a suggestion box in our reception whereby each and every client is supposed to give his or her ideas or any mistreatment." There was little indication that any of the complaints were followed up.

The fact that only health care workers knew about complaint mechanisms indicates that they are not very well promoted. NGOs working directly with sex workers indicated that while

forms or complaint boxes are a positive step towards meaningful feedback, many sex workers are illiterate and would be unable to complete the forms required. Moreover, if a complaint has to be launched in person, it would require additional time and resources, something that this population does not have.

## **3.2 Culture and Society**

The second major barrier for sex workers in accessing health services is the prevailing culture of stigma in Malawi. Some cultural norms, perceptions, and practices make it very difficult for sex workers to access adequate services because stigma can make them feel unwanted and discriminated against.

### **3.2.1 Stigma**

All the informants expressed that the view held by the general population towards sex work as “unholy,” “horrible, horrible and disgusting,” that they were “outcasts,” “unacceptable,” and that it was a “dirty job.” One sex worker explained that people “don’t consider sex workers, they are useless people, ignored by police and people don’t care.” All stakeholders agreed that most of these perceptions came from strong religious beliefs and cultural beliefs instilled through community and familial institutions. One nurse explained, “a lot of individuals are full of misconceptions and for those misconceptions to change in their minds, there is still a long way to go.”

With the onset of HIV, some of the informants indicated that sex workers became scapegoats, blamed for transmitting the virus. A sex worker clarified, “they take us as people who spread HIV and also those who destroy other people’s lives.” One of the nurses agreed, that people “don’t feel for the person, they feel the person is doing it [getting sick] deliberately.”

Some of the stakeholders even used stigmatizing language during the interviews, calling the sex workers “drunkards” and made generalizations including that all sex workers have low

condom use and disregard information about their health. Some officials believe that sex workers forget to take their medication making their treatment “not consistent nor correct.” That being said, all the interviewees claimed that they held different views from the population in general. As one government official indicated, he recognized that sex workers were “normal people make a living” indicating that other people would not see it that way.

For issues of stigma related to PLHIVs, most respondents indicated that while it is better, there are still instances of stigma and discrimination. NAPHAM cited name-calling as one way they find stigma manifests itself: “you PLHIV, whatever, whatever, maybe these ARVs are making you mad!” An HIV positive sex worker has to contend with both types of stigma, for being a sex worker and for being HIV positive, compounding experiences of stigma and discrimination.

It is evident that the stigma faced by sex workers is gendered. Contradictory to the literature (Kagee et al., 2010), the interviewed male sex workers believed that it was easier for them to access health services than their female counterparts. One male sex worker explained that female sex workers are often more subject to stigma than males because many people “don’t know that there are male sex workers. So the women face a lot of problems than men.” Another indicated “they [health workers] would never know that I was a sex worker... it’s been established in people’s minds that sex workers are female so they are the ones that get identified because for a man, they can never think that a man is a sex worker.” This means that in terms of access, unless they identify themselves, male sex workers may not be treated differently from the general population. It is unknown, however, what the typical response would be should a male sex worker identify himself to a health worker.

### **3.2.1.1 Motivations for becoming a sex worker**

All parties indicated that the primary reason for engaging in sex work is poverty. One respondent from TfaC described that, “most young girls are vulnerable to sex work. They are vulnerable to sex work because of poverty. It’s easy for them to get into it.” Further exploring poverty led to discussions around broken families, orphan-hood, and preferential treatment for the boy child. One of the nurses explained, “most of them [sex workers] have attended some education, but because they can’t get a job, they end up joining the sex work business.” One respondent characterized sex work as “low hanging fruit” with no entry barriers.

Several respondents characterized the motivations pursuing sex work as lack of familial support or a desire to pursue enjoyment and pleasure. One government official explained that if “they [sex workers] are not getting the same support that they could have received from their parents they also drift into sex work.” She laid out a scenario in which a young woman left an affluent home to engage in sex work so that her parents would notice her and she could enjoy herself. Neither the sex workers nor the sex work organizations mentioned this factor. Many of the informants indicated that poverty was the primary driver for becoming a sex worker, but the few that mentioned other reasons could be echoing the feelings of the general population. If people believe that women and men become sex workers for pleasure, they believe that the person has a choice, making it easier to blame them for their decisions. This attitude further reinforces stigma.

### **3.2.2 Personal Barriers**

The prevailing cultural attitudes and stigma directed towards sex workers influences barriers to health access on a personal level. This section explores two types of personal barriers: self-imposed barriers and provider-imposed barriers.

### **3.2.2.1 Self-imposed Barriers**

Many stakeholders identified that self-stigma played a role in reducing health access. One nurse working at an STI clinic had encountered sex workers who felt “shy because of their profession.” The negative connotations associated with sex work are not lost on sex workers. The stigma others have towards them is also felt internally. This leads them to become demoralized and feel undeserving of services. A nurse indicated that, “they feel like everyone around them knows about it.” The doctor from PIH indicated that sex workers that his organization works with often are self-denigrating and feel like they lack options. When the sex worker is seropositive for HIV, the self-stigma can worsen.

### **3.2.2.2 Provider-imposed barriers**

Sex workers, NGOs that work with them, and the UN agencies cited provider-imposed as the most important barrier in accessing services at general health clinics. Compounded with self-stigma, discrimination from health care workers makes access to health services challenging. One UN representative agreed that, “just to walk into the facility [for a sex worker] is a challenge in itself.” A sex worker said, “I’ve never been treated properly at the hospital when I was a sex worker, it would always be inappropriate treatment.” Like many of the sex workers, one claimed, “after I stopped being a sex worker, things got better, but when I was a sex worker, things were not so easy, we would still be ill-treated.” Without push back from society to challenge this behaviour, the PIH representative notes that these attitudes and actions will continue to persist.

Most of the stakeholders recognized that health workers were intolerant towards sex workers. As one stakeholder explained “with the laws of Malawi, they are not allowed to discriminate, they do this on their own.” In the great majority of cases, sex workers cited examples in which providers ignored them. One of the nurses added that even though “there is a professional understanding that they are human beings and therefore they should be able to access services,” there are many ways that providers can impede or deter service. One sex worker said,

“most doctors wouldn’t care to help, of course there a very few that are willing to help a person like that, but the majority of the healthcare workers didn’t care.” Another sex worker maintained, “they would ignore you and not help you.” Others cited examples where people who came after them would be treated first. Some respondents pointed to the fact that some health care workers treated the sex worker patient in a rushed way, using negative body language and facial expressions, or ignoring them for long periods.

Health workers also use verbal and physical abuse when treating the sex workers. Specific themes around this abuse were centred on blame, that they “deserve it” that they “did it deliberately” - “contracted HIV willingly and continue to spread it.” The sex workers indicated that this kind of treatment from health workers was the norm: one stated, “there is more mistreatment [than not].” One of the nurses had seen other nurses treating sex workers “like animals,” or engaging in minor forms of physical abuse such as slapping. Especially after obvious physical abuse, one sex worker reported that a health care worker told her it was “my own fault, that I had a problem” or that “we should not waste medication on sex workers.”

A final way that health workers can be discriminating is by providing the wrong or simplified treatment. One sex worker indicated, “I would get the wrong treatment, perhaps because they viewed us sex workers as the ones spreading diseases or as troublesome, and so they would give me treatment but not the appropriate treatment.” Other sex workers had similar stories. One of the nurses pointed to the fact that with self-stigma, provider stigma caused increased “emotional trauma” for the sex worker, which might make them uncooperative and anxious. This could further perpetuate the negative response from the health care worker.

In several cases, the respondents suggested that to mitigate provider-imposed barriers, the sex worker could lie about her or his occupation. The sex workers and some other stakeholders challenged this suggestion on several fronts. First, some proposed that health workers could identify sex workers by their clothing and decorum: “a sex worker can be easily identified by her



conduct or presentation” and “they would know that we are sex workers by our dressing and then we would dress anyhow as sex workers.”

Second, sex workers have different health concerns than the general population. In many instances, sex workers present with conditions unique to their occupation, such as STIs and wounds from beatings. The doctor at the DHO explained that due to exposure to disease, “you would expect to see more different kind of spectrum [of disease] on top of the ordinary spectra you may expect to be seeing.” Many of the stakeholders pointed out that in some cases, presenting with an STI as an unmarried woman would make health care workers assume that they are involved in sex work. Some of the sex workers confessed that in these situations, if they could they would lie about their marital status.

Despite all of this negative behaviour, there were some cases where interactions with health providers were positive. The nurse at the STI clinic indicated that her clinic was less stigmatizing than most. She explained, “we might be different because we at the STI unit are dealing with STIs but others are dealing with just general problems, so our understanding can be different because we understand what the sexual infection is while our friends in the hospital wards can’t understand.” She confessed that, “I also was biased; I would feel bad if they would tell me that this one is a sex worker.” Through these comments, it can be interpreted that once nurses like this one have regular exposure to sex workers, their attitudes change and they are less discriminating.

### **3.2.3 Alternative Medicine**

As mentioned previously, most of the sex workers conceded that before they would try to access public health services, they would self-medicate with over-the-counter pharmaceuticals or consult traditional healers. Some NGOs mentioned that sex workers might seek traditional healers as someone that they could trust implicitly. A sex worker corroborated, “they don’t discriminate

against you, they give you medicine, maybe the only thing could be that the medicine they give you is not appropriate for your problem, but they don't discriminate against you.”

From the experiences of the sex workers, it seemed that they would go to the clinic only as a measure of last resort. Some of the sex workers mentioned: “first you would buy drugs from a store,” and moreover, “getting treatment was challenging and it would take long before we got treatment, so we would go to the herbalist so we could get treatment fast.” Many such as the sex worker quote here, would prefer to go to a herbalist, “considering what I face when I go to the hospital.” This is related to the previous section in which economics and health literacy were described as a reason that health services are not sought earlier. This reasoning could be compounded by the same social factors that push sex workers to access alternative medicine first. Taken together, sex workers may avoid accessing care until their condition becomes critical. In this example, like many in this section, it is not merely structural or social factors that limit access to health services for sex workers, but a combination thereof. Responses, therefore, must seek to effectively address both.

## 4: Policy Options

Policy action is often impeded by the magnitude of structural changes necessary to transform existing systems. As present, while there is opportunity to make smaller changes, Malawi is not in a position to implement large-scale systematic shift. Its status as a lower-income country means that many of the barriers sex workers face in accessing health services are linked to broader development issues, such as the organization of the health care system, lack of human resources, and poor educational attainment. Change at the macro level is slow and incorporates many variables that this research does not consider. While this study acknowledges that broad-scale changes would address some of these concerns, it focuses on solutions that are effective, acceptable, feasible, quickly acted upon, and would require minimal resources. Micro level change in Malawi is possible.

The policy options presented in this section confront specifically the structural and social barriers pertaining to sex workers and offer solutions that are as comprehensive as possible in the given context. Each option is not mutually exclusive and therefore more than one could be implemented simultaneously. It is important to recall that most sex workers in Malawi are impoverished and have limited literacy skills, which limit the type of solutions that could be considered. Further, each policy option presented below reflects the reality that neither the Malawian government nor the NGOs that work in Malawi have sufficient capacity on their own to address the problem. All of the options require collaboration between state and non-state actors to reach the desired objectives.

In addition to the options presented, the research led to two additional options, which were subsequently discarded. This included the recommendation for separate clinics for sex workers. However, there is little support in the literature for options that keep sex workers

separate from the general population. In addition to the high costs for the government to maintain separate, equivalent health facilities, literature indicates that such separation can cause heightened discrimination and marginalization of this community (Overs, 2002; UNAIDS, 2002; NSWP, 1997). This research takes the stance that integration in health clinics can be successful when there is greater public acceptance brought about by education and stigma-reduction strategies.

The second option considered was the incorporation of traditional medicine within conventional health practices. The data collected from this study and literature on Malawian society indicate that traditional practices are a part of people's lives (Kaspin, 1995). To devise appropriate policy that would integrate these cultural elements, however, was beyond the scope of this research. This option should be further researched in the future, but will not be included in the policy options for this paper.

#### **4.1 Policy Option A: The Status Quo**

The first option maintains the status quo, as outlined in the background of this study. NGOs would continue to provide direct services to sex workers in the areas of Lilongwe in which they work. Not all sex workers would have access to these services. At the government level, two current projects would potentially have a future impact on sex workers. First is the ongoing collaboration of the working group between the Ministries of Health and Gender with input from UNFPA and UNAIDS. While there is a great deal of potential for this group, at the time of writing, after two years of meeting, there was no indication of the group's outcome or plans for implementation. However, those involved seemed committed to action, but indicate that they are still establishing working relationships and laying out how the group will function.

The second government action that could affect sex workers in the status quo would be the HIV bill, were it passed into law. From media scans and follow up questions to interviewees, there is little evidence to suggest that government has taken any further action since August 2010.

Although this may be the case now, the government has laid the groundwork for mandatory testing should the current or any future governments choose to revisit the issue.

The status quo option relies on civil society and government to act independently in the provision of service for sex workers. NGOs, like TfaC and FPAM, provide varying levels of service to some sex workers in Lilongwe. These organizations only work with sex workers in specific areas of Lilongwe and do not have the capacity to address the systemic factors that limit sex workers' access to health services. Although some of the NGOs engage with policy makers and decision makers, their contribution to the advocacy effort is largely uncoordinated. Currently, there is little being done to changing the attitudes of health care workers. In sum, this option would not necessarily provide worse access for sex workers to health services, but would contribute little to widespread change.

## **4.2 Policy Option B: Sex workers as Stakeholders**

In the second policy option, the Ministry of Gender would support the creation of a national network of NGOs that serve sex workers and community organizations that are comprised of sex workers. This network would allow for better communication and sharing of best practices between members, would provide reliable information regarding the health needs of sex work to policymakers, and would improve communication between government and sex workers. Government would rely on this network as an advisory group.

While the Ministry of Gender would act as institutional support and an advocate in government, the network would remain autonomous. A managerial board comprised of representatives from each organization as well as other stakeholder groups, such as police officers and government representatives, would coordinate central efforts. The board would provide analysis and evaluation of policy as well as facilitate engagement at all levels of government. The board would also consolidate information about services available to sex workers in Lilongwe

and Malawi and distribute the information through its membership. A smaller, executive group made up of sex workers and other representatives, as decided by the members, would engage higher levels of government, with the assistance of the liaison from the Ministry of Gender. This executive could advise decision makers on the views of sex workers and would advocate for policy change.

At the District Health or even the clinic level, the network would support individual sex workers to give in meaningful feedback to the service providers. For clinics, feedback could include a discussion of opening hours and range of services offered. The network could also advocate for formal feedback mechanisms. In the interim, could consolidate and channel feedback to the appropriate place. This would allow sex workers to give oral accounts, if they were illiterate.

The network would have a diverse membership. NGOs that work with sex workers would be included but also other grassroots community based organizations (CBOs) would be encouraged to form and join the network. Sex workers empowered by participating in programs with NGOs could facilitate this. The representative from Christian Aid explained the benefit to this: “I can see an NGO precisely focusing on sex work, run by sex workers, and looking at interacting with policy makers, or looking at challenging the traditional beliefs about sex workers, or trying to sensitize people that this a group of people that needs to be within us and needs and we need to support them [...] because they will be speaking from experience.” NGOs could also help to identify strategies for reaching sex workers not currently linked to formal organizations.

This policy option addresses information asymmetry, providing solutions that allow for frequent, facilitated information sharing between policymakers and sex workers or their representatives. Many of the stakeholders indicated that there is little government interaction with sex workers and decision makers lack basic data about sex workers. This makes any governmental response uninformed and therefore problematic for sex workers, so when policies

aim to incorporate them, one government respondent indicates that the policymakers are “groping in the dark.” Several of the UN agencies called for a meaningful needs assessment to identify gaps that are present in health service provision. This network could collaborate with government and assist in the facilitation of this assessment.

Static demographic data is only the first step in acquiring adequate information to inform policy. Dynamic interaction with the sex worker population is required to effectively address the needs of the entire population. Engaging with sex workers and sex work organizations is key to producing comprehensive input to policy-making that affects sex workers. The best way to facilitate the interaction between sex workers and policy makers is through a sex worker network, allowing the population to be adequately represented. The creation of an advocacy network would be following a successful trend occurring globally (Adams & Kang, 2007). Public policy theory notes that networks are more influential than individuals or small groups on designing policy (Waarden, 1992). Formalized networks provide credibility for policymakers and act as a source that they can rely upon as the voice for a particular issue. They also provide analyses of policies produced by the government with a specific lens.

There is a great deal of literature on community and advocacy networks. Overall, literature indicates that when communities organize themselves, they tend to become more empowered and willing to engage political leaders (Ranghelli, 2005). That empowerment can produce an overall benefit for the community, as the individuals feel engaged and able to work with policy makers to devise collaborative solutions. Furthermore, with organization comes support and bestowal of agency its members (Mendizabal, 2006). Mendizabal indicates that these networks, if organized well, should fill six functions:

1. Filter information: organise the appropriate information together;
2. Amplify: make ideas understood;

3. Invest: provide resources to members;
4. Convene: bring together different people or groups of people;
5. Community building: encourage interlinking behaviour; and
6. Facilitate: carry out programs more effectively.

The structure outlined for this policy option includes each of these areas.

In addition to the positive aspects of community building, the literature points to the challenges of creating networks (Hassim, 2005; Adams & Kang, 2007). Networks take time to become established and to empower members to instigate change. In Lilongwe, however, the network could build on context-specific best practices by working with NGOs, like Theatre for a Change, that have experimented with facilitating community-based networks.

A successful incarnation of a sex worker organization is the Sex Worker Education and Advocacy Taskforce (SWEAT), a national organization of sex workers in nearby South Africa. The group engages government as an advocacy group, synthesizes data and research regarding sex work, and promotes outreach to sex workers across the country. Since 2006, SWEAT has worked alongside government in service delivery to sex workers and has been a reliable source of research on the dimensions for sex work in South Africa (SWEAT, 2010).

Another successful government outreach program is in Brazil. As part of their national movement to curtail STIs and HIV, the National STD/AIDS Program, a division of the Ministry of Health, established an effective sex worker advisory committee<sup>9</sup> to provide counsel on health policy decisions related to sex work (Levi & Vitória, 2002). With collaboration with government, a network in Malawi could also serve this purpose.

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<sup>9</sup> There are also advisory committees for MSM, prison populations, and the population living in poverty



In Malawi, there is an important precedent for an issue-specific network. MANET+ acts as a liaison between government and organizations that deliver programming for PLHIVs. The network is a unified voice, speaking for the common concerns of all the organizations it serves as a whole. Policymakers in government routinely approach the network as a stakeholder in issues relating to HIV and AIDS. Furthermore, the network supports individuals and community organizations to engage with local leaders and lower levels of government to improve life for PLHIVs (Mbewe [int.], 2010; MANET+, 2010). The literature cites this multi-layered activism as most effective (Rekart, 2006). One of the member organizations, NAPHAM, accepts complaints or feedback that PLHIVs have with the health system and passes them on to the appropriate authority (Manjolo [int.], 2010).

This model could be adapted for sex workers. Currently in Malawi, there are NGOs that work with sex workers directly, but no unifying voice to act as a meaningful stakeholder on issues pertaining to sex work. Many of the interviewed stakeholders called for a formalized sex worker network; the CHRR emphasized, “it’s important for sex workers to be more mobilized and organized if their voice is going to be heard because we need to change the perception of the general public.” Without exception, the literature providing recommendations on improving the lives of sex workers advocates for input of sex workers in the formation of policy and programming (Overs, 2002). This option would provide sex workers with that voice.

### **4.3 Policy Option C: *mHealth* – Mobile Phone Counselling and Information Service**

This policy option provides sex workers with a tool to easily access health information and receive an immediate response when a health issue is urgent. In this option, sex workers would use mobile phones to connect with a councillor, who would be a nurse or other specialized community health worker, with training in the specific needs of sex workers. The councillor would provide health information including prevention strategies, help to navigate the health

system, and assist with referrals to appropriate health centres and responsive health professionals. By taking the first letter in the word mobile, this type of program has been termed *mHealth*. There are organizations, such as Theatre for a Change, which have trained former sex workers in peer counselling and with additional training, they could manage calls (Ndovie [int.], 2010). To save substantial infrastructure costs, the service need not have a physical presence. Due to the prevalence of mobile phones, calls could simply be forwarded to available councillors. To eliminate payment from the sex worker, the service would be set-up to respond to flashed calls<sup>10</sup>, meaning that the program would incur the cost of the call.

Any sex worker with access to a mobile phone could use this form of support. Since the instances of mobile technology are increasing in Malawi (WB, 2011), even for sex workers with a low income, there would be a high likelihood that a mobile phone could be found to make the call. The program would be financed through the Ministry of Health and would be under the purview of the local DHO. While the program would be autonomous from other DHO administration, the location within the office would allow councillors to access localized information and connection to local services.

Technical consultation and implementation would need to be established first, which could model existing tele-counselling programs in Malawi (see below). A lead councillor would be employed by the DHO to train and manage human resources, coordinate promotion and information sharing about the program, and act as the program's primary contact. The lead councillor would also work with NGOs that provide services to sex workers to aid in promotion of the program and to link sex workers to services that they provide.

Telehealth and helpline solutions have emerged over the last ten years in North America and Europe to alleviate issues associated with geographic remoteness and to provide a simple way

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<sup>10</sup> Flashing on a mobile phone refers to the practice of calling but disconnecting after one ring. This allows the recipient to see the caller's phone number and incurs minimal or no charge to the caller.

for people to seek medical advice from a health professional at their convenience (Ivatury, Moore, & Bloch, 2009). In the context of high-income countries, there is an array of tools that could be considered, such as web-based programs or video conferencing. In countries like Malawi where internet access is limited (WB, 2011), however, high-tech approaches are not appropriate. Instead, innovate programs have been developed to use mobile phones to respond to health needs (Ivatury, Moore, & Bloch, 2009). In a South African study conducted by AfriAfya, results revealed that the best technology to use in addressing issues of HIV and AIDS is mobile phones and SMS (Wootton, 2009).

According to Wootton, the *World Health Report 2006* indicates that *mHealth* is ideal for low-income countries where there are shortages in resources and sporadic infrastructure. Start up and operating costs over time, are relatively low and there is minimal organizational complexity. In developing a case for the further use of *mHealth* in a developing country context, Patricia Mechael (2009) notes:

The [mobile] phone's most notable feature is its capacity to communicate and transfer information within both literate and illiterate populations. Its relatively low start-up cost and flexible payment plans have put the technology into the hands of significant proportions of the general public; when subscribers share their mobile phones with others, they extend their health and emergency-related benefits even farther (Mechael, 2009, 107)

This option has the advantage of addressing both structural and social barriers. Structural barriers would be mitigated in that the only requirement to use the program is a cell phone. Sex workers need not wait in line to see a health worker, deal with issues pertaining to corruption, or have issues of literacy as a barrier. Social barriers would be reduced since the councillor would understand the issues that sex workers face and work to find an appropriate solution.

In Malawi, a recent model shows how *mHealth* could be implemented. YONECO, one of the interviewed stakeholders, launched a mobile phone counselling service in 2006 to provide youth with access to councillors twenty-four hours a day. The councillors give advice on sexual

health, human rights, and any other concerns the caller has. In the case of child abuse, the service can contact local authorities and arrange evacuations for the children. Due to its success, in mid-2010, the project started to expand to the national level, with the support of the Ministry of Gender<sup>11</sup> (Mkawdawire, 2010). Since it has been only operational for a few months at the time of writing, as of yet there has been no evaluation of the program. This successful model could be drawn on to develop a similar program to assist and benefit sex workers.

#### **4.4 Policy Option D: Peer Education**

This policy option builds on the peer support programs that some NGOs provide. The option builds on these programs, strongly links them to the health system and makes them accessible to all sex workers in Lilongwe. Peer leaders would be trained by a nurse from the DHO at all clinics around Lilongwe and then would be encouraged to network with other sex workers to disseminate information. The peer leaders could distribute information one-on-one or hold group sessions. The sessions would focus on preventative health, navigation of the health system, and human rights empowerment. Similar to other organizations that currently provide peer support (TfaC, FPAM, and PIH), this program could grow to include other elements as well, such as literacy and vocational training.

This program would be administered by the DHO with the support of NGOs. The office would employ a nurse to run the program who could work with NGOs, such as TfaC, FPAM, and the Centre for the Development of People, to identify leaders and build on the established relationships with sex workers in Lilongwe. Best practices from the initial recruitment exercise could be used to recruit peer leaders that are not connected to NGOs. The nurse would then travel between health clinics and meet with peer leaders, providing on-going training, distributing preventative resources such as condoms, and supporting the leaders in facilitating discussion and

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<sup>11</sup> The official name is the Ministry of Gender, Child Welfare, and Community Services.

dialogue with the sex workers. The peer leaders would use this information to recruit and train sex workers in their communities. The clinics could be used during off-hours as spaces to meet or the nurse and peer leader could identify other appropriate community spaces. NGOs could integrate their provision of services with this program to create a more comprehensive program.

This option addresses both the structural and cultural barriers sex workers experience when accessing health services. Structural barriers are reduced because sex workers can seek out peer mentors on their own schedule in their community. Furthermore, since it is a peer providing information and counselling, there would be significantly less stigma attached to the interaction and much more trust. Where this option differs in its effectiveness from *mHealth* is that the DHO nurse could be used as a resource to address more crucial health needs or act as an advocate in the health system for sex workers.

In the literature, peer education and mentoring programs are cited as a way to effectively disseminate information and induce health-seeking behaviours. It shifts health promotion from a top-down approach to a method that is participatory and with the goal of health empowerment. In theoretical models of health promotion through empowerment, the education is community-based so that the peer educator acts as a facilitator to make shared decision-making and instigates community-centred control (Jacobs, 2011). Studies in other low-income countries, African and otherwise, reveal that peer-mediated education increases health literacy, induces safer sexual practices and reduces the instance of HIV and other STIs (Ngugi, Wilson, Sebstad, Plummer, & Moses, 1996; Ford, Wirawan, Suastina, Reed, & Muliawan, 2000). These outcomes mean that sex workers stay healthier thereby reducing the need for access to health clinics and medical professionals. Furthermore it can help to create a system of support for people when they get sick, which can aid in a faster recovery (Wermuth, 2003).

While the literature above discusses the positive measured effects of peer education, there is literature that cautions that if not administered well, peer education is less effective. Campbell

& Mzaidume (2001) indicate that there are three factors that dictate the success of peer education: empowerment of the peer leaders to impart health-seeking behaviours with their peers; providing appropriate linkages and material to the population; and changing social identities to include a focus on health. To ensure that these factors are all addressed in this program, it would be crucial that its design be collaborative. The DHO should develop best practices with the consistent feedback of sex workers and NGOs with a focus on effective monitoring and evaluation. Several sources indicate that time should be taken in choosing an effective peer leader and securing a safe meeting space to ensure the best possible result (Ngugi, Wilson, Sebstad, Plummer, & Moses, 1996). Furthermore, monitoring and evaluation is a challenge for peer education because it can be unclear what measures are used to indicate success (Jacobs, 2011). For example, since it is a community-based program, tension may exist between measuring the attainment of the community's health goals and the goals of the DHO. This speaks further to the importance of a collaborative approach to this program between the DHO, sex workers, and NGOs. The three groups will need to establish common goals, targets and strategies for implementation to be successful.

There is a precedent in Lilongwe for the DHO to administer peer-led health programs. Since 2003, the DHO has been running a health-based peer-mentoring program for youth. One of the interviewed stakeholders is the DHO liaison with the peer leaders. She emphasized, “we believe in peer education.” In the catchment area for each health clinic, the nurse recruits a peer mentor. They use either the clinic or another public facility as a base for training and a meeting space for the mentors to facilitate own programming. The nurse travels between health clinics in Lilongwe monitoring and supporting the groups. She acts as their liaison with the health system and provides health and administrative support (Kachigamiba [int.], 2010).

Further evidence to the success of peer education in Malawi is in Baylor International AIDS Initiative's (BIAI) community health program. In that program, community leaders are

identified by the organization and travel through the community providing health advice, reminding patients of upcoming appointments, and dispensing prevention resources. The program is a tested success (Kreps-Falk [int.], 2011) because it establishes trust in the interchange of information. A doctor from BIAI explains:

“[gaining] trust and respect of the people you’re talking to and that doesn’t always happen if you’re from a completely different culture or a completely different class or completely different whatever and you have to have buy in and when you are talking to people from within their community that they know and they can make this a community issue, that’s much more real to people than someone just telling them what they should or shouldn’t do.”

The option presented here is based on these pre-existing models. Integrated with existing NGO-run programs, this option would offer comprehensive health support to sex workers.

#### **4.5 Policy Option E: Training of Health Care Workers**

The next option confronts the problems related to the supply-side barriers specifically those caused by social interactions between health care workers and sex workers. This option endeavours to create a more conducive social environment for sex workers to receive treatment, thus mitigating stigma and discrimination, which acts as a barrier to accessing health services. This social barrier would be reduced if health workers provided an understanding and welcoming environment to receive treatment. This could also increase timely and preventative health-seeking behaviour for sex workers in Lilongwe.

In this option, training would be mandatory for health workers through on-going professional development every two to three years. It would work to bridge knowledge gaps about the sex worker population to promote a better understanding of the issues that sex workers face. Sex workers would be involved in the training to provide an opportunity for participatory feedback between health care workers and sex workers. The training would be facilitated through the Ministry of Gender in collaboration with NGOs that would be useful in helping to create material and trained facilitators. Additional training would also be integrated into medical and

nursing school curriculum. Currently in the nursing curriculum, there is a class on ethics, which could incorporate specific material on sex workers (Phiri [int.], 2010).

Sensitization training for public service providers is cited in the literature as essential to a holistic response to sex work (Alexander, 1992). Training is typically aimed at reducing stigma and fostering an understanding of sex workers' background, including their reasons for entering sex work. In the data collected for this research, it was the experience of many of the respondents that Malawians are socialized from an early age to have negative views towards sex work and sex workers. As such, general sensitization training, a strategy used in the past (Kachigamiba [int.], 2010), would not be as effective as the stigma attached to other marginalized groups is different.

Evidence from this research suggests that sensitization training would be effective. All the interviewed nurses indicated that their opinions about sex work changed when they interacted with sex workers at a professional level. The nurse at KCH explained:

“people need that understanding, for example, before I came to the STI unit, I was very biased [...] when I understood their reasons for joining that profession, that's when I got the understanding that perhaps my friend [the sex worker] had nowhere to go, nothing to do so that she could be assisted. So they join that profession as a noble profession, so maybe if there are awareness campaigns to all health workers, they might also understand that there is a problem in our country that needs to be dealt with.”

The other nurses had similar sentiments. Some further indicated that nurses in private clinics receive additional training about sex work, which maybe a contributing factor to the more positive treatment sex workers receive there. In all, providing training and a chance for health workers to interact with sex workers would give them a better understanding of the issues, which could lead to a better treatment environment.

A nursing student interviewed for this study indicated that she found that younger nurses tended to have better attitudes towards sex workers. She ascribes this to recent educational practices that teach trainees to be “here because of the patient.” Sex workers verified that in their



experience younger nurses treat them better. The young nurse indicated, however, that even with this training in school the pressures of a health system over capacity, over time, some nurses lose this compassion. This underscores the importance of on-going professional training.

Currently in Malawi, there is very little on-going professional training after the health worker graduates from school (Phiri [int.], 2010). The CHRR has done some sessions with selected health workers, but it has not been a generalized approach (Mwakasungula [int.], 2010). In the official training that does happen, the District Health Officer contended that they try not to categorize people and emphasize that everyone should be treated the same in order for health workers to “give out more friendly service.” He deemed this type of general training sufficient and thought it unnecessary to provide further training. From other parts of the interview, however, he did not seem to be aware of the discrimination that transpired toward sex workers in Lilongwe clinics. As a doctor, he would also participate in these trainings, which ideally in the end would influence his policy decisions. Furthermore, the representatives from NAC indicated that they believe that health care workers need a “special orientation to working with sex workers.” While it would be ideal to sensitize the entire population to gain an overall population acceptance of sex work, it is neither within the scope of this research nor practically feasible with this method. This option makes the environment better for sex workers when they access health services.

#### **4.6 Policy Option F: Vouchers for Private Clinics**

The final option addresses the barriers sex workers face by diverting them from the public system into the private. For this option, the government would issue vouchers that could be redeemed by sex workers at private clinics. These clinics would then redeem the voucher for payment from the government. NGOs would act as distribution points for the vouchers, since they have established relationships with sex workers in various communities in Lilongwe. NGO workers would dispense vouchers at a physical location or could actively distribute in the

communities. The vouchers would be linked to the sex worker's health passport<sup>12</sup> to prevent fraud and resale.

The data indicate that many of the interviewed sex workers would use private clinics if they had the choice. They cited that at private clinics they received better care in a friendlier environment. Sex workers and other stakeholders indicated that due to prohibitive costs of these clinics, sex workers do not use them often.

In this option, the Ministry of Health would administer the program with support of NGOs. The Ministry would raise the funds to pay the private clinics. Similar to the examples listed below, this may require additional funds from donor governments or organizations. NGOs would be required to find sources of funding to cover the additional costs incurred for distribution and promotion of the program. Where the budget could support it, this funding could be routed from the Ministry as remuneration for program implementation.

Voucher programs have been used extensively in other countries, largely in the context of education, to allow people access to a service that they otherwise could not afford (Levin, 1998; Manski, 1992). Whereas large-scale subsidies to social programs are made through an injection of resources on the supply-side, vouchers allow for smaller subsidies to be applied to a targeted population on the demand-side. In this way, the voucher accounts for some of the market failure supply-side subsidies create in their inability to adequately redistribute the resources to benefit the most needy. Since the user controls the voucher, it can empower them to use it when it is medically necessary and convenient (Borghi, 2005).

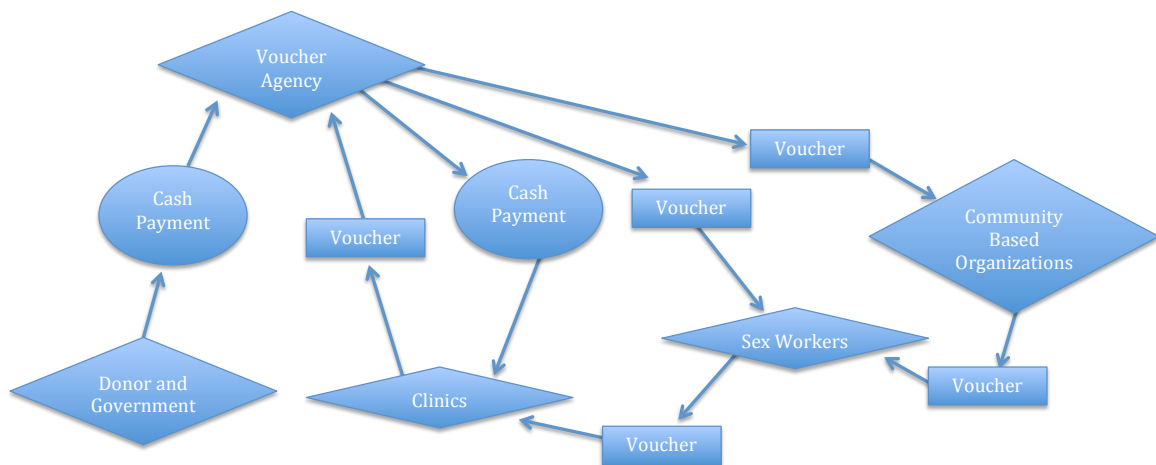
In a highly cited and successful health voucher program in Nicaragua, donors and government created a program to distribute vouchers to sex workers thereby lowering the instance of STIs, including HIV and AIDS (Sandiford, Gorter, & Salvetto, 2002). The program

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<sup>12</sup> Health passport is the government health document each person has which contains basic health information and is used to access health services in Malawi.

distributed vouchers directly and through community-based organizations working with sex workers. The vouchers could be used at select private clinics. The clinics competed with each other for business, which during the program period increased the quality of service and value for money (Borgh, 2005). While the scheme was successful in reducing the disease burden for sex workers and improving condom use, the administrative costs of the program were high: almost half of the program cost used to dispense the vouchers ("Voucher Program," 2009). In the Malawian context, the government and NGOs would have to work to ensure that the program would have to follow best practices and streamline the administrative process so that program costs could be minimal.

Figure 2 — Flow Chart of Voucher Program in Nicaragua



Adapted from Sandiford, Gorter, & Salvetto, 2002

## 5: Evaluation of Policy Options

### 5.1 Criteria and Measures

This section examines the six proposed policy options against a set of comprehensive criteria to determine which is the most viable and effective for addressing the barriers to health care experienced by sex workers. Table 3 summarizes the criteria and measures.

Table 3 — Criteria and Measures

<i>Criterion</i>	<i>Descriptive Question</i>	<i>Measure</i>
Effectiveness: Reduction of Structural Barriers	How much does the option reduce structural barriers to health access?	<p>High Sex workers can access health services with little to no structural barriers.</p> <p>Medium Sex workers have improved access to health services, but some barriers still exist.</p> <p>Low Access to health services remains the same and there are many barriers.</p>
Effectiveness: Reduction of Social Barriers	How much does the option reduce social barriers to health access?	<p>High Sex workers have access to health services with few to no barriers.</p> <p>Medium Sex workers have improved access to health services, but some barriers still exist.</p> <p>Low Access to health services remains the same and there are many barriers.</p>
Government Acceptability	Do the government, and health care workers accept the option?	<p>High Fully support from health workers, government and its agencies.</p> <p>Medium Some support from health workers, government and its agencies.</p> <p>Low Low support from health workers, government and its agencies.</p>
Public Acceptability	Does the public accept the option?	<p>High Fully support from the public.</p> <p>Medium Some support from the public.</p> <p>Low Low support from the public.</p>
Stakeholder Acceptability	Do sex workers and the NGOs that work with them accept the option?	<p>High Full support from all stakeholders.</p> <p>Medium Some support from stakeholders or unequal support from stakeholders.</p> <p>Low Little support from stakeholders.</p>

<i>Criterion</i>	<i>Descriptive Question</i>	<i>Measure</i>
Feasibility	The ability for all stakeholders (sex workers, government, NGOs) to fully and completely carry out their role in the implementation.	<p>High All or most of the affected stakeholders have the capacity.</p> <p>Medium Many, although not all, of the stakeholders have the capacity.</p> <p>Low Few or none of the stakeholders have the capacity.</p>
Horizontal Equity	Equal benefit to sex workers across Lilongwe.	<p>High Sex workers across Lilongwe benefit equally.</p> <p>Medium There are some sex workers that will benefit more than others.</p> <p>Low There is a high degree of variability for benefit of sex workers across Lilongwe.</p>
Cost and Financial Sustainability	The overall expected cost of implementation and requirement for sustained funding over time.	<p>High The capital and operating costs are high.</p> <p>Medium The capital and operating costs are moderate or either the capital or operating cost is high while the corresponding cost is low.</p> <p>Low The capital and operating costs are low.</p>
<p><b>Note: for the purposes of scoring, except for the final criterion: High=5; Medium-High=4; Medium=3; Low-Medium=2; Low=1.</b></p> <p><b>In the cost criterion: High=1; Medium-High=2; Medium=3; Low-Medium=4; Low=5</b></p>		

## 5.2 Assessment of Policy Options

The evaluation of the policy options is summarized in the following matrix (Table 4) by evaluating each option against each criterion. The matrix allows for a simplified view of the decision factors in the policy analysis with an assessment of each factor's significance with the expected output. The matrix was completed using the data collected for this project of the matrix as well as the basis of literature used to ground each option. A ranking was assigned to the output using the measures described in Table 3.

The ratings are only meant to be a guide to allow for an overall analysis. As decision makers in government and NGOs may have different priorities and weigh each criterion differently, for the purposes of this project, the criteria were not weighted. By presenting the table unweighted, all decision makers can assess overall how each option fares. In further research, a

sensitivity analysis could be used to test the resilience of each option, but was beyond the scope of this study.

Table 4 — Matrix of Criteria and Policy Options

	Status Quo	Sex Workers as Stakeholders	mHealth — Counselling and Information Service	Peer Education	Training of Health Care Workers	Vouchers for Private Clinics
Effectiveness: Reduction of Structural Barriers	<p><b>Low</b> – The structures in which the sex worker accesses health do not change.</p>	<p><b>High</b> – Sex workers are empowered to shape parts of the system by engaging with NGOs or with government directly. Empowerment leads to the creation of structures and systems in which health services can be easily accessed.</p>	<p><b>High</b> – Sex workers are empowered to take control of their own health and access information when they need thereby increasing their overall health literacy and generating health-seeking behaviour. Cost of transportation and opportunity cost of waiting are eliminated.</p>	<p><b>Medium-High</b> – Similar to mHealth, sex workers are empowered to take control of their health and have easier access to information, thereby increasing their overall health literacy and improving health-seeking behaviour. There may be some issues in distances to access group-based activities.</p>	<p><b>Low</b> – The structures in which the sex worker accesses health do not change.</p>	<p><b>Medium</b> – Sex workers go to private clinics at their convenience. There still could be problems related to distance, but would be considerably less waiting for services.</p>

	<i>Status Quo</i>	<i>Sex Workers as Stakeholders</i>	<i>mHealth – Counselling and Information Service</i>	<i>Peer Education</i>	<i>Training of Health Care Workers</i>	<i>Vouchers for Private Clinics</i>
Effectiveness: Reduction of Social Barriers	<b>Low</b> – The social setting in which the sex worker accesses health does not change.	<b>High</b> – The conditions for sex workers change reducing instances of discriminatory-based stigma.	<b>Medium</b> – Since the service connects sex workers to counsellors, who would be welcoming and non-stigmatizing to the sex workers, there is a highly conducive environment for an effective health discussion. Anonymity can be retained and calls can be made from a private locations reducing self-stigmatization. However, in cases of substantial disease or injury, sex workers will need to access services through the traditional methods, under which the existing social barriers will still persist.	<b>Medium-High</b> – Similar to <i>mHealth</i> , while sex workers may have increased information about preventative health and treatment options, there would be little reduction to the barriers that still exist in accessing health services. Initially accessing the program, however, may pose problems due to self-stigma and mistrust of interacting with health workers. Contrary to the <i>mHealth</i> option, however, since the service is provided through clinics, there could be some improved access since the nurse could act as an advocate.	<b>High</b> – With comprehensive training, the environment would change such that sex workers would be able to access services in a friendly and helpful environment.	<b>Medium</b> – Many of the private clinics do not impose the same social barriers to sex workers as the public clinics do. However, with an increase in sex workers and the switch to a government-subsidized program may induce stigma.



	<i>Status Quo</i>	<i>Sex Workers as Stakeholders</i>	<i>mHealth – Counselling and Information Service</i>	<i>Peer Education</i>	<i>Training of Health Care Workers</i>	<i>Vouchers for Private Clinics</i>
Government Acceptability	<b>High</b> – the government need not change anything. It has already put together an interdepartmental group in which to discuss barriers to health care among other things.	<b>Medium-low</b> – For government to openly facilitate the creation of a sex worker network could be politically difficult. Some government workers would require additional sensitization training, as there is a range in understanding of sex workers among government workers.	<b>High</b> – The government has a history of providing information services to marginalized populations. It would also relieve some pressure from the health system, which would benefit health care workers.	<b>Medium-High</b> – The government has a history of providing this type of service to youth populations. There is recognition in government that peer education is a worthwhile activity. Better prevention could lead to relief of pressure from the health system.	<b>Medium</b> – There may be some resistance from officials, as the perception exists that health care workers are already trained to appropriately treat sex workers and do not need additional training. There may be resistance from health care workers to attending training and workshops due to time constraints and pre-existing stigma.	<b>Medium-high</b> – There is little interaction between the public and private health systems and thus there could be apathy to sending sex workers to that system. Vouchers would reduce the need for interaction between health workers and sex workers in the public system.
Public Acceptability	<b>High</b> – The public is currently not involved with the government response to sex work.	<b>Low</b> – The public perception of sex workers is not positive and as such, an increased role in government policy and consultation may not be well taken.	<b>High</b> – Since this option allows for privacy when accessing the service, there would be very little public involvement.	<b>Medium</b> – There is some concealment of the program from the public when mentoring is on an individual basis, however, when peer meet in a public space, there could be some displeasure from the public.	<b>High</b> – The public need not be involved with the training of health care workers.	<b>Medium</b> – The public who access the private system may not be in favour since there would be an increase of sex workers using the same clinics.

	<i>Status Quo</i>	<i>Sex Workers as Stakeholders</i>	<i>mHealth – Counselling and Information Service</i>	<i>Peer Education</i>	<i>Training of Health Care Workers</i>	<i>Vouchers for Private Clinics</i>
Stakeholder Acceptability	<p><b>Low</b> – Stakeholders continue to operate with no formal government mechanisms to support their work. The pending HIV bill in its current form leads to a rejection of this option.</p>	<p><b>High</b> – Stakeholders have called for increased participation in the policy process of government.</p>	<p><b>High</b> – Sex workers indicated access to information is important; NGOs working with them have started to provide some of this service, indicating willingness.</p>	<p><b>High</b> – Peer mentorship programs already exist in the many of the NGOs that work with sex workers and have been received positively.</p>	<p><b>High</b> – Sex workers are acutely aware of the positive externalities induced when the attitudes of health care workers change. Some NGOs have done some training already, indicating willingness.</p>	<p><b>Low-Medium</b> – While some sex workers prefer private clinics to public clinics, there is an understanding among other stakeholders that the quality of care can be reduced in private clinics.</p>

	<i>Status Quo</i>	<i>Sex Workers as Stakeholders</i>	<i>mHealth – Counselling and Information Service</i>	<i>Peer Education</i>	<i>Training of Health Care Workers</i>	<i>Vouchers for Private Clinics</i>
Feasibility	<p><b>High</b> – No additional changes required.</p>	<p><b>Medium-low</b> – A great degree of organization would be required at the level of NGO and CBO. Some NGOs organize sex workers already in specific areas of Lilongwe, but there could be challenges moving into areas that have not been worked in previously. Facilitation of government to consult and engage the network would be similar to engagement with other networks and thus few new procedures would need to be established.</p>	<p><b>Medium-High</b> – Since a program similar to this has been scaled to the national level, the technical knowledge already exists. This requires hiring health workers, which could strain supply within the health system. However, NGOs could provide some non-professional support.</p>	<p><b>High</b> – Since an analogous program exists already, existing program infrastructure could be built upon. Based on that model, only a small number of people would be required to facilitate the program and engage with the NGOs and sex workers.</p>	<p><b>Medium</b> – Organization between NGOs, government, and health care workers would be required and could prove to be difficult. Since some training has already occurred, the basis for material already exists.</p>	<p><b>Low</b> – While the use of vouchers may not pose problems, distributing and ensuring their proper use (i.e. not reselling them) would present difficulties.</p>

	<i>Status Quo</i>	<i>Sex Workers as Stakeholders</i>	<i>mHealth – Counselling and Information Service</i>	<i>Peer Education</i>	<i>Training of Health Care Workers</i>	<i>Vouchers for Private Clinics</i>
Horizontal Equity	<b>Low</b> – Not all sex workers have access to the services provided by NGOs. Should the HIV bill be brought in with mandatory HIV testing, there could be high horizontal inequity as certain areas would be targeted more than others.	<b>High</b> – Better policies and programs for sex workers would benefit all sex workers.	<b>Medium</b> – Would be limited to sex workers who know about the service and have regular access to a mobile phone.	<b>Medium</b> – As not all health clinics are equally dispersed across the city, there would be geographical challenges for some sex workers. Also, there would be an advantage to sex workers who already live in an area serviced by an NGO, since they will be at an advantage in connecting to their peer educator.	<b>High</b> – If all health workers are trained and are equally receptive, sex workers across Lilongwe would benefit equally.	<b>Medium</b> – Equity would be highly variable on how the vouchers were distributed.
Cost and Financial Sustainability	<b>Low</b> – No additional costs required in creating or maintaining the current system.	<b>Medium</b> – There would be a cost incurred for establishing the network and forming the organizations. There would be ongoing administrative costs to maintain the network.	<b>Medium-High</b> – There would be ongoing technical and human resources expenses to maintain the program.	<b>Medium-low</b> – Expenses would only be on-going to employ the link person between the health sector and the sex workers. Paying the sex worker point person would add to the on-going expense.	<b>Medium</b> – There would be initial expenses to devise a curriculum and pool best practices and knowledge. Expenses would be on-going for training and workshop facilitators and lost work hours.	<b>High</b> – Private clinics in Malawi are extremely expensive relative to the public system. Vouchers would be valued at a very high rate.
<b>Total (max.30)</b>	24	28	32	32	30	20

## 6: Recommendation

Based on the evaluation of the policy options in the previous section, the only option that should not be considered is the voucher program. While it does offer better access to health for sex workers by reducing structural barriers and stigma, the operationalization of this option is problematic and very expensive. As such, it did not score well in the analysis. Other policy options achieve similar effectiveness results without the same shortcomings. Therefore, the government of Malawi should build on the status quo and work towards implementing the other four policy options.

This is an opportunity to take meaningful action towards the provision of adequate services for sex workers. Currently, NGOs are providing this support to some sex workers. This effort is commendable, but not far reaching enough. Government should build on these existing programs and provide a comprehensive health response for sex workers in Lilongwe. Momentum has been established by creating the working group. This positive step should be encouraged further and pushed to fulfil its considerable potential.

The policy options can provide direction for the working group, who should take the lead on their implementation of the four policies. In the short term, the *mHealth* and Peer Education options should be rolled out as soon as possible. Both of these options have the capacity to produce quick results and empower sex workers to take control of their health. Making these health services available would foster health-seeking behaviour in a minimal-risk setting. Furthermore, to generate interest, the programs could cross-promote each other.

Currently, similar programs in Malawi exist and their best practices can be built upon. For instance, the peer education program could launch as a scaled-up, district-wide program

based on the expertise that the NGOs and DHO already have. In addition to health benefits, the peer educators and *mHealth* councillors could be consulted to determine sex workers' most relevant health needs, where the populations are located, and where there are gaps in service. The data collected from these two programs could be used as the basis for a comprehensive citywide needs assessment on sex workers' health. This effort could be coordinated by NGOs already working with sex workers. The data would help to inform future policy.

Over the medium to long term, government should implement the Sex Workers as Stakeholders and Training for Health Care Workers options. These options will require more time to achieve their full effect, but are crucial for ensuring on-going adequate access to health services and quality care by health care workers. A sex worker network would take time to formalize, but there are examples, such as MANET+, that could be used as models. Since many NGOs would support this effort, this option has high feasibility. By implementing this option, sex workers could contribute to shaping parts of the health system, making it more responsive to their needs. Training health workers would also be a longer process, but if steps were taken to build curriculum in collaboration with NGOs that have done training already, this option could immediately begin to show results. Sensitized health care workers would make a more positive clinical environment for sex workers.

Over time, the sex worker network could attain more responsibility and help in providing the policy direction for the future of sex workers in Lilongwe and, more broadly, Malawi. Since many of these options are interrelated, the network could also link the programs together. This could facilitate the development of an integrated response that would be more efficient and effective overall.

In all the options, it is imperative that government encourage further collaboration within itself and work well with NGOs. Malawi already uses this approach in some of its other program fields, such as the National AIDS Commission (NAC). Integrated programming allows for the

government to pool its resources, address complex problems, and incorporate the achievements already made by non-state actors. Instead of being implemented exclusively from the government level or exclusively from the grassroots, working collaboratively delivers success by creating common ground where government and NGOs can both contribute their expertise. Such an approach could appease all parties and be the foundation of effective and efficient solutions. In the context of Malawi, where change needs to occur at both the micro and the macro levels, this type of intersectoral approach is essential.

Finally, in adopting these options, the government would better address the human rights concerns of a vulnerable population. The government has an obligation to protect the health rights of all its citizens, as outlined in the Constitution and reinforced in the *Patient Charter*. When there are barriers to specific populations, the government has the duty to intervene to ensure equality for all its citizens.

## **7: Conclusion**

Until poverty can be alleviated in Malawi, strong pull factors to sex work will continue to exist. Due to the nature of their work, sex workers will always require additional access to health services, as their probability for contracting disease is higher than that of the general population. Presently, government has an opportunity to work together with NGOs to ensure that sex workers have more complete access to health services, which will improve their health and the health of their clients. The policy solutions presented here form the basis of low cost change that can improve upon and provide direction to programs already in place.

Once implemented, options could go beyond merely health access to provide support for other services for sex workers. For example, if training health care workers is successful, it could be adapted to a larger program to educate other service providers and the general population. Moreover, the sex worker network could grow to include other issues in addition to health and could help to facilitate other programs linked to sex work. This would further reduce stigma and allow sex workers to better integrate into the community and provide them easier access to services and alternative economic opportunities.

Other marginalized populations could benefit from the options described in this study. By addressing one of the most stigmatized and vulnerable populations first, it would be easier to create programs for other priority populations. The government will establish best practices that could be used to address similar barriers to health in other populations.

While this research comes to similar conclusions that are known to many of the stakeholders in Malawi, it brings to the fore the perspectives of all key stakeholder groups and identifies opportunities for change in the given context. This is unprecedented in the academic



study of Malawian sex workers adding specifically to how sex workers in Lilongwe interact with the health care system. The study will provide the foundation for others to add to the body of research and could start a discourse about health access for sex workers in Lilongwe.

There are limitations to this study that could have affected the scope of the research. The sex workers interviewed were mostly from a single area in Lilongwe and many of them had a long-term relationship Theatre for a Change. By using a selective study sample, the research is limited to their experiences, which may not reflect the entire population of sex workers in Lilongwe. The incorporation of stakeholders, who have worked with sex workers across the country, and consulting the literature on sex work in the region, it is clear that many of the issues presented by the sex workers in this study are similar to those faced more broadly by their peers.

To reduce these limitations and seek a broader understanding of the issues, further research should be done to focus on three priority areas: demographic data, traditional medicine, and health human resources. First, as this research demonstrated, there is a need for further study about the nature of Malawian sex work. There is little quantitative data on Malawian sex workers; the available data used to direct policy is based on ‘best guesses’ and disjointed information. There is a call for government to act quickly on this. This data should be used a starting point to better understand the demographics of sex workers. Further research is needed to expand beyond the issue of health to ensure that programs and policies produced in Malawi address the needs of sex workers and all Malawians. As many of the counties in the region face similar challenges, in securing resources and combating high prevalence of disease, Malawi could be an example in the region for good sex work policy.

Gathering demographic data across Malawi will help to identify the similarities and differences across populations of sex work. This study, for instance, focussed only on sex workers who were urban adults. With better data, government and NGOs would be able to better assess how to adapt these options, or create new ones, to be effective for rural populations or

youth. Moreover, data would help to further evaluate the challenges faced by male sex workers. This study only included a small number of male sex workers and it is unclear whether their experiences are typical of their peers or unique to those respondents. Without any Malawi-specific data on male sex work and only a small amount of literature that identifies male sex workers in Southern Africa, further research is necessary to determine how to best address the needs of this population.

The second research priority should be the integration of traditional health practice into regular Malawian health delivery. Since they have respect from the Malawian people, there could be an opportunity to creatively engage leaders and healers to contribute to the government-administered health care system. Sex workers cite that traditional healers are generally non-stigmatizing. There could be a place for them to provide advice, prevention, and appropriate treatment. Additional research would require extensive ethnographic examination of Malawian culture, which was out of the scope of this study.

Finally, further research is required on the ways in which to improve the Malawian health care system. Policy should be formulated that provides incentives for health workers to stay in Malawi and encourages international donor investment into the general health care system. Best practices from the international community should be investigated so that the Malawian government can ensure a sustainable and effective health care system.

While sex work is a high-risk occupation, it should not equate inevitable sickness. There is incredible opportunity for all stakeholders in Malawi to take action on this issue now, ensure the right to health for sex workers and their clients, and curtail the spread of HIV and STIs. Lilongwe is ideal centre to serve as a test case for many of the options presented due to the confluence of active NGOs, the current political situation, and the willingness of the public to engage with the ideas. After the pilot phase and further research, there should be a comprehensive plan to broadly implement these policies in other Malawian and Southern African cities. Malawi

has already proven with its ARV program and Patient Charter that it is a health leader in Southern Africa. The momentum for a healthy Malawi has started and it should not be allowed to stop now.

## **Appendices**

## **Appendix A: List of Organizations**

Note: only those respondents who consented to have their names released are listed

### Government

Charles Chabuka, Ministry of Gender, Child Welfare, and Community Services

Linley Kamtengi, Ministry of Gender, Child Welfare, and Community Services

HIV Unit, Ministry of Health

Maria Mukwala, National AIDS Commission (NAC)

Lucesia Kuchande, National AIDS Commission (NAC)

### Health

Lilongwe District Health Officer

Annie Kachigamba, District Health Office Nurse

Sarah C. Phiri, Nursing Student

Nurse, STI Unit, Kamuzu Central Hospital

Dr. Rachel Kreps-Falk, Baylor Paediatric AIDS Initiative (BPAI)

### NGOs connected to sex work

Macbain Mkawdawire, YouthNet and Counselling (YONECO)

Rhoda Ndovie, Theatre for a Change

Dr. Keith Joseph, Partners in Health (Malawi)

### HIV and AIDS NGOs

Amanda Manjolo, National Association of People Living with HIV/AIDS (NAPHAM)

Safari Mbewe, Malawi Network of People Living with HIV and AIDS (MANET+)

### Human Rights Organizations

Undule Mwakasungula, Centre for Human Rights and Rehabilitation (CHRR)

Martha Kwataine, Malawi Health Equity Network (MHEN)

### Other NGOs

Howard Nkhome, Christian Aid

### United Nations

Roberto Campos, United Nations Joint Programme on HIV/AIDS (UNAIDS)

Humphrey Shumba, United Nations Population Fund (UNFPA)

## Appendix B: Sex Worker Interview Schedule

1. What are some of the reasons why you got into sex work?
2. In general, how do Malawians view sex workers?
3. Did you ever access the health system while you are a sex worker?
  - a. What kind of services did you access?
  - b. Do you ever go to herbalists or pharmacists? Why? When?
4. In particular to health (clinics or hospitals), was it easy to access treatment?
  - a. Could you see any barriers to accessing treatment?
  - b. Does stigma exist? What kind? How often do you feel it? How does it get manifested?
  - c. What clinics did you access?
  - d. Does it make a difference for a female or male sex worker?
5. Would you go anywhere else besides a public clinic?
  - a. What are some reasons why you would not go to a public clinic or hospital?
6. What kind of experiences have you had when accessing health services?
  - a. Have you ever had difficulties?
  - b. Negative experiences?
  - c. Positive experiences?
  - d. Where would you complain if you had a bad experience?
7. Would you ever lie about your health history or that you were a sex worker to a healthcare worker?
  - a. Do health workers always know you are a sex worker? How do they find out?
8. What makes sex workers health needs different from the average Malawian?
9. Have you ever given something to a healthcare worker to receive better treatment?
  - a. What did you give?
  - b. Describe the circumstances
10. Are sex workers involved in any way with the policy or government process?
  - a. How can sex workers voices be heard?
  - b. What kinds of issues need to be discussed?
11. Is it easy to access ARVs? Why?
12. Do you or someone you know well take ARVs?
  - a. Can you describe the process that took you from testing to getting on the drugs?
  - b. Are there any particular problems for sex workers when accessing ART?
  - c. Is it possible to adhere to the ART regimen? What challenges exist?
  - d. Do you think that ART has made people use condoms less?
13. What kind of public health campaigns reach sex workers?
  - a. Posters, HTC days, public information or education, open days?
  - b. Are they effective?
  - c. Should there be more?

## **Appendix C: Interview Schedule for Other Informants (Sample – UNAIDS)**

1. Why do you think that people would get into sex work in Malawi?
2. What is the perception of sex workers in Malawi?
  - a. How do you think this conservativeness manifests itself in people's attitudes towards sex workers?
  - b. Do you think that the perception of sex workers is different than other places in the region to Malawi or do you think that they share some of the same perceptions of sex workers?
3. Sex workers have a high prevalence of HIV. Where do you think the disconnect is for government? Why aren't they doing more?
4. What do you think then about the HIV bill being talked about in parliament right now?
  - a. Is Malawi following a trend or leading?
  - b. Are there implications that would result in mandatory testing?
5. In terms of health of sex workers, is there any ways that they access health differently from other Malawians?
  - a. Is it ever more than just verbal discrimination?
  - b. Are there any ways to report inequities?
  - c. Are there ways to change healthcare workers to make them more accepting?
  - d. Are you aware of any training or sensitization that goes on in healthcare in how they can deal with marginalized and vulnerable groups?
  - e. What do you think should be the most priority area fixing the problem?
6. Do you think it's different for sex workers who access the health system who are HIV positive?
7. Can sex workers have a voice in public discourse or civil society?
8. In terms of UNAIDS, what are the official channels that you use to influence or talk about policy with Malawi government?
  - a. Do you think the process the government uses to engage stakeholders is effective? Have you been part of engagement with government?
  - b. Is UNAIDS considered good to have at the table?

## **Appendix D: Charter on Patients' Rights and Responsibilities**

The following text was copied from the Medical Rights Watch website (Malawi, 2000), however it was a document created in collaboration with government. A copy hangs in the District Health Office.

### **CHARTER ON PATIENTS' RIGHTS AND RESPONSIBILITIES (2000)**

#### **INTRODUCTION**

Health, defined as a complete state of physical, mental, social and spiritual well-being is a fundamental right. The responsibility of the State is to provide adequate health care commensurate with the health needs of Malawi society and international standards of health care as provided in section 13(b) of the Constitution of the Republic of Malawi.

We are all patients, one time or the other. Oftentimes health service delivery is less than optimal, sometimes due to lack of observance of fundamental human rights and responsibilities on the part of patients and health care workers. The Patients' Charter of Rights and Responsibilities is an attempt by the Government and Civil Society in Malawi to raise the general health status of all Malawians through the respect of the rights and responsibilities by both patients and their guardians and health care workers.

#### **PATIENTS' RIGHTS**

1. **Right of access to appropriate health care**
  - Every individual shall have access to health care and treatment according to his/her health need.
  - Every patient has the right to be cared for by a competent health worker regardless of age, gender, ethnicity, religion, economic status and without any form of discrimination.
  - Every patient has the right to access medicines, vaccines and other pharmaceutical supplies of acceptable standards in terms of quality, efficacy and safety as determined by the Pharmacy, Medicines, and Poisons Board.
  - Every individual has the right to prompt emergency treatment from the nearest public or private health facility.
2. **Right to choice and second opinion**
  - Every patient has the right to choose a health facility from which to obtain care in line with the prescribed health delivery system.
  - Every patient has the right to a second opinion at any time.
3. **Right to adequate information and health education**
  - Every patient has the right to know the identity and professional status of the person providing the care.
  - Every patient has the right to have adequate information regarding all aspects of care, including the right to adequate information on diagnosis and tests performed; medicines prescribed; reason for prescription, the dose, duration of taking medicine, side effects and safety.



- Every patient shall be informed of the reason for any referral to another health facility or health care provider.
  - Every patient shall be given information about self-care, drug administration and preventive measures which may be necessary.
  - Every individual has the right to seek and obtain information regarding preventive, curative and rehabilitative medicine.
  - Every patient has the right to know his or her prognosis.
4. **Right to informed consent or refusal of treatment**
- Every patient or guardian shall provide informed consent before any surgical procedure is carried, but so however that such consent may be waived in case of emergency or in certain psychiatric cases.
5. **Right to participation or representation in decision making regarding his or her care**
- Every patient has the right to participate in decision-making affecting his/her health through –
    - Discussion with the health professionals and personnel involved in direct health care.
    - consumer and community representation in planning and evaluating the system of health services, the types and qualities of service and the conditions under which health services are or were delivered.
6. **Right to respect and dignity**
- Every patient shall be treated with kindness, consideration, respect and dignity without regard to age, gender, ethnicity, religion, economic status and without any form of discrimination.
7. **Right to a guardian**
- Every child admitted to a hospital shall, wherever possible, have the right to the company of a parent or guardian.
8. **Right to privacy and confidentiality**
- Every individual has the right to have the details regarding his/her diagnosis, treatment, prognosis and other aspects of his/her care kept confidential. There may be situations when there may be need to disclose the patient's information, for instance –
    - If authorized by the patient.
    - Public health reason.
    - If patient is unable to consent and it is the patient's own interest to disclose such information.
    - If the information is required for due legal process. If the information is required for due legal process. s own in health care provider.
9. **Right to a safe environment**
- Every individual has the right to a safe and clean health care facility.
10. **Right to complain about health services**
- Everyone has the right to complain about health care services and to have such complaints investigated and to receive a full response on such investigation.

## **PATIENTS' RESPONSIBILITY**

1. Every patient shall ensure that he/she knows and understands what the patients' rights are and shall exercise the rights reasonable and responsibly.
2. Every patient shall conduct himself/herself so as not to interfere with the rights or well being of other patients and health care providers.
3. Every patient shall accept all the consequences of the patient's own informed decisions.
4. Every patient has the responsibility to ensure or maintain his/her own health and that of society by refraining from -
  - consumption of unhealthy food and water.
  - consumption of alcohol, drugs, substances of abuse and tobacco.
  - irresponsible sexual activity and other life styles that are hazardous to health.
  - degradation of the environment.
5. Every patient has the responsibility to provide health care providers with relevant and accurate information for diagnostic treatment, rehabilitation or counselling purposes.
6. Every patient must know his/her local health care providers and what services they offer.
7. Where applicable, every patient is responsible for settling his/her bills at times as requested by the health providers.
8. Every patient shall comply with the prescribed treatment and keep appointments and shall inform the health professional in good time if unable to do so.
9. Every patient has the responsibility to take care of his/her health records in his/her possession.

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