

# Accountability and redress for discrimination in healthcare in Botswana, Malawi and Zambia





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## **SALC REPORT**

Accountability and redress for discrimination in healthcare in Botswana, Malawi and Zambia

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The Southern Africa Litigation Centre (SALC), established in 2005, aims to provide support – both technical and financial – to human rights and public interest initiatives undertaken by domestic lawyers in southern Africa. SALC works in Angola, Botswana, Democratic Republic of Congo, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia and Zimbabwe. Its model is to work in conjunction with domestic lawyers in each jurisdiction who are litigating public interest cases involving human rights or the rule of law. SALC supports these lawyers in a variety of ways, as appropriate, including providing legal research and drafting, training and mentoring, and monetary support. SALC's objectives include the provision of training and the facilitation of legal networks within the region.

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# Acronyms and abbreviations

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>ART</b>	Anti-retroviral treatment
<b>BHPC</b>	Botswana Health Professions Council
<b>CBO</b>	Community-based organisation
<b>CEDAW</b>	Convention on the Elimination of All Forms of Discrimination against Women
<b>CESCR</b>	United Nations Committee on Economic, Social and Cultural Rights
<b>COHSASA</b>	Council for Health Service Accreditation of Southern Africa
<b>CRC</b>	Convention on the Rights of the Child
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>EHP</b>	Essential Health Package
<b>GNCZ</b>	General Nurses Council of Zambia
<b>HCAC</b>	Healthcare advisory committee
<b>HIV</b>	Human immunodeficiency virus
<b>HPCZ</b>	Health Professions Council of Zambia
<b>HRCZ</b>	Human Rights Commission of Zambia
<b>ICESCR</b>	International Covenant on Economic, Social and Cultural Rights
<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>LEGABIBO</b>	Lesbians, Gays and Bisexuals of Botswana
<b>LGBT</b>	Lesbian, gay, bisexual, and transgender
<b>MCM</b>	Medical Council of Malawi
<b>MHRC</b>	Malawi Human Rights Commission

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<b>NASF</b>	National AIDS Strategic Framework, Zambia
<b>NGO</b>	Non-governmental organisation
<b>NMCB</b>	Nursing and Midwifery Council of Botswana
<b>NMCM</b>	Nurses and Midwives Council of Malawi
<b>NONM</b>	National Organisation of Nurses and Midwives of Malawi
<b>NORAD</b>	Norwegian Agency for Development and Cooperation
<b>SALC</b>	Southern Africa Litigation Centre
<b>STI</b>	Sexually transmitted infection
<b>PEP</b>	Post-exposure prophylaxis to prevent HIV
<b>PHRCZ</b>	Permanent Human Rights Commission of Zambia
<b>UDHR</b>	Universal Declaration of Human Rights
<b>UN GA</b>	United Nations General Assembly
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNDP</b>	United Nations Development Programme
<b>VCT</b>	Voluntary counselling and testing
<b>VHC</b>	Village health committee
<b>WHO</b>	World Health Organisation

# Executive summary

Stigma and discrimination violate human rights and are barriers to HIV prevention and treatment. This report is concerned with the availability, effectiveness and sufficiency of systems providing accountability and redress for persons who experience discrimination in healthcare settings. The report focuses on the experiences of sex workers, lesbian, gay, bisexual and transgender (LGBT) persons, women living with HIV, and persons with disabilities in Botswana, Malawi and Zambia.



## Research findings

Legal protections and policy commitments in Botswana, Malawi and Zambia prohibit discrimination in broad terms and emphasise commitments to equitable access to quality healthcare, despite not providing for many explicit protections for key populations and vulnerable populations. It is not a crime to be a sex worker in Botswana, Malawi or Zambia, and LGBT persons are not criminalised in themselves – even if certain same-sex sexual acts are criminalised in these countries. Healthcare workers are ethically and legally bound not to discriminate unfairly against healthcare users and need to respect their inherent human dignity.

Anecdotal accounts from key populations and vulnerable populations indicate serious and varied experiences of discrimination in healthcare in Botswana, Malawi and Zambia, based on a number of grounds. These include health and HIV-status, gender, sexual orientation, disability, socio-economic status, occupation, and rural location. Conduct described as discriminatory by healthcare workers and institutions includes:

- Treatment denial.
- Abusive language.
- Failure to properly examine healthcare users before providing treatment.
- Sexual coercion and abuse.
- Physical abuse such as slapping and hitting.
- Failure to observe healthcare users' confidentiality, including health-status confidentiality and confidentiality relating to healthcare users' sexual orientation, gender identity, and occupation.
- Failure to conduct proper informed consent procedures.
- Failure to provide reasonable accommodation for persons with disabilities.
- Denial of access to sexually-transmitted infection (STI) and HIV testing, counselling and treatment, in the absence of (heterosexual) sexual partners.
- Blaming healthcare users for their health status.
- Segregation and the use of identifying practices for people living with HIV.
- Failure to accommodate the particular healthcare and access needs of sex workers, persons with disabilities, gay and transgender persons in particular.

There are various options to relate complaints of discrimination in healthcare outside of the formal court process. However, these processes provide for varying levels of availability, effectiveness, and sufficiency in holding healthcare workers and systems to account and in providing healthcare users with the right to redress. The complaints bodies analysed include facility-level or internal complaints processes, health professions and nursing councils, national human rights institutions and one specialised body dealing with persons with disabilities.

While having some potential for healthcare users to lodge complaints, these processes all require significant investment and improved procedural clarity and consistency to ensure that States are complying with their obligations to fulfil the right to redress for victims of discrimination. Greater

sensitivity to the needs of key populations and vulnerable populations must be guaranteed within these systems to ensure that the processes in themselves are not discriminatory by excluding certain persons from meaningful, safe and effective access.

## Key recommendations

From the preliminary research findings in this report, several recommendations are made. Key recommendations include:

**Legislative reform:** Including: the decriminalisation of consensual same-sex sexual acts; review of laws used to unlawfully target and harass sex workers; the development of legal protections and procedures for healthcare complaints; comprehensive disability legislation in Botswana; the entrenchment of healthcare users' rights to access their medical records; and the establishment of a national human rights institution in Botswana.

**Policy reform:** Including: developing commitments to ending discrimination in healthcare, with particular measures to protect sex workers, LGBT persons, women living with HIV and persons with disabilities; budgetary and personnel commitments to enable available, effective and sufficient complaints processes for healthcare users to lodge grievances; and improved health management policies to ensure persons with diverse disabilities are able to access healthcare services independently and with due respect for their dignity, safety, and right to informed consent and information.

**Development of ethical standards and guidelines:** Including: updating professional ethical codes to include concepts relating to discrimination and to address the particular forms of discrimination and healthcare needs experienced by key populations and vulnerable populations.

**Training of healthcare workers:** Including: training on revised concepts and examples of discrimination developed in consultation with key populations and vulnerable populations to ensure that diverse needs and experiences are sensitively accommodated.

**Improving the availability, effectiveness and sufficiency of complaints bodies:** Including: clarification and streamlining of facility-level complaints processes; improved safety and accessibility guarantees in all complaints mechanisms; and the incorporation of complaints analysis processes to ensure that systemic problems are identified and that healthcare workers are supported to be responsive to concerns about discrimination.

**Capacity-building and education for healthcare users and key stakeholders:** Including: the empowerment of healthcare users and key stakeholders on issues of health rights and the use of complaints processes; and training of complaints body staff on strategies to ensure the safety and protection of key populations and vulnerable populations.

# 1. Introduction

## 1.1 Background and purpose of the research

Southern Africa bears a disproportionate burden of HIV globally and indications are that stigma and discrimination remain high, not only amongst people living with HIV but also amongst those most vulnerable to HIV. Stigma and discrimination are one of the biggest barriers to HIV prevention and treatment.<sup>1</sup> This report is concerned with the availability, effectiveness and sufficiency of systems providing accountability and redress for persons who experience discrimination in healthcare settings. The report focuses on sex workers, lesbian, gay, bisexual and transgender (LGBT) persons, women living with HIV, and persons with disabilities in Botswana, Malawi and Zambia. This is in recognition that these groups may experience increased and multiple forms of discrimination and might find it more difficult to access processes to obtain redress.

The research aims to understand the experiences of these persons in terms of discrimination in healthcare and how access to accountability and redress might be expanded through the use of quasi-judicial processes and complaints mechanisms. This is a preliminary research report which is primarily aimed at assisting the Southern Africa Litigation Centre (SALC) to develop relevant advocacy and litigation strategies to address systemic healthcare discrimination in the three countries in which SALC is currently focusing its health-related litigation efforts.

## 1.2 Methodology

This report is based on a combination of desktop research and qualitative field research in Botswana, Malawi and Zambia. Further details of the methodology are detailed in the Annexures.

In addition to a literature review to develop the report's analytical framework in Chapter 3, desktop research included a review of the legal, policy and ethical frameworks in Chapter 4, and which informed the analysis of qualitative data represented in Chapters 5, 6 and 7.

Through working together with partner organisations in Botswana, Malawi and Zambia, focus-group discussions were conducted with persons identified as key populations<sup>2</sup> and vulnerable

<sup>1</sup> Joint United Nations Programme on HIV/AIDS (UNAIDS) *Reduction of HIV-Related Stigma and Discrimination: Guidance Note* (2014), available at: [http://www.unaids.org/sites/default/files/media\\_asset/2014unaidsguidancenote\\_stigma\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf), 2.

<sup>2</sup> The World Health Organisation (WHO) *Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care of Key Populations* (2014), available at: [http://apps.who.int/iris/bitstream/10665/128048/1/9789241507431\\_eng.pdf?ua=1&ua=1](http://apps.who.int/iris/bitstream/10665/128048/1/9789241507431_eng.pdf?ua=1&ua=1), at xii, defines "key populations" as: "groups who, due to specific higher-risk behaviours, are at increased risk of HIV irrespective of the epidemic type or local context. Also, they often have legal and social issues related to their behaviours that increase their vulnerability to HIV. ... The key populations are important to the dynamics of HIV transmission. They also are essential partners in

populations.<sup>3</sup> For the purpose of this research, selected participants included persons who self-identified as (1) LGBT persons; (2) sex workers; (3) women living with HIV; and (4) persons with physical disabilities. A total of fourteen focus groups were held with 211 participants across the three countries. The purpose of these focus groups was twofold: firstly to understand participants' experiences of stigma and discrimination in healthcare; and secondly to develop an understanding of the participants' experiences, if any, of seeking accountability or redress for discrimination and the participants' particular needs and preferences in order for justice to be an obtainable ideal. This information is primarily reflected in Chapter 6.

Questionnaires were distributed and interviews conducted with non-governmental organisations (NGOs) and community-based organisations (CBOs). This was to verify desktop research, and to gain an understanding of the experiences and capacities of these organisations to support healthcare users to seek accountability and redress when experiencing discrimination. A total of sixteen in-person interviews and 25 questionnaires were completed. This information is primarily reflected in Chapters 5, 6 and 7.

Lastly, key informant interviews were conducted with several institutions and organisations whose functions include the handling of complaints relating to healthcare and human rights violations. A total of eleven key informant interviews were conducted across the three countries. Together with desktop research, this information is used in Chapter 6 to determine the potential of these mechanisms to deal with healthcare discrimination complaints.

## 1.3. Limitations

### Scope and nature of the report

In all three countries, healthcare is provided by both public and private facilities. This report focuses on accountability and redress for discrimination in relation to public healthcare. Where reference is made to any distinction between public and private facilities, these have been raised by the participants in the research.

The report's ambit does not include traditional medicine and dispute-resolution processes.

Any numerical indications in the report are intended solely to emphasise observations. There is no assertion intended or made that any of the qualitative data in the report are appropriate for statistical extrapolation or generalisations.

### Focus-group discussions

This report presents anecdotal accounts of treatment in accessing healthcare that is perceived as discriminatory by healthcare users. No assertion is made or intended that the experiences

an effective response to the epidemic.”

<sup>3</sup> WHO, as above, defines “vulnerable populations” as: “groups of people who are particularly vulnerable to HIV infection in certain situations or contexts, such as adolescents (particularly adolescent girls in sub-Saharan Africa), orphans, street children, people with disabilities and migrant and mobile workers. These populations are not affected by HIV uniformly across all countries and epidemics.”

represented in this report reflect the prevalence of healthcare discrimination.

Some focus-group discussions were not conducted in English. While researchers have endeavoured to ensure accuracy of translations, the margin for inaccuracy is noted.

We acknowledge that various external factors also impact on the extent to which persons choose to access complaints mechanisms, including time-constraints, workload, childcare responsibilities, and risks to or consequences of gender-based violence. These issues were not canvassed with participants.

## Information about laws, policies and complaints procedures

Publically-available information was used to develop an account of the complaints mechanisms examined. Key informant interviews were conducted with persons from the complaints bodies where possible to supplement this information. In addition, a verification process was undertaken to ensure the accuracy of the information presented. We acknowledge, however, the prospect for inaccuracy, particularly with respect to internal complaints processes for which minimal publically-accessible information is available.

Due to time constraints, no interviews were conducted with healthcare providers or ministries of health. While some persons who are healthcare providers participated in the key informant interviews, their perspectives were as members of their relevant organisations and not as healthcare providers *per se*.

In addition, it is acknowledged that there may be additional avenues for accountability and redress for discrimination in healthcare that are not included in the report. The report does not purport to be a comprehensive account of all complaints procedures.

## 1.4 Structure of the report

This report is divided into eight sections:

1. This introduction sets out the justification and methodology of the report.
2. In Chapter 2, the context of the healthcare systems are briefly described in Botswana, Malawi and Zambia.
3. In Chapter 3, an analytical framework is developed on understandings of stigma and discrimination in the context of healthcare and to frame the assessment of complaints mechanisms as systems of accountability and redress. This section is based on international human rights law standards.
4. In Chapter 4, domestic protections against stigma and discrimination in healthcare settings are set out in the three countries, in terms of legal and policy frameworks and ethical standards governing the conduct of healthcare workers.
5. Chapter 5 sets out various mechanisms in the three countries that are available for healthcare users to refer complaints. These include brief analyses of facility-level complaints processes, health professions councils, nursing councils, and (where available) national human rights institutions.

6. In Chapter 6 experiences of discrimination in healthcare of various key populations and vulnerable populations are described. This includes sex workers, LGBT persons, women living with HIV, and persons with disabilities. The Chapter also relates experiences of justice-seeking behaviour and the preferences and needs of these persons for effective complaints processes to be safe, accessible and responsive.
7. Chapter 7 considers the barriers that key populations and vulnerable populations face in seeking accountability and redress for discrimination in healthcare and considers, from the views of respondents, how systems for accountability and redress can be strengthened.
8. Finally, in Chapter 8, recommendations are made.

## 2. Context

### 2.1 Botswana



#### Demographics

Botswana is a semi-arid land-locked country in the centre of southern Africa, with a population of just over two million persons.<sup>4</sup> It is rated as a middle-income country at “medium” on the United Nations Development Programme’s Human Development Index – at 106 of 188 countries.<sup>5</sup>

#### HIV burden

Botswana has an estimated national HIV prevalence rate of 18.5%.<sup>6</sup> Due to an effective anti-retroviral treatment (ART)<sup>7</sup> programme, mortality due to AIDS has been declining over the past four years, but remains a major concern.<sup>8</sup> The Botswana government recognises that the HIV epidemic is generally driven through sexual transmission.<sup>9</sup>

#### The healthcare system

Botswana’s healthcare system includes public and private (for-profit and not-for-profit) healthcare. The public sector is, however, the predominant provider of healthcare services: more than 80% of persons who access healthcare do so through public facilities and programmes.<sup>10</sup> The system

<sup>4</sup> Republic of Botswana *Population and Housing Census: Preliminary Result Brief* (2011).

<sup>5</sup> United Nations Development Programme (UNDP) *Human Development Report 2015: Work for Human Development* (2015), available at: [http://hdr.undp.org/sites/default/files/2015\\_human\\_development\\_report\\_1.pdf](http://hdr.undp.org/sites/default/files/2015_human_development_report_1.pdf), 210.

<sup>6</sup> Statistics Botswana *Botswana AIDS Impact Survey IV (BAIS IV)* (2013).

<sup>7</sup> Standard ART is a combination of antiretroviral drugs used to suppress the HIV virus and stop the progression of HIV disease.

<sup>8</sup> Republic of Botswana *National Health Policy: Towards a Healthier Botswana* (2011) at para 2.5.1.

<sup>9</sup> Republic of Botswana *The Second Botswana National Strategic Framework for HIV and AIDS 2010-2016* (2009) at para 1.2.

<sup>10</sup> National Health Policy: Towards a Healthier Botswana, note 8 above, at para 2.7.1.

is decentralised and comprises 29 health districts based on a primary healthcare approach.<sup>11</sup> Public healthcare services are delivered through hospitals, clinics, health posts, and mobile health clinics. Despite Botswana's sparse population density, 95% of the total population (89% of the rural population) live within an 8 km radius of a health facility.<sup>12</sup>

Botswana suffers from a shortage of trained and qualified healthcare staff<sup>13</sup> with a higher scarcity of doctors than nurses.<sup>14</sup> Services in public facilities are subject a “cost recovery system”, with the exemption of “vulnerable” populations.<sup>15</sup> Additional charges include admission fees, ambulance charges, and other charges for private healthcare users and non-citizens. The government admits that the extent to which these costs compromise access to essential services has not been assessed while acknowledging that collection costs are likely higher than the funds received.<sup>16</sup>

## Stigma and discrimination

Research in Botswana has shown that stigma leads many people to seek testing and treatment services too late in the progression of the disease, beyond the optimal stages for drug intervention.<sup>17</sup> Stigma in healthcare settings has also been shown to inhibit healthcare workers themselves from seeking testing and treatment.<sup>18</sup> The Botswana government estimates that 24% of people living with HIV have experienced internalised stigma, while 13% have experienced external stigma.<sup>19</sup> The government recognises that its interventions to reduce stigma and discrimination are not being implemented on “the right scale and intensity to adequately address gender-based stigma and discrimination against people living with HIV and other key populations.”<sup>20</sup>

<sup>11</sup> Statistics Botswana *Health Statistics Report 2009* (2012), available at: [http://www.cso.gov.bw/templates/cso/file/File/Health%20Statistics%20Annual%20Report\\_2009\[2\].pdf](http://www.cso.gov.bw/templates/cso/file/File/Health%20Statistics%20Annual%20Report_2009[2].pdf), 9.

<sup>12</sup> Statistics Botswana *Statistical Brief No 2007/4: Access to Health Services in Botswana* (2007).

<sup>13</sup> National Health Policy: Towards a Healthier Botswana, note 8 above, at para 2.8.1.

<sup>14</sup> Statistics Botswana *Health Statistics Report 2009* (2012), available at: [http://www.cso.gov.bw/templates/cso/file/File/Health%20Statistics%20Annual%20Report\\_2009\[2\].pdf](http://www.cso.gov.bw/templates/cso/file/File/Health%20Statistics%20Annual%20Report_2009[2].pdf), 8.

<sup>15</sup> National Health Policy, note 8 above, at para 2.9.2.

<sup>16</sup> As above, at para 2.9.2.

<sup>17</sup> WR Wolfe et al. “Effects of HIV-Related Stigma among an Early Sample of Patients Receiving Antiretroviral Therapy in Botswana” (2006) 18 *AIDS Care* 931.

<sup>18</sup> KE Uebel et al. “Caring for the Caregivers: Models of HIV/AIDS Care and Treatment Provision for Health Care Workers in Southern Africa” (2007) 196 *J Infect Dis.* Suppl 3.

<sup>19</sup> Republic of Botswana *Progress Report of the National Response to the 2011 Declaration of Commitments on HIV and AIDS* (2015), available at: [http://www.unaids.org/sites/default/files/country/documents/BWA\\_narrative\\_report\\_2015.pdf](http://www.unaids.org/sites/default/files/country/documents/BWA_narrative_report_2015.pdf), 25.

<sup>20</sup> As above.

## 2.2 Malawi



### Demographics

Malawi is a landlocked country in southern Africa, with a population of about 15.8 million.<sup>21</sup> It is among the world's least developed countries and is heavily dependent on aid. Malawi is rated as having low human development on the Human Development Index, at 173 out of 188 countries.<sup>22</sup>

### HIV burden

HIV prevalence in Malawi is estimated by the National Statistics Office at 10.6%, with higher prevalence in urban areas than rural areas.<sup>23</sup> Malawi's Southern Region has the highest HIV prevalence nationally. The primary mode of HIV transmission is through heterosexual sexual contact.<sup>24</sup>

### The healthcare system

Health services in Malawi are provided by both public and private (for-profit and not-for-profit) facilities. Public healthcare facilities are by policy required to provide services free of charge<sup>25</sup> while user fees are usually levied in private facilities.<sup>26</sup> The Ministry of Health has, in addition, encouraged District Health Officers to sign service-level agreements with the Christian Health Association of Malawi, a private not-for-profit service provider, to expand access to health services particularly in rural areas. Since 2004, the government has implemented an "Essential Health Package" aimed at expanding healthcare towards universal access.<sup>27</sup> The healthcare system in Malawi faces "acute and complex" human resources challenges: health staff are vastly inadequate to serve population needs.<sup>28</sup>

<sup>21</sup> 2014 estimate. National Statistics Office *Statistical Yearbook (2015)*, available at: [http://www.nsomalawi.mw/images/stories/data\\_on\\_line/general/yearbook/2015%20Statistical%20Yearbook.pdf](http://www.nsomalawi.mw/images/stories/data_on_line/general/yearbook/2015%20Statistical%20Yearbook.pdf).

<sup>22</sup> Human Development Report 2015: Work for Human Development, note 5 above, 211.

<sup>23</sup> National Statistics Office *Malawi Demographic and Health Survey (2010)*.

<sup>24</sup> "The People Living with HIV Stigma Index: Malawi" *Malawi Network of People Living with HIV and AIDS (MANET+)* (2012), available at: [http://www.stigmaindex.org/sites/default/files/reports/Malawi\\_LowRes\\_ForWeb.pdf](http://www.stigmaindex.org/sites/default/files/reports/Malawi_LowRes_ForWeb.pdf), 19.

<sup>25</sup> Malawi Government *Malawi Public Service Charter: Raising the Bar of Excellence* (2013).

<sup>26</sup> The Malawi government has, however, made steps towards introducing user fees in public health facilities from July 2016. See, for example, W Mwale "User Fee in Public Hospitals Starts July" *The Times Group* (20 May 2016), available at: <http://www.times.mw/user-fee-in-public-hospitals-starts-july/>. This move has been met with criticism from non-governmental organisations in Malawi.

<sup>27</sup> AG Abiuro et al. "Gaps in Universal Health Coverage in Malawi: A Qualitative Study in Rural Communities" (2014) *BMC Health Services Research*, available at: <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-234>.

<sup>28</sup> Government of Malawi: Ministry of Health *Malawi Health Sector Strategic Plan 2011-2016: Moving Towards Equity and Quality* (2016), 30.

## Stigma and discrimination

Government policy recognises stigma and discrimination, difficulties reaching vulnerable populations and discriminatory legislation as drivers of the HIV epidemic in Malawi.<sup>29</sup> Despite research indicating low levels of internalised stigma, people living with HIV experience high levels of interpersonal discrimination and relatively higher levels of discrimination in healthcare settings.<sup>30</sup> In Malawi's 2012 People Living with HIV Stigma Index study, 4.5% of respondents reported being denied health services because of their HIV status in the twelve months prior to being surveyed, 8.3% reported being denied sexual and reproductive services because of their HIV status, and 7.9% reported being denied family-planning services because of their HIV status.<sup>31</sup> At the time of writing, Malawi was undertaking its second Stigma Index study. Key informants indicated that Stigma and Discrimination Guidelines were in the process of being developed.

## 2.3 Zambia



### Demographics

Zambia is a landlocked country in southern Africa. It is a lower-middle income country and is rated as having medium human development on the Human Development Index, at number 139 out of 188 countries.<sup>32</sup> The Central Statistics Office, Zambia, estimated the national population in 2016 to be almost 16 million.

### HIV burden

2012 estimates placed Zambia's HIV prevalence at about 14.3% of the adult population, with prevalence highest in the Lusaka Province.<sup>33</sup> Zambia has a generalised epidemic with HIV transmission occurring predominantly through heterosexual sexual contact.<sup>34</sup>

<sup>29</sup> Malawi National AIDS Commission *Malawi National HIV and AIDS Strategic Plan 2011-2016* (2011), 2.

<sup>30</sup> M Neuman et al. "Experiences of Stigma, Discrimination, Care and Support among People Living with HIV: A Four Country Study" (2013) 17 *AIDS Behav* 1796.

<sup>31</sup> "The People Living with HIV Stigma Index: Malawi", note 24 above. See, also: M Chirwa et al. *Stigma and Discrimination Experienced by People Living with HIV and AIDS in Malawi*, available at: <http://www.ndr.mw:8080/xmlui/bitstream/handle/123456789/974/STIGMA%20AND.pdf?sequence=1>.

<sup>32</sup> Human Development Report 2015: Work for Human Development, note 5 above, 210.

<sup>33</sup> "The People Living with HIV Stigma Index: Zambia" *Network of Zambia People Living with HIV/AIDS (NZP+)* (2012), available at: <http://www.stigmaindex.org/sites/default/files/reports/Zambia%20People%20Living%20with%20HIV%20Stigma%20Index%20Report%20%202009%20published%202012.pdf>, 17.

<sup>34</sup> Republic of Zambia: National AIDS Council *Zambia Country Report: Monitoring the Declaration of the Commitment on HIV and AIDS and the Universal Access* (2015), available at: [http://www.unaids.org/sites/default/files/country/documents/ZMB\\_narrative\\_report\\_2015.pdf](http://www.unaids.org/sites/default/files/country/documents/ZMB_narrative_report_2015.pdf), 6.

## The healthcare system

Zambia's healthcare system includes public and private (for-profit and not-for-profit) facilities, most of which are publically owned and managed. Public healthcare in Zambia is organised on three levels: primary care (predominantly health centres and health posts); secondary care (provincial and general hospitals and district hospitals); and tertiary care (teaching hospitals). In 2006, user fees were abolished from health centres and district hospitals in the rural areas, and this was extended to peri-urban areas in 2007.<sup>35</sup> ART is offered free of charge at public health facilities.

Zambia faces a significant human resource crisis in its healthcare system.<sup>36</sup> In addition, significant disparities exist in terms of accessing care for rural populations. Approximately 46% of residents live within a 5 km radius of a health centre (i.e. primary healthcare services) – but many residents must travel more than 50 km to reach a healthcare facility.<sup>37</sup>

## Stigma and discrimination

In Zambia's 2012 People Living with HIV Stigma Index, respondents were recruited through healthcare facilities. Despite this, 8.4% nevertheless reported being denied healthcare services in the twelve months prior to being surveyed.<sup>38</sup> In addition, 9.7% reported being denied family planning services and 11.8% reported being denied reproductive health services as a result of their HIV status.<sup>39</sup>

<sup>35</sup> S Carasso et al. "Health Worker Perspectives on User Fee Removal in Zambia" (2012) 10 *Human Resources for Health*, available at: <http://human-resources-health.biomedcentral.com/articles/10.1186/1478-4491-10-40>.

<sup>36</sup> E Makasa "The Human Resource Crisis in the Zambian Health Sector – A Discussion Paper" 35 *Medical Journal of Zambia* (2012).

<sup>37</sup> "Key Health Challenges for Zambia" *Association of Chartered Certified Accountants* (2013), available at: <http://www.accaglobal.com/content/dam/acca/global/PDF-technical/health-sector/tech-tp-khcz.pdf>, 7.

<sup>38</sup> The People Living with HIV Stigma Index: Zambia, notes 33 and 34 above.

<sup>39</sup> As above.

## 3. Analytical framework

### 3.1 What is the meaning of “stigma and discrimination”?

#### Introduction

Research participants, including focus-group participants, NGO and CBO interviewees, and key informants from complaints mechanisms, were invited to give meaning to the terms “stigma” and “discrimination” in their own words. This was done to ensure participants had the conceptual freedom to identify practices and behaviours experienced as discriminatory or stigmatising. Some rich definitions were offered by the participants:

#### Stigma

NGO and CBO respondents broadly understood stigma as being a prejudicial, degrading or debasing attitude which results in a shameful or disgraceful stereotype, label or status imposed on a person. Respondents, in addition, included notions of exclusion, outcasting, disassociation and isolation in their understandings of stigma. These respondents, in all three countries, distinguished between social stigma and self-stigma:

*“[Stigma is the] status of an individual when he is not taken as he is. [A] status that makes you not the same as others. [It is the] disassociation of a group or individual because of a certain status they have.” (NGO respondent – Lilongwe, Malawi)*

*“Self-stigmatisation means persons with disabilities withdrawing from public life and affairs with the thought that society neglects them and that they are less human than others. Therefore in the health sector societal stigma is linked to the fact that the disability of a person is sometimes directly the cause of their health problem.” (NGO respondent – Lusaka, Zambia)*

Key informants from complaints mechanisms in the three countries emphasised notions of dishonour, humiliation and ridicule of a person or group and the results of stigma in terms of isolation, disempowerment and social withdrawal.

*“It is a set of negative and often unfair beliefs that a society or group of people have about something.” (Complaints mechanism respondent – Malawi)*

## Discrimination

Focus-group participants across categories had inter-related understandings of stigma and discrimination, drawing on the causal relationship between the two ideas:

*“Discrimination, it can be in a way of... not being treated the same. Like in our case just because of what you are or what affects you, people will definitely isolate you in a certain manner. Also discrimination leads to stigma when a person is being discriminated, you will be labelled and people begin to call you all sorts of things. So I think discrimination and stigma are interrelated in a way.”* (LGBT respondent – Kitwe, Zambia)

Some civil society and CBO respondents shared the idea of discrimination as stigma enacted:<sup>40</sup>

*“[Discrimination] is the manifestation of the stigma behaviour. For example, when a nurse calls the police because a transman has presented an [identity document] which is different from their gender presentation.”* (NGO respondent – Gaborone, Botswana)

In explaining discrimination, focus-group participants captured, in their own words, three constituent elements of discrimination of: (1) prejudicial treatment that is (2) different to how others are treated, and (3) because one belongs to a particular group:

*“Being treated unfavourably with a comparison to another person. Like when a certain group of people are being denied to enjoy a certain treatment which another group is enjoying.”* (LGBT respondent – Zambia)

Sex worker respondents picked up on notions of power and social status:

*“[Discrimination is] a misunderstanding between two or more people where one of the parties considers themselves superior to another in one way or other. The individual claiming superiority can do so due to their position, power and wealth.”* (Sex worker respondent – Selebi Phikwe, Botswana)

Persons with disabilities participating in focus groups, in addition highlighted notions of indirect discrimination, in experiences where reasonable accommodation of differential needs was not provided:

*“We are made to stay in the queue for a long time, even when they are giving out medical papers they don’t consider that we may have difficulties. Discrimination is when you make other people in society feel oppressed or deprived of that which others are enjoying. This refers to differences in treatment based on how we live here; they can look at how we look and what have you and judge you based on your disability.”* (Person with disabilities respondent – Ndola, Zambia)

NGO and CBO respondents similarly described discrimination as including notions of unfair, differential treatment based on a person’s status or identity:

<sup>40</sup> The idea of discrimination as “enacted stigma” is described in “The People Living with HIV Stigma Index: An Index to Measure the Stigma and Discrimination Experienced by People Living with HIV” *User Guide* (2008), available at: [http://www.stigmaindex.org/sites/default/files/page-attachments/UserGuide\\_FINAL\\_complete0055.pdf](http://www.stigmaindex.org/sites/default/files/page-attachments/UserGuide_FINAL_complete0055.pdf), 43.

*“Discrimination is a kind of abuse but not all abuse is discriminatory – it is selective abuse; the unequal treatment of equals.” (NGO respondent – Lilongwe, Malawi)*

*“Systematically or systemically treating a patient or client seeking healthcare services differently – by either the service provider or communities – on the basis of that person’s race, sex, origin, colour, age, disability, religion, conscience, belief, culture, language, tribe, ethnic, social or economic status.” (NGO respondent – Lusaka, Zambia)*

**Key informants from complaints mechanisms generally provided less detailed understandings of discrimination but referred predominantly to prejudicial treatment that differentiated between persons. In some cases, respondents gave dismissive or defensive accounts of the term:**

*“Some cases are blatant, clear ‘discrimination’ while others are not. The term discrimination is not a concept that we ... employ. We classify such behaviours towards patients as professional misconduct, as nurses and midwives are expected to work by the regulations provided for.” (Complaints mechanism respondent – Malawi)*

*“[Discrimination is] a perception where one feels they are being denied a service because of their medical condition.” (Complaints mechanism respondent – Zambia)*

#### **UNAIDS describes HIV-related stigma and discrimination in the following ways:<sup>41</sup>**

**HIV-related stigma** refers to the negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. the families of people living with HIV) and other key populations at higher risk of HIV infection – such as people who inject drugs, sex workers, men who have sex with men, and transgender people.

**HIV-related discrimination** refers to the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status. Discrimination in the context of HIV also includes the unfair treatment of other key populations, such as some social contexts, women, sex workers, people who inject drugs, men who have sex with men, transgender people, people in prisons and other closed settings and, in some social contexts, women, young people, migrants, refugees and internally displaced people. HIV-related discrimination is usually based on stigmatising attitudes and beliefs about populations, behaviours, practices, sex, illness and death. Discrimination can be institutionalised through existing laws, policies and practices that negatively focus on people living with HIV and marginalised groups, including criminalised populations.”

<sup>41</sup> Joint United Nations Programme on HIV/AIDS (UNAIDS) *Reduction of HIV-Related Stigma and Discrimination: Guidance Note* (2014), available at: [http://www.unaids.org/sites/default/files/media\\_asset/2014unaidsguidancenote\\_stigma\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf), 2.

## International human rights law

The right to freedom from discrimination is central to international human rights law. Article 2(1) of the International Covenant on Civil Political and Rights (ICCPR)<sup>42</sup> obliges States to respect the rights of all individuals in its jurisdiction–

*“without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”<sup>43</sup>*

Article 26 of the ICCPR provides for the right to equality in the following terms:

*“All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”*

Article 2 of the African Charter on Human and Peoples’ Rights<sup>44</sup> similarly provides for the right to freedom from discrimination<sup>45</sup> and article 3 creates a broad right to equal protection.

The prohibition against discrimination under international and regional African law<sup>46</sup> includes both direct<sup>47</sup> and indirect<sup>48</sup> discrimination. The grounds of discrimination that are prohibited are considered non-exhaustive<sup>49</sup> and include health status, actual or perceived HIV status,<sup>50</sup> age, disability, marital or family status, sexual orientation,<sup>51</sup> and gender identity.

The Convention on the Rights of Persons with Disabilities (CRPD)<sup>52</sup> prohibits discrimination against persons with disabilities. NGO respondents described the CRPD’s vision of “discrimination” in the following words:

<sup>42</sup> Botswana ratified the ICCPR in 2000, Malawi in 1993, and Zambia in 1984.

<sup>43</sup> See, also, article 2 of the Universal Declaration of Human Rights (UDHR) United Nations General Assembly (UN GA) Res 217 A (III) UN Doc A/810 (10 December 1948); and article 2(2) of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (16 December 1966) 993 UNTS 3, amongst others.

<sup>44</sup> (1982) 21 ILM 58. Botswana ratified the Charter in 1986, Malawi in 1989, and Zambia in 1984.

<sup>45</sup> See, also, Article 18(3) (for specific provisions on the prohibition of discrimination against women) and article 2(1) of the Protocol to the African Charter on Human and People’s Rights on the Rights of Women in Africa (“Maseru Protocol”) (11 July 2013).

<sup>46</sup> See: *Good v Republic of Botswana* (African Commission on Human and Peoples’ Rights Recommendation) 313/05 (26 May 2010), at para 219.

<sup>47</sup> UN Committee on Economic, Social and Cultural Rights (CESCR) *General Comment No. 20: Non-Discrimination in Economic, Social and Cultural Rights (Art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights)* (2 July 2009), at para 10(a).

<sup>48</sup> As above, at para 10(b).

<sup>49</sup> General Comment 20: Non-Discrimination in Economic, Social and Cultural Rights (Art 2, para 2, of the International Covenant on Economic, Social and Cultural Rights note 47 above, at paras 28-35. See, also, *Good v Botswana*, note 46 above, at para 218.

<sup>50</sup> See, also, UN Human Rights Committee (HRC) *Concluding Observations of the Human Rights Committee: Republic of Moldova* (4 November 2009), at para12.

<sup>51</sup> See, for example, *Zimbabwe Lawyers for Human Rights and Associated Newspapers of Zimbabwe v Zimbabwe* (African Commission on Human and Peoples’ Rights Recommendation) 284/03, at para 155.

<sup>52</sup> Botswana has not yet ratified the CRPD, Malawi ratified the CRPD in 2009, and Zambia did so in 2010.

*“Discrimination according to the CRPD is about distinction, exclusion, and restriction on the basis of disability with the purpose of nullifying or impairing the enjoyment or recognition of the right to access quality health. So any form of different treatment or inaccessibility or denial to quality health on the basis of disability is discrimination. This includes failure to provide reasonable accommodation to the health facility and restriction of informed consent to medical care and treatment.” (NGO respondent – Lusaka, Zambia)*

Because the rights to non-discrimination and equality are both self-standing as well as applicable to the enjoyment of other human rights under regional and international law, jurisprudence on the right to health under international law<sup>53</sup> and regional African law<sup>54</sup> is inclusive of the obligation on states to ensure these rights are enjoyed without discrimination. The Committee on Economic, Social and Cultural Rights has stated, for example, in relation to the right to health under the International Covenant on Economic, Social and Cultural Rights (ICESCR):<sup>55</sup>

*“Health care and services must be available, in sufficient quantity, accessible (physically and economically) to all without discrimination, culturally acceptable and of good quality.”<sup>56</sup>*

While the right to health under international law is understood as subject to “progressive realisation” by States, the obligation not to discriminate in the provision of services and to provide those services equitably, paying attention to vulnerable and marginalised populations, is immediately realisable.<sup>57</sup>

## 3.2 Effects of stigma and discrimination

Stigma and discrimination undermine people’s dignity and violate human rights protections. In addition, stigma and discrimination by healthcare workers and in healthcare facilities is prejudicial to the provision of quality care that is critical to ensure adherence to HIV treatment and the adoption of HIV-preventative behaviours, and creates barriers to accessing adequate care and

<sup>53</sup> Article 25 of the Universal Declaration of Human Rights UN GA Res 217 A (III) UN Doc A/810 (10 December 1948) provides: “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services”. Article 12(1) of the ICESCR provides that: “The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” See, also, article 24 of the Convention on the Rights of the Child (CRC) UN GA Res 25 (XLIV) UN Doc A/RES/44/25 (1989) and article 12 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) UN GA Res 54/180 UN Doc A/34/46 (1980).

<sup>54</sup> Article 16 of the African Charter provides: “1. Every individual shall have the right to enjoy the best attainable state of physical and mental health. 2. State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.”

<sup>55</sup> Botswana has not yet ratified the ICESCR, Malawi ratified the ICESCR in 1993, and Zambia did so in 1984.

<sup>56</sup> CESCR *General Comment No 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)* (11 August 2000), at para 12.

<sup>57</sup> The Committee identified the following, amongst others, as “minimum core” obligations of the right to health:

“(a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups; ...

(e) To ensure equitable distribution of all health facilities, goods and services.”

treatment.<sup>58</sup> Among others,<sup>59</sup> discrimination in healthcare may inhibit affected persons from taking HIV tests or may delay testing beyond the point of optimal treatment initiation. Affected persons may refrain from seeking healthcare or from disclosing important information to healthcare providers to enable appropriate care. Affected persons may travel to different areas outside of their communities to access ART in secret, which may result in inconsistency in taking treatment. Healthcare workers living with HIV may also themselves experience difficulties accessing care from their own colleagues, in an environment of stigma and discrimination.

- The Joint United Nations Programme on HIV/AIDS (UNAIDS) has stated that “over thirty years into the epidemic, stigma remains high ... and access to justice in the context of HIV is very low.”<sup>60</sup>
- The World Health Organisation (WHO) has stated that countries “should work towards implementing and enforcing antidiscrimination and protective laws, derived from human rights standards, to eliminate stigma and discrimination against people from key populations”.<sup>61</sup>
- Civil society organisations have recognised that despite progress in combatting HIV in sub-Saharan Africa, stigma and discrimination and human rights violations against people living with and at higher risk of HIV continue to undermine effective HIV responses.<sup>62</sup>

### 3.3 The role of mechanisms for accountability and redress

#### International human rights law

*“If we had effective and responsive complaints systems we would have seen a lot of improvements in the healthcare system. Healthcare workers should know they are accountable to the Health Professions Council and the public. Healthcare workers also don’t always know when what they are doing is discriminatory.” (NGO respondent – Lusaka, Zambia)*

It is an established principle of law that for every right there must be a remedy.<sup>63</sup> International human rights law affirms States’ obligations to ensure everyone has the right to an effective remedy for acts violating fundamental rights.<sup>64</sup> The ICCPR provides for the right to an effective remedy in Article 2(3):

<sup>58</sup> L Nyblade et al. “Combatting HIV Stigma in Health Care Settings: What Works?” 12 J Int AIDS Soc (2009).

<sup>59</sup> See, for example, D Carr et al. *Achieving a Stigma-Free Health Facility and HIV Services: Resources for Administrators* (2015).

<sup>60</sup> Joint United Nations Programme on HIV/AIDS (UNAIDS) *Guidance Note: Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses* (2012).

<sup>61</sup> Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, note 2 above.

<sup>62</sup> “Civil Society Statement on Strengthening Linkages to Address Stigma and Discrimination in Sub-Saharan Africa” (29 November 2015), available at: [http://www.arasa.info/files/2614/4905/8869/African\\_CSO\\_Stigma\\_and\\_Discrimination\\_Pre-conference\\_Outcome\\_Statement\\_1\\_December.pdf](http://www.arasa.info/files/2614/4905/8869/African_CSO_Stigma_and_Discrimination_Pre-conference_Outcome_Statement_1_December.pdf).

<sup>63</sup> The Latin maxim *ubi jus ibi remedium* (“where there is a right there is a remedy”) is often cited as an embodiment of this idea.

<sup>64</sup> See article 8 of the UDHR.

*“Each State Party to the present Covenant undertakes:*

- (a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;*
- (b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal system of the State, and to develop the possibilities of judicial remedy;*
- (c) To ensure that the competent authorities shall enforce such remedies when granted.”*

The right to equality before the law under Article 14(1) further specifies the entitlement to a fair and public hearing by a competent, independent and impartial tribunal enshrined by law in the determination of their rights and obligations. States are obliged under international law to make available “adequate, effective, prompt and appropriate remedies, including reparation” for victims of gross violations of human rights law.<sup>65</sup>

The United Nations Human Rights Committee (HRC) has explained that the right to an effective remedy under the ICCPR requires states to appropriately adapt remedies to take account of the special vulnerabilities of certain persons.<sup>66</sup> The Committee understands that the provision further requires that reparations are made when a person’s rights have been violated, which can involve, where appropriate, compensation as well as:

*“restitution, rehabilitation and measures of satisfaction, such as public apologies, ... guarantees of non-repetition and changes in relevant laws and practices, as well as bringing to justice the perpetrators of human rights violations.”<sup>67</sup>*

States are further obliged to provide *access* to an effective remedy to ensure that, in practice, people can use these remedies.<sup>68</sup> Processes must be affordable and accessible,<sup>69</sup> and rights holders must have sufficient information to enforce their rights.<sup>70</sup>

Article 7 of the African Charter on Human and Peoples’ Rights provides that “every individual shall have the right to have his cause heard”. The Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa, also requires that states “provide for appropriate

<sup>65</sup> *Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law*, Resolution Adopted by the General Assembly on 16 December 2005 UN Doc A/RES/60/147 (21 March 2006). See, also, *Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power*: Resolution Adopted by the General Assembly UN Doc A/RES/40/34 (29 November 1985).

<sup>66</sup> HRC *General Comment No 31: The Nature of the General Legal Obligation Imposed on States Parties to the Covenant* (26 May 2004) CCPR/C/21/Rev.1/Add.13, at para 15.

<sup>67</sup> As above, at para 16.

<sup>68</sup> HRC *General Comment 3: Implementation at the National Level* (29 July 1981); United Nations Committee on the Elimination of Discrimination Against Women (CEDAW) *General Recommendation No. 28 on the Core Obligations of States Parties under Article 2 of the Convention on the Elimination of All Forms of Discrimination against Women* (16 December 2010).

<sup>69</sup> *General Recommendation No 28*, as above, at para 34; HRC *General Comment No 32: Article 14, Right to Equality before Courts and Tribunals and to Fair Trial* (23 August 2007).

<sup>70</sup> See, for example, *General Comment 3*, note 68 above; *General Recommendation No 28*, note 68 above, at para 2; CEDAW *General Recommendation No 26 on Women Migrant Workers* (5 December 2008), at para 26.

remedies to any woman whose rights or freedoms ... have been violated”<sup>71</sup>

For the purpose of this research, access to accountability and redress is understood to embody these principles of international human rights law relating to the right to an effective remedy as including both substantive and procedural protections for rights holders.

## Accountability and redress for healthcare discrimination

In order to combat stigma and discrimination in healthcare, research indicates that interventions need to focus on individual, environmental, and policy levels.<sup>72</sup> A lack of clear policies and guidance relating to HIV-positive healthcare users and other vulnerable populations reinforces discriminatory behaviours amongst healthcare workers.<sup>73</sup> To be effective, such policies need to be routinely monitored and implemented.<sup>74</sup>

For the purpose of this report, “complaints” are understood to include any process or conduct in which a person can hold a healthcare worker or institution accountable, demand redress for wrongs experienced, or relate dissatisfaction with an experience, conduct or policy, in a healthcare setting. This includes both formal and informal processes and behaviours from direct confrontation of an individual healthcare worker to seeking legal redress in the courts.

Access to accountability and redress for healthcare users who experience discrimination in healthcare is an important component of reducing stigma and discrimination and in the fight against HIV and AIDS while serving a number of other functions for healthcare systems.<sup>75</sup> Importantly, this need not be isolated to litigation in courts. Strategies for accountability and redress can include the use of decentralised complaints mechanisms, quasi-judicial processes at health professions counsel level and with national human rights institutions, and the use of the legal process and advocacy outside of the courts. Aside from providing redress for individual grievances and deterring undesirable conduct by service providers, complaints systems can also provide an opportunity for healthcare facilities and governments to access information which is vital to improve services, systems and policies at a systemic level and to identify trouble areas, which can contribute to improving self-regulation by healthcare providers. In addition, effective complaints systems can improve user confidence and citizen participation, and improve service-provider morale.<sup>76</sup>

<sup>71</sup> Article 25(a) of the Maseru Protocol note 45 above.

<sup>72</sup> L Nyblade et al., note 58 above.

<sup>73</sup> As above.

<sup>74</sup> As above.

<sup>75</sup> See, for example, TW Reader et al. “Patient Complaints in Healthcare Systems: A Systemic Review and Coding Taxonomy” (2014) 23 *BMJ Qual Saf* 678; T Vian “Complaints Mechanisms in Health Organisations” *Anti-Corruption Resource Centre* (2013), 6.

<sup>76</sup> T Vian, note 75 above, 1.

## What makes a good complaints process?

In order to evaluate the efficacy of the complaints processes in providing for accountability and redress, it is necessary to determine the features of a good complaints process. In a decision of the African Commission on Human and Peoples' Rights, *Jawara v The Gambia*, three elements of an effective remedy were set out: availability, effectiveness and sufficiency.<sup>77</sup> The Commission stated:

*"A remedy is considered available if the petitioner can pursue it without impediment, it is deemed effective if it offers a prospect of success, and it is found sufficient if it is capable of redressing the complaint."*

Broadly speaking, a good complaints' system can be considered **available** if it is accessible and easy to use. Accessibility should include physical accessibility and safety concerns for vulnerable populations. User needs in the community must be accommodated to ensure availability including considerations of literacy levels, access to telephonic communications, diverse needs of persons with disabilities, and language and cultural preferences. For these reasons, some analysts recommend multiple entry points for complaints lodging, including options of parties laying complaints on behalf of others or making anonymous complaints.<sup>78</sup> Ease of access is further measurable on the clarity of rules or processes in place on how reports are made and to whom.<sup>79</sup>

A measurement of the **effectiveness** of a complaints process can include the extent to which a complainant is able to access information about the status of their complaint and to which they can participate in the complaints proceedings. The transparency, efficiency, independence and accountability of the complaints system also contribute to its effectiveness by ensuring a complainant has an objective prospect of succeeding in pursuing redress.

**Sufficiency** is measurable by the capacity of the complaints system to deliver redress for the complainant. Research indicates greater efficacy and trust of complaints systems where they are empowered to provide some level of redress beyond advisory functions.<sup>80</sup> The remedial powers of a complaints body are therefore important together with the prospect of enforcement.

For the purposes of a qualitative analysis of the effectiveness of the complaints systems detailed in Chapter 5, the table below indicates a series of indices taken from the human rights principles on which the evaluation is based.

<sup>77</sup> 147/95-149/96 (2000), at para 32.

<sup>78</sup> M Chêne "Good Practice in Community Complaints Mechanisms" *Transparency International* (2013), available at: [http://www.transparency.org/files/content/corruptionqas/Complaint\\_mechanisms.pdf](http://www.transparency.org/files/content/corruptionqas/Complaint_mechanisms.pdf), 1.

<sup>79</sup> As above, at 3.

<sup>80</sup> As above, 2.

## Indices to assess the effectiveness of complaints systems

### Available

#### Physical accessibility

- How are complainants outside of urban centres able to access the system to make a complaint?
- Is the system accessible for persons with disabilities to complain independently?

#### Financial accessibility

- Are there cost implications for complainants?
- Is legal assistance needed to succeed in a complaint?

#### Safety for vulnerable populations

- Can a person or organisation complain on behalf of another?
- Is there a possibility to complain anonymously?
- Can a complainant request that their identity be concealed?

#### Diverse entry points

- Must the complaint be in writing?
- How many options are there for methods of submitting a complaint?
- Does the body provide assistance to persons in making complaints?

#### Clarity of rules and procedures

- Were NGO and CBO respondents aware of these procedures and how to access them?
- Did any respondents give examples of engaging this body to refer any healthcare-related complaints?
- Are the rules and procedures formalised in policy or law?
- Was there a disparity between how key informants described processes and the formal procedures as written in law or policy?

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### Effective

#### Complainant access to information and right to make representations

- Is the complainant entitled to information on the status of their complaint, and is that entitlement guaranteed in law or policy?
- Is the complainant entitled to present evidence or make representations during investigatory and decision-making processes?
- Are both complainants and accused parties entitled to legal representation, or is only the accused entitled? In the alternative, are neither entitled to legal representation?

#### Transparency

- Are procedures publically accessible?
- Are decision-makers required to give reasons for their decision?

**Efficiency**

- How long does a complaint take to resolve?
- How many complaints are dealt with in a year?
- Is the body's budget sufficient?

**Independence**

- How are decision-makers appointed?
- Are there protections to ensure the independence of the decision-makers?

**Sufficient****Scope of redress**

- Can decision-makers impose sanctions on accused parties?
- Can decision-makers require that the complainant's loss is redressed (e.g. order compensation, restitution or an apology?)
- Can the decision-maker impose systemic or policy change?
- Are complaints processed systemically to ensure information feedback into the healthcare system?

**Enforcement powers**

- Is the complaints body's decision binding on the accused?
- Can the complaints body make binding decisions against the government?
- Does the complaints body have external support for the enforcement of its decisions?

**Appeal or review**

- Is the decision of the complaints body subject to appeal by complainants?
- Is the decision of the complaints body subject to review by complainants?

# 4. Domestic protections against stigma and discrimination: Legal, policy and ethical standards

## 4.1 Introduction

In this chapter, an assessment is made of the domestic legal and policy environments in Botswana, Malawi and Zambia. The purpose is to understand to what extent healthcare users can expect to be treated equally and without discrimination in law and policy, and in terms of the ethical standards by which healthcare providers are bound.

## 4.2 Botswana

### Legal framework

Botswana's laws do not permit discrimination against healthcare users. Any discrimination would need to be strictly justifiable under the Constitution.<sup>81</sup>

#### Constitution

Section 15 of the Constitution provides for the prohibition against discrimination:

*"Protection from discrimination on the grounds of race, etc.*

*(1 Subject to the provisions of subsections (4), (5) and (7) of this section, no law shall make any provision that is discriminatory either of itself or in its effect.*

*(2) Subject to the provisions of subsections (6), (7) and (8) of this section, no person shall be treated in a discriminatory manner by any person acting by virtue of any written law or in the performance of the functions of any public office or any public authority.*

*(3 In this section, the expression "discriminatory" means affording different treatment to different persons, attributable wholly or*

<sup>81</sup> 1966.

*mainly to their respective descriptions by race, tribe, place of origin, political opinions, colour, creed or sex whereby persons of one such description are subjected to disabilities or restrictions to which persons of another such description are not made subject or are accorded privileges or advantages which are not accorded to persons of another such description."*

Section 3 of the Constitution provides for the enjoyment by every person of fundamental rights and freedoms:

*"Fundamental rights and freedoms of the individual*

*Whereas every person in Botswana is entitled to the fundamental rights and freedoms of the individual, that is to say, the right, whatever his race, place of origin, political opinions, colour, creed or sex, but subject to respect for the rights and freedoms of others and for the public interest".*

The Botswana Court of Appeal has held in addition that the protection under section 3 of the Constitution is enjoyed by members of the gay, lesbian and transgender community, affirming their recognition under the Constitution.<sup>82</sup>

### Public Health Act

The Public Health Act<sup>83</sup> does not provide for any general prohibition against discrimination in healthcare but does prohibit discrimination against healthcare providers by heads of health facilities on account of the healthcare provider's health status.<sup>84</sup> The definition of "public health" however details services aimed at ensuring "**every individual** in the community, a standard of living adequate for the maintenance of health."<sup>85</sup> It is noted that certain practices identified by research participants as being "discriminatory" (as described in Chapter 6) may also fall within the ambit of the Public Health Act. This includes the prohibition on conducting HIV tests on persons without their informed consent.<sup>86</sup>

### Health Professions Act

The Botswana Health Professions (Professional Conduct) Regulations<sup>87</sup> is subsidiary legislation passed in terms of the Botswana Health Professions Act.<sup>88</sup> The Regulations address a number of obligations on healthcare practitioners subject to the Act, which include a prohibition on divulging any information on a patient's ailments without the patient's express consent.<sup>89</sup> An exception is made where the healthcare practitioner is summoned to appear in court and ordered to disclose the information. Reporting patients to the police who present with medical ailments that may indicate the occurrence of prohibited same-sex sexual activity, sex work, or having undergone an abortion, for example, is therefore prohibited.

<sup>82</sup> *Attorney General v Rammoge and Others* (Court of Appeal Case CACGB-128-14), at paras 57-60.

<sup>83</sup> 11 of 2013.

<sup>84</sup> Section 148(1).

<sup>85</sup> Section 2 (emphasis added).

<sup>86</sup> Section 105(1)(a).

<sup>87</sup> Chapter 61:02.

<sup>88</sup> 2001: Chapter 61:02.

<sup>89</sup> See Regulation 21.

## Nurses and Midwives Act

The Nurses and Midwives (Disciplinary) Regulations, passed in terms of the Nurses and Midwives Act,<sup>90</sup> do not explicitly address the issue of discriminatory conduct but describe “disciplinary offences”<sup>91</sup> that include careless, incompetent and improper conduct, the provision of services inappropriate for a patient’s wellbeing, divulging confidential matters which are a duty to keep secret, failing to apply due care and attention, conducting oneself in a manner unbecoming of a nurse or midwife, and breaching the Code of Professional and Ethical Conduct for Nurses and Midwives.

## Policy framework

The policy framework in Botswana supports a non-discriminatory approach to healthcare in the broad sense and makes commitments to providing healthcare equitably. Particular provision is made for interventions targeted at HIV treatment and prevention services and sexual and reproductive health services for women. The policy framework does not, however, target interventions or make explicit the prohibition on healthcare workers and healthcare systems from discriminating against key populations in particular. Nor does it provide for mechanisms to report or monitor discriminatory conduct in healthcare service delivery.

## Public Service Charter

The Botswana Public Service Charter<sup>92</sup> requires the public service to be executed according to a number of values, including neutrality:

*“Neutrality encompasses ... fairness ... to the public, and equality of treatment. ... Equality demands fair and equal treatment of all persons without discrimination on the grounds of religion, gender, status, place of origin, tribe, colour or religious affiliation.”*

## National Health Policy

Botswana’s 2011 National Health Policy: Towards a Healthier Botswana (National Health Policy)<sup>93</sup> can be interpreted to include protections against discrimination on a superficial level. The Policy states its vision to be an “enabling environment whereby **all people living in Botswana** have the opportunity to achieve and maintain the highest level of health and well-being.”<sup>94</sup> In addition, the implementation of the National Health Policy is guided by the principles and values of respect for human dignity, rights, and confidentiality and the “equitable distribution of resources to guarantee accessibility to quality services, especially for the vulnerable, marginalised, and underserved, irrespective of political, ethnic or religious affiliations and place of domicile.”

While the National Health Policy makes repeated reference to the goal of equity, it makes no mention of the term “discrimination”, and does not include measures of equality or discrimination in monitoring and evaluation and in norms and standards enforcement plans.

<sup>90</sup> 1 of 1995: Chapter 61:03.

<sup>91</sup> See regulation 3(d), (g), (l), (m) and (v).

<sup>92</sup> Available at <http://www.gov.bw/Global/DPSM/public%20service%20CHARTER.pdf?epslanguage=en>.

<sup>93</sup> Republic of Botswana *National Health Policy: Towards a Healthier Botswana* (2011).

<sup>94</sup> As above, at para 31 (emphasis added).

“Stigma” is only mentioned in relation to access to rehabilitative services for persons with “alcohol-related problems”.

While persons with disabilities are acknowledged as suffering from social exclusion,<sup>95</sup> the only planned intervention relates to activities to ensure that health-facility buildings have special provision for the needs of healthcare users with (physical) disabilities.<sup>96</sup> No mention is made of sex workers, men who have sex with men, transgender persons, or LGBT health users in general. The policy’s statement on “Gender Equity” appears to address a gender binary approach to ensuring “gender sensitive and responsive issues including equal involvement of men and women in decision-making.”<sup>97</sup>

### HIV Policy

The 2012 Botswana National Policy on HIV and AIDS (HIV Policy) includes the policy objective:

*“To reduce HIV and AIDS related stigma and discrimination towards persons infected with or affected by HIV and AIDS and draw attention to the compelling public health rationale for overcoming stigmatisation and discrimination against them in society.”<sup>98</sup>*

In the Foreword, the Minister for Presidential Affairs and Public Administration states the HIV Policy “takes cognisance of the fact that due to age, gender, socio-economic status, sexual orientation or disability, some Batswana are more vulnerable” to HIV and AIDS.<sup>99</sup> In the policy itself, however, the definition of “vulnerability” makes no mention of LGBT persons nor are any particular interventions detailed in the Policy to address the particular needs of vulnerable populations.

Nevertheless, the HIV Policy does provide that:

*“Every person in Botswana shall not be discriminated against in terms of access to health services.”<sup>100</sup>*

The HIV Policy acknowledges the protection against discrimination in the Botswana Constitution and the effect of discrimination “especially in relation to an individual’s HIV status” on the effectiveness of the national response to HIV.<sup>101</sup> While making several targeted interventions in relation to discrimination in employment, education, and legal and financial services,<sup>102</sup> the HIV Policy does not direct particular attention to key populations or vulnerable populations, embracing a notion of discrimination largely understood as based on HIV-status.

<sup>95</sup> As above, at para 2.6.6.

<sup>96</sup> As above, at para 4.5.3.3 (d).

<sup>97</sup> As above, at para 3.3.

<sup>98</sup> Republic of Botswana *Botswana National Policy on HIV and AIDS* (Revised edition, 2012), at para 2.1.3.

<sup>99</sup> As above, 3.

<sup>100</sup> As above, at para 7.1.5.

<sup>101</sup> As above, at para 7.1.

<sup>102</sup> See, for example, HIV Policy, as above, at paras 7.1.1-7.1.6.

## HIV Strategic Framework

The Second Botswana National Strategic Framework for HIV and AIDS 2010-2016 (HIV Strategic Framework)<sup>103</sup> states:

*“Stigma and associated discrimination are socially embedded phenomena that impact negatively on the national response as they collude to constrain the coverage and effectiveness of HIV and AIDS interventions and increase the vulnerabilities of particular groups in society.”<sup>104</sup>*

The HIV Strategic Framework makes repeated reference to increased access to health services,<sup>105</sup> and to improving ethical and legal frameworks for “universal access” to HIV services.<sup>106</sup> The Framework provides further that even where supportive laws and policies exist, “non-existent or weak enforcement of these laws may facilitate the perpetuation of stigma and discrimination and limit the general success of the response to HIV.”<sup>107</sup>

While acknowledging the need for more research and the gaps in targeting the “unique profile and specialised needs” of specific groups,<sup>108</sup> the Strategic Framework does not mention key populations, LGBT persons or persons with disabilities. The Guiding Principles of the national response to HIV in the HIV Strategic Framework are stated to include human rights: “promoting dignity, non-discrimination ... of all people and ensuring equal access to health and social support services regardless of race, creed, religious or political affiliation, sexual orientation or socio-economic status.”<sup>109</sup> The inclusion of Guiding Principles based on “gender sensitivity” are framed exclusively in relation to the view that the HIV epidemic has become “feminised”.<sup>110</sup>

## HIV Treatment Guidelines

The 2012 Botswana National HIV and AIDS Treatment Guidelines<sup>111</sup> provide clinical guidelines on HIV prevention, testing, treatment initiation and management. The concepts of stigma and discrimination are referred to briefly in relation to counselling women living with HIV to avoid breastfeeding<sup>112</sup> and in relation to a caregiver’s disclosure of a child’s HIV status to the child.<sup>113</sup> The Guidelines do not provide resources for clinicians in relation to key populations or persons with disabilities but for the brief statement that the safe implementation of pre-exposure prophylaxis for men who have sex with men and commercial sex workers remains to be established.<sup>114</sup> The Botswana TB/HIV Policy Guidelines<sup>115</sup> make no mention of issues relating to stigma and discrimination.

<sup>103</sup> Republic of Botswana *The Second Botswana National Strategic Framework for HIV and AIDS 2010-2016* (2009).

<sup>104</sup> As above, at para 1.2.4.

<sup>105</sup> As above, at para 2.4.1 (1).

<sup>106</sup> As above, at para 2.4.1 (6).

<sup>107</sup> As above, at para 3.2.1.

<sup>108</sup> As above, at para 1.3.5.

<sup>109</sup> As above, at para 2.3.

<sup>110</sup> As above, at para 2.3.

<sup>111</sup> Government of Botswana: Ministry of Health *2012 Botswana National HIV & AIDS Treatment Guidelines* (2012).

<sup>112</sup> As above, at 75.

<sup>113</sup> As above, at 78.

<sup>114</sup> As above, at 20.

<sup>115</sup> Republic of Botswana: Ministry of Health *Botswana TB/HIV Policy Guidelines* (2011).

## Disability Policy

The National Policy on Care for People with Disabilities<sup>116</sup> states as a first principle of the Policy, the “recognition and protection of the human rights of every individual.”<sup>117</sup> There is no explicit mention of discrimination or rights to equitable access. However, certain obligations are placed on the State to ensure that persons with disabilities can access healthcare services among others.<sup>118</sup> A respondent from the Office of People with Disability in the Office of the President – interviewed for this research – criticised Botswana’s policy approach towards persons with disabilities, as focussing on a medical model of “caring” and “treatment” of persons with disabilities, premised on assumptions of them being abnormal objects of pity and charity. The respondent expressed a need for this new Office to embrace a social model of disability, more conducive to respect for persons with disabilities as equal members of society.

## Ethical standards

Professional ethical standards to which healthcare workers are subject are not specific on concepts of discrimination or stigma. However, a range of conduct described under these frameworks would be easily accommodated under practices described by focus-group participants in Chapter 6 as discriminatory.

## Health Professionals

Health professionals are required to register with the Botswana Health Professions Council (BHPC) and to pledge to practise their professions according to the ethical standards articulated in the BCHP Code of Ethical and Professional Conduct (Code of Conduct). The Code of Conduct for health professionals is not captured in subsidiary legislation, like in the Nurses and Midwives Regulations.

The Code of Conduct makes direct mention of “discrimination” only in relation to the treatment of colleagues and not in relation to obligations towards patients. However certain provisions relating to the duties and ethical obligations of healthcare professionals to patients find direct application. The Code of Conduct articulates certain “Core Values” to include:

*“Justice: to treat all persons and groups impartially and fairly, and to make access to quality care equitable for all.”<sup>119</sup>*

In addition, a number of the Code’s ethical obligations describe duties that would be violated in the types of practices described by participants in this research as discriminatory. Most prominently, these include the ethical obligations to:

*“3 Regard every patient with respect, taking care to safeguard the patient’s dignity.*

*9. Ensure that one’s own personal beliefs and opinions do not prejudice the type and quality of care given to the patient.*

*23. Refrain from any abuse of the privileged relationship that exists*

<sup>116</sup> Republic of Botswana *National Policy on Care for People with Disabilities* (1996).

<sup>117</sup> As above, at para 4.2.

<sup>118</sup> See, as above, at paras 4.3.1, 4.3.1.3.

<sup>119</sup> Botswana Health Professions Council *Code of Ethical Professional Conduct* (2012).

*between the health professional and the patient.*<sup>120</sup>

Notable duties to patients described by the Code of Conduct include:

*"1.7. Care for the patient in need of care, irrespective of status, religion, race, tribe, nationality, political affiliation, gender, sexual orientation or occupation."*

In addition to these core values, ethical obligations and duties, several other provisions are more particular to the types and variations of conduct described as "discriminatory" in healthcare settings. Applicable ethical obligations include the obligation to provide patient-centred care in the patient's best interests; to assess the patient comprehensively; to inform and counsel the patient on their health condition; to be sympathetic, courteous and honest with patients; to alleviate pain, anxiety and distress; and to respect and protect confidential information."

Relevant duties owed to patients include respecting the patient's privacy and dignity at all times; allowing the patient to access his records; seeking and obtaining informed consent following providing adequate information and a full discussion of the patient's options; and refraining from indecent sexual acts, violence or threatening behaviour towards patients.

### **Nurse's Pledge of Service**

In addition to the Nurses and Midwives (Disciplinary) Regulations above, nurses and midwives registered under the Nursing and Midwifery Council of Botswana undertake a pledge of service. This pledge includes a promise to care for the sick:

*"without regard to race, creed, colour, politics and social status, sparing no effort to conserve life, alleviate suffering and to promote health."*

The pledge further states an undertaking to respect healthcare users' dignity and to hold in confidence "all personal information entrusted to me".

## **4.3 Malawi**

### **Legal framework**

Like Botswana, discrimination is prohibited in broad terms under constitutional law. In addition, particular provisions exist for the protection of persons with disabilities.

#### **Constitution**

The Malawi Constitution was adopted in 1994 and strongly embodies the value of equality. Section 4 provides:

*"This Constitution shall bind all executive, legislative and judicial organs of the State at all levels of Government and all the peoples of Malawi are entitled to the **equal protection** of this Constitution, and laws made under it."*<sup>121</sup>

<sup>120</sup>As above.

<sup>121</sup>Emphasis added.

In addition, section 20 provides for a human right to equality and freedom from discrimination and recognises a notion of substantive equality:

*“(1) Discrimination of persons in any form is prohibited and all persons are, under any law, guaranteed equal and effective protection against discrimination on grounds of race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, disability, property, birth or other status or condition.*

*“(2) Legislation may be passed addressing inequalities in society and prohibiting discriminatory practices and the propagation of such practices and may render such practices criminally punishable by the courts.”*

Further to this, the inherent dignity and worth of all persons,<sup>122</sup> and the equal status of all persons before the law<sup>123</sup> are recognised as “fundamental” constitutional principles. The right to equality and recognition before the law is a non-derogable right under the Constitution.<sup>124</sup> The Constitution provides that the only justifiable limitations to lawful rights are those necessary to ensure peaceful human interaction in an open and democratic society.<sup>125</sup>

The “inviolable” right to dignity of “all persons” is protected under section 19 of the Constitution, which includes the right not to be subjected to medical or scientific experimentation without consent.<sup>126</sup> Furthermore, individuals are obliged under the Constitution to respect other individuals and to refrain from discrimination:

*“Every individual shall have duties towards other individuals, his or her family and society, the State and other legally recognized communities and the international community and these duties shall include the **duty to respect his or her fellow beings without discrimination and to maintain relations aimed at promoting, safeguarding and reinforcing mutual respect and tolerance**; and in recognition of these duties, individual rights and freedoms shall be exercised with due regard for the rights of others, collective security, morality and the common interest.”<sup>127</sup>*

The right to confidentiality over one’s health status is arguably guaranteed under section 21 of the Constitution, which provides for the right of every person to personal privacy.

The right to development under section 30 of the Constitution extends to “all persons”, making special provision for women and persons with disabilities, and requiring that the State takes all necessary measures to realise the right including ensuring equality of opportunity for all in access to health services.<sup>128</sup>

<sup>122</sup> Section 12(1)(d).

<sup>123</sup> Section 12(1)(e).

<sup>124</sup> Section 45(2)(g).

<sup>125</sup> Section 12(1).

<sup>126</sup> See section 19(5).

<sup>127</sup> Section 12(2) (emphasis added).

<sup>128</sup> Section 30 provides that:

“(1) All persons and peoples have a right to development and therefore to the enjoyment of economic, social, cultural and political development and women, children and the disabled in particular shall be given special consideration in the application of this right.

(2) The State shall take all necessary measures for the realization of the right to development. Such measures shall include,

Women are afforded special protection under section 24 of the Constitution which includes that they “have the right to full and equal protection by the law”.<sup>129</sup> The State is obliged to take action to eliminate customs and practices that discriminate against women.<sup>130</sup> Children are also entitled to equal treatment before the law, regardless of the circumstances of their birth. The child’s best interests and the welfare of children shall be the primary consideration in all decisions affecting them.<sup>131</sup>

In the enjoyment of one’s rights, the Constitution entrenches the right to access to justice and effective legal remedies, affirming the obligation of the State to ensure that all persons can access accountability and redress when their rights are violated. Section 40 provides that:

*“(1) Every person shall have a right to recognition as a person before the law.*

*“(2) Every person shall have the right of access to any court of law or any other tribunal with jurisdiction for final settlement of legal issues.*

*“(3) Every person shall have the right to an effective remedy by a court of law or tribunal for acts violating the rights and freedoms granted to him or her by this Constitution or any other law.”*

Finally, while merely of directory and interpretive value,<sup>132</sup> “principles of national policy” under the Malawi Constitution provide specifically for the State to achieve adequate healthcare and to enhance the protection of rural life and the dignity of persons with disabilities.<sup>133</sup>

## Gender Equality Act

Malawi’s Gender Equality Act guarantees “every person” the right to “adequate sexual and reproductive health” – which includes access to sexual and reproductive health services, family planning, and protection from sexually transmitted infections without discrimination.<sup>134</sup> The Act stresses the obligation on healthcare providers to secure the informed consent of persons accessing sexual and reproductive health and family-planning services.

amongst other things, equality of opportunity for all in their access to basic resources, education, health services, food, shelter, employment and infrastructure.

(3) The State shall take measures to introduce reforms aimed at eradicating social injustices and inequalities.

(4) The State has a responsibility to respect the right to development and to justify its policies in accordance with this responsibility.”

<sup>129</sup> Section 24(1).

<sup>130</sup> Section 24(2).

<sup>131</sup> Section 23(1).

<sup>132</sup> See section 14.

<sup>133</sup> Section 13 provides in relevant part:

“The State shall actively promote the welfare and development of the people of Malawi by progressively adopting and implementing policies and legislation aimed at achieving the following goals—

(c) Health

To provide adequate health care, commensurate with the health needs of Malawian society and international standards of health care.

(e) Rural Life

To enhance the quality of life in rural communities and to recognize rural standards of living as a key indicator of the success of Government policies.

(g) Persons with Disabilities

To enhance the dignity and quality of life of persons with disabilities by providing—

(i) adequate and suitable access to public places;

(ii) fair opportunities in employment; and

(iii) the fullest possible participation in all spheres of Malawian society.”

<sup>134</sup> Sections 19 – 20.

## Disability Act

Malawi's Disability Act 8 of 2012 provides for progressive protections against discrimination, which it defines as:

*"a distinction, exclusion or restriction on the basis of disability, which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, of any human rights or fundamental freedoms, in the political, social, cultural, civil or other field".<sup>135</sup>*

Persons with disabilities are afforded a right to healthcare services, to which government is obliged to:

*"provide persons with disabilities the same range, quality and standard of free or affordable health care services as provided to other persons, including sexual and reproductive health services and population based public health programmes".<sup>136</sup>*

Several provisions under the Disability Act prohibit discrimination particular to the context of healthcare<sup>137</sup> and create obligations to ensure accessibility<sup>138</sup> and to provide for reasonable accommodation<sup>139</sup> of the needs of persons with disabilities. The Act provides for civil remedies in the case of a violation of certain provisions in the Act through the court process.<sup>140</sup> The Minister of Gender, Children, Disability and Social Welfare is also empowered to impose administrative provisions on a person or institution that contravenes the Act.<sup>141</sup>

## Nurses and Midwives Act

Under the Nurses and Midwives (Scope of Nursing Practice) Regulations,<sup>142</sup> promulgated under the Nurses and Midwives Act,<sup>143</sup> registered nurses and midwives are obliged to respect the rights of healthcare users<sup>144</sup> to practice nursing in a non-discriminatory and non-judgmental manner,<sup>145</sup> and to "maintain confidential information relating to clients or patients unless, in the particular circumstances, breach of confidentiality is required".<sup>146</sup> Furthermore, under the Nurses and Midwives (Professional Practice Standards) Regulations,<sup>147</sup> registered nurses and midwives are required to demonstrate "courteous behaviour, based on culture, tradition and respect" to healthcare users.

<sup>135</sup> Section 2.

<sup>136</sup> Section 6(2)(c).

<sup>137</sup> See section 7.

<sup>138</sup> See sections 8 and 9.

<sup>139</sup> "Reasonable accommodation" is defined in section 2 of the Act as: "means necessary and appropriate modifications and adjustments that ensure that persons with disabilities enjoy or exercise all human rights and fundamental freedoms on (an) equal basis with other persons, without imposing disproportionate or undue burdens on the other persons".

<sup>140</sup> Section 31.

<sup>141</sup> Section 32.

<sup>142</sup> GN 12/2002.

<sup>143</sup> Promulgated in terms of section 85 of the Nurses and Midwives Act 16 of 1995.

<sup>144</sup> Regulation 8(d).

<sup>145</sup> Regulation 8(f).

<sup>146</sup> Regulation 8(l).

<sup>147</sup> G/N 13/2002, promulgated in terms of section 85 of the Nurses and Midwives Act.

## Policy framework

The policy framework in Malawi strongly supports an approach to healthcare founded in “equity” and non-discrimination.

### Health Sector Strategic Plan

In the Malawi Health Sector Strategic Plan 2011-2016: Moving Towards Equity and Quality, the notion of universal and equitable access to healthcare services is emphasised. The Ministry of Health is stated as being “committed to ensuring that services in the [Essential Health Package] are available with universal coverage for all Malawians.”<sup>148</sup> The notion of “universal coverage” is explained with explicit reference to socio-economic disparity, geographical coverage, and to persons with disabilities.<sup>149</sup> “Equity” is repeatedly emphasised in Malawi’s health policy framework.<sup>150</sup>

### National HIV Policy

While the HIV and AIDS Policy: Sustaining the National Response (National HIV Policy) fails to explicitly recognise LGBT persons and persons with disabilities as key populations or vulnerable populations, it recognises stigma and discrimination as a “key challenge” as well as the:

*“marginalisation of [people living with HIV], key populations such as sex workers, injecting drug users and people in close settings and other vulnerable groups; limited access to quality HIV and AIDS and health services, and other human rights violations”.*<sup>151</sup>

The National HIV Policy objectives include reducing vulnerability to HIV infection among various population groups and offering enhanced support to vulnerable populations, making particular mention of persons with disabilities.<sup>152</sup> Universal access, uptake, and retention of quality HIV-related services and the protection, participation and empowerment of people living with HIV and vulnerable populations are detailed as priority areas in the Policy.<sup>153</sup>

### HIV and AIDS Strategic Plan

The Malawi National HIV and AIDS Strategic Plan 2011-2016, despite making repeated mention of the failures to include certain vulnerable populations (such as men who have sex with men) in targeted interventions, fails to include LGBT persons in its understanding of “vulnerable persons”.<sup>154</sup>

### Health Sector Plan

The 2011-2016 Malawi Health Sector Strategic Plan (the Health Sector Plan) states its purpose

<sup>148</sup> Government of Malawi: Ministry of Health *Malawi Health Sector Strategic Plan 2011-2016: Moving Towards Equity and Quality* (2012), 34.

<sup>149</sup> As above.

<sup>150</sup> See, for example, the Vision in: Government of Malawi *National Sexual and Reproductive Health and Rights Plan* (2009).

<sup>151</sup> Republic of Malawi *National HIV and AIDS Policy: Sustaining the National Response* 2nd edition (2013), 9.

<sup>152</sup> See: 2.4 (ii), (iii) and (v). The Malawi Health Sector Strategic Plan 2011-2016: Moving Towards Equity and Quality, note 142 above, at 50, identifies in the Essential Health Package, the following as vulnerable persons: “poor people, women, children, orphans, people with disabilities and the elderly, people living in hard to serve areas, and displaced persons.”

<sup>153</sup> See paras 3.2.1 and 3.5.

<sup>154</sup> See subtheme 2.

to be “moving towards equity and quality”. The Health Sector Plan preserves and extends the Essential Health Package (EHP), which includes free-of-charge services and treatment for diseases and conditions that affect the majority of the population, especially the poor.<sup>155</sup> The EHP includes services for malaria, tuberculosis, sexually transmitted infections (STIs), and HIV/AIDS, amongst others. The Plan interprets the Constitution to guarantee that all Malawians will be provided with free health care and other social services at the highest quality within the resources available, and guarantees equality to all people in accessing health services.<sup>156</sup> The Health Sector Plan elaborates its vision to include:

*“All the people of Malawi shall have access to health services without distinction by ethnicity, gender, disability, religion, political belief, economic and social condition or geographical location. The rights of health care users and their families, providers and support staff shall be respected and protected.”<sup>157</sup>*

It states further that the “ethical requirement of confidentiality, safety and efficacy in both the provision of healthcare and healthcare research shall be adhered to”.<sup>158</sup> Accountability is a guiding principle of the Plan envisioning that:

*“[a]ll stakeholders shall discharge their respective mandates in a manner that takes full responsibility for the decisions made in the course of providing health care. All health workers at all levels and all DPs shall be accountable to the people of Malawi.*

*Community participation shall be encouraged in the planning, management and delivery of health services.”<sup>159</sup>*

In order to ensure “client satisfaction”, the Plan includes the goal to establish and support health centre committees and to set up customer complaints desks to address client concerns.

### **National Sexual and Reproductive Health and Rights Plan**

The 2009 National Sexual and Reproductive Health and Rights Plan speaks to the free choice of individuals and couples to be empowered to determine their reproductive choices without coercion.<sup>160</sup> The goals to reduce stigma and discrimination and to empower rights-holders is elaborated in the Plan.<sup>161</sup>

### **National HIV and AIDS Strategic Plan**

The Malawi National HIV and AIDS Strategic Plan acknowledges a number of failures in programming for the needs of key populations and vulnerable populations, including the failure to target services to meet the needs of men who have sex with men and persons with

<sup>155</sup> Health Sector Plan, notes 18 and 142 above.

<sup>156</sup> As above, 33.

<sup>157</sup> As above, 48. See also the Guiding Principles in: Government of Malawi *National Sexual and Reproductive Health and Rights Plan* (2009), at para 2.5.

<sup>158</sup> Notes 142, 48-49 above.

<sup>159</sup> As above, 48.

<sup>160</sup> National Sexual and Reproductive Health and Rights Plan, note 151 above. See, for example, para 3.1.2.4.

<sup>161</sup> Malawi National HIV and AIDS Strategic Plan 2011-2016, note 29 above. See, for example, the Guiding Principles, Theme 5, and Strategy 5.1.

disabilities.<sup>162</sup> While identifying stigma and discrimination as a strategic concern, the Plan does not include any processes for accountability or redress for patients in its implementation framework on stigma and discrimination.<sup>163</sup>

### **National HIV and AIDS Monitoring and Evaluation Plan**

The Malawi National HIV and AIDS Monitoring and Evaluation Framework 2015-2020 requires a biannual Quality of Health Related HIV Services Survey to be conducted by the Ministry of Health. It is unclear whether this survey must include the measurement of stigma and discrimination experienced by healthcare users.

### **HIV Treatment Guidelines**

Guidelines for HIV treatment do not provide for distinctions between patients and require no obligatory testing for high-risk patients, while emphasising the rights of patients to refuse treatment.<sup>164</sup>

### **Charter on Patients' and Health Service Providers' Rights and Responsibilities**

In addition to these policies and plans, the Malawi Government has developed a Charter on Patients' and Health Service Providers' Rights and Responsibilities (the Charter). The language of the Charter is inclusive, referring to the rights of "every individual" and "every patient". The Charter states explicitly that:

*'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.'*<sup>165</sup>

Further to a number of provisions articulating patients' health rights, the Charter provides for the right of every patient to be "treated with kindness, consideration and dignity without regard to age, gender, ethnicity, religion, economic status and without any form of discrimination." A right to complain about health services is entrenched in broad terms in the Charter:

*"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."*

<sup>162</sup> National Sexual and Reproductive Health and Rights Plan, notes 143 and 28 above.

<sup>163</sup> See, as above, 211.

<sup>164</sup> See, for example, Ministry of Health *Clinical Management of HIV in Children and Adults: Malawi Integrated Guidelines for Providing HIV Services in: Antenatal Care, Maternity Care, Under 5 Clinics, Family Planning Clinics, HIV Exposed Child / Pre-ART Clinic, ART Clinics* (2014).

<sup>165</sup> Republic of Malawi *Charter on Patients' and Health Service Providers' Rights and Responsibilities*, 1.

## Ethical standards

Medical practitioners in Malawi are explicitly prohibited from discriminating against healthcare users.

### Medical Practitioners and Dentists Code of Ethics

A Code of Ethics (the Code) for medical practitioners, dentists, paramedics and allied health professionals has been developed by the Medical Council of Malawi as required under the Medical Practitioners and Dentists Act.<sup>166</sup> The Code specifically requires practitioners not to discriminate against patients,<sup>167</sup> that they “respect all aspects of human life”,<sup>168</sup> and respect patients’ confidentiality,<sup>169</sup> and ensure that in “as far as possible” informed consent is obtained from patients before any procedure.<sup>170</sup> The only stated exclusion from the obligation to respect patient confidentiality is if so required in a court of law. However, the protection of patients from breaches on confidentiality is undermined by a subsequent provision in the Code which provides for types of actions that may constitute professional misconduct and result in disciplinary action:

*“A practitioner shall not disclose to a third party information, which he obtained in confidence from a patient in the course of the professional relationship between the patient and the practitioner. Provided that in the following circumstances, the confidential information may be disclosed to a third party:*

- 1. Where there is a valid consent from the patient or his legal adviser or guardian, provided that information may be given to a relative or appropriate person if in the circumstances of the case in question it is reasonably undesirable on medical grounds to seek the patient’s consent;*
- 2. Where the information may be required by law;*
- 3. Where public interest persuades a practitioner that his duty to the community overrides that to his patients; and*
- 4. In the interests of research and medical education, information may be divulged, but at all times the patient’s name shall not be revealed.*

*A practitioner shall always be prepared to justify his action whenever he disclosed confidential information.”*

<sup>166</sup> Chapter 36:01 of the Laws of Malawi.

<sup>167</sup> Medical Council of Malawi *Code of Ethics and Professional Conduct* 2 ed, at section 1, para 1.5. The Code states that every practitioner shall: “Not discriminate against any person on the basis of race, colour, sex, language, religion, political or other opinion, nationality, ethnic or social origin, disability, property, birth status, or any other status”.

<sup>168</sup> As above, at section 1, para 1(1)2.

<sup>169</sup> As above, at section 1, para 1(4).

<sup>170</sup> As above, at section 5, para 5.6.

## 4.4 Zambia

### Legal framework

Zambia's Constitution protects against discrimination, which should include protection in the context of healthcare. Zambian legislation further prohibits certain forms of professional misconduct by healthcare workers.

#### Constitution

Zambia's Constitution was enacted in 1996, subject to significant amendments in 2016. Human dignity, equity, social justice, equality and non-discrimination are founding values of the Constitution.<sup>171</sup> The guiding values and principles of the public service include the "effective, impartial, fair and equitable provision of public services".<sup>172</sup>

Article 11 of the Constitution<sup>173</sup> guarantees "every person in Zambia" the enjoyment of rights and freedoms whatever their race, place of origin, political opinion, colour, creed, sex or marital status. Article 23 provides for protection against discrimination by any law or person. "Discrimination is defined as–

*"affording different treatment to different persons attributable, wholly or mainly to their respective descriptions by race, tribe, sex, place of origin, marital status, political opinions, colour or creed whereby persons of one such description are subjected to disabilities or restrictions to which persons of another such description are not made subject or are accorded privileges or advantages which are not accorded to persons of another such description."*<sup>174</sup>

The Constitution does not provide for a justiciable right to health. However, Article 112 specifies non-binding Directive Principles of State Policy that include that–

*"(d) the State shall endeavour to provide clean and safe water, adequate medical and health facilities and decent shelter for all persons, and take measures to constantly improve such facilities and amenities*

*(f) the State shall endeavour to provide to persons with disabilities, the aged and other disadvantaged persons such social benefits and amenities as are suitable to their needs and are just and equitable".*<sup>175</sup>

#### Nurses and Midwives Act

For nurses and midwives, the Nurses and Midwives Rules, promulgated under the Nurses and Midwives Act, specify professional misconduct under rule 29 as "any act or omission contrary to the generally recognised responsibility of such persons towards patients or contrary to professional ethics."

<sup>171</sup> Article 8 of the Constitution of Zambia (Amendment) Act 2 of 2016.

<sup>172</sup> As above, at Article 173(1)(c).

<sup>173</sup> Constitution of Zambia Act 18 of 1996.

<sup>174</sup> As above, at Article 23(3).

<sup>175</sup> As above, at Article 112. Article 111 of the 1996 Constitution states that the Directive Principles are not justiciable or enforceable, by themselves, in a court of law.

Rule 29(2) includes the following behaviour as amounting to professional misconduct

*“(a) immorality or other improper conduct or association with patients;*

*(c) wilful or deliberate betrayal of a professional confidence;*

*(d) abandonment of a patient in danger;*

*(h) dishonesty, negligence or incompetence in the performance of duties;*

*(i) refusal without lawful excuse or proper excuse to obey a lawful order given in the course of duty by a person in authority;*

*(j) unkindness to or ill-treatment of patients or, except in self defence or the interest of a patient, the use of excessive force or violence in the performance of duties.”*

## Gender Equity and Equality Act

Zambia’s 2015 Gender Equity and Equality Act<sup>176</sup> prohibits discrimination against “any sex”<sup>177</sup> and prohibits both public and private persons and bodies from “abusive, violent or degrading treatment” against “any person”.<sup>178</sup>

Women’s rights to “adequate sexual and reproductive health” are guaranteed as inclusive of protection from sexually-transmitted infections, and access to sexual and reproductive health and family planning services.<sup>179</sup> The Minister of Health is obliged to take appropriate measures to ensure that women are able to access healthcare services on an equal basis with men and to enjoy “appropriate services” in connection with pregnancy and postnatal care.<sup>180</sup> The obligation on healthcare providers to obtain informed consent from persons accessing sexual and reproductive healthcare services is strongly emphasised in the Act.<sup>181</sup> Special measures are mandated under the Act to ensure that women in rural and peri-urban areas are able to access adequate healthcare facilities.<sup>182</sup>

It is noted that the Act contemplates a complaints procedure with the Gender Equity and Equality Commission.<sup>183</sup> At the time of writing, the Commission was not yet in operation.

## Persons with Disabilities Act

The Persons with Disabilities Act 6 of 2012 prohibits discrimination<sup>184</sup> which is defined as–

*“any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of imparting or nullifying the recognition, enjoyment or exercise on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field, and includes all forms of discrimination,*

<sup>176</sup> 22 of 2015.

<sup>177</sup> Section 15.

<sup>178</sup> Section 16.

<sup>179</sup> Section 21.

<sup>180</sup> Section 32.

<sup>181</sup> Section 32(3).

<sup>182</sup> Section 26(2).

<sup>183</sup> See sections 41-46.

<sup>184</sup> Section 6(1).

*such as the denial of reasonable accommodation.*<sup>185</sup>

The law creates an obligation on all persons to uphold the rights of persons with disabilities and to safeguard the dignity of persons with disabilities.<sup>186</sup> It prohibits the use of derogatory names for persons with disabilities.<sup>187</sup>

"Appropriate measures" must be taken by the relevant Minister to ensure that persons with disabilities can access health services that are gender sensitive, including sexual and reproductive healthcare services and services of the same range, quality, and standard of free or affordable healthcare, as enjoyed by others.<sup>188</sup> The Act stresses the right to informed consent for persons with disabilities in healthcare and explicitly requires measures to be taken to prevent the discriminatory denial of healthcare and services on the basis of disability.<sup>189</sup>

## Policy framework

The policy framework in Zambia states a commitment by government to provide healthcare without discrimination while providing for particular protections in the context of HIV.

### National Health Policy

Zambia's National Health Policy 2013 speaks to ensuring access to healthcare for all people of Zambia, regardless of their geographical location, gender, age, race, social and economic, and cultural or political status. The 2010 National Community Health Worker Strategy adopts a vision of "equity of access" to health services<sup>190</sup> and seeks to address rural/urban disparities in healthcare provision.

### HIV Policy and Strategic Framework

The National HIV/AIDS/STI/TB Policy of 2005 includes the aims to address stigma and discrimination and to protect human rights.<sup>191</sup> The National AIDS Strategic Framework 2011-2015 (NASF) prioritises strategies for an enabling policy and legal framework to address HIV as including a priority to ensure that human rights are adequately addressed to reduce stigma and discrimination. While it notes the inadequate focus on key populations, the NASF proposes no specific interventions for key populations. The revised NASF 2014-2016 prioritises strategies that include enhancing the implementation of human rights and equal access to services; facilitating community-based advocacy on stigma and discrimination; advocating legal reform to ensure that all Zambian citizens are equally able to access HIV health and social services; and improving access to legal services for key populations.

### HIV Treatment Guidelines

The Zambia Consolidated Guidelines for Treatment Prevention of HIV Infection<sup>192</sup> state that individuals must give informed consent for HIV testing and counselling, and should be

<sup>185</sup> Section 2.

<sup>186</sup> Section 5.

<sup>187</sup> Section 6(3).

<sup>188</sup> Section 27(a).

<sup>189</sup> Section 27(f).

<sup>190</sup> Republic of Zambia: Ministry of Health *National Community Health Worker Strategy in Zambia* (2010), 14.

<sup>191</sup> Republic of Zambia: Ministry of Health *National HIV/AIDS/STI/TB Policy* (2005). See the Main Objective, at 4.1; and Broad objectives, at 4.2 (h) and 5.8.

<sup>192</sup> December 2013.

informed of the right to refuse testing; mandatory or coerced testing is never appropriate.<sup>193</sup> The confidentiality of HIV testing and counselling services is further emphasised. Post-exposure prophylaxis (PEP)<sup>194</sup> is recommended under the Guidelines following a determination of the need for PEP based on the risk of transmission and the risks and benefits of taking or not undertaking the intervention.<sup>195</sup>

## Ethical standards

Ethical standards in Zambia governing the conduct of health professionals prohibit discrimination between healthcare users and recognise the right to complain.

### Patients' Rights and Responsibilities Charter

The Health Professions Council of Zambia (HPCZ) has developed a Patients' Rights and Responsibilities Charter, posters of which are displayed in many healthcare facilities. The Charter states that all patients have the right to treatment without discrimination, to informed consent, to privacy and confidential treatment, and to access their medical records, among others. The Charter also states that patients have the "freedom to provide suggestions or grievances". The right to complain is further affirmed under the "responsibilities" component of the Charter, which states that patients have a responsibility to "report anything that appears unsafe".

### Health Professions Code of Ethics

The HPCZ has a Professional Code of Ethics and Discipline: Fitness to Practice.<sup>196</sup> The Code applies to all health practitioners registered under the Health Professions Act, thus excluding application to nurses and midwives. The Code of Ethics makes clear mention of the obligation on practitioners not to discriminate between patients:

*"Treatment, care and welfare of the patient or client should take into account the patient's/client's needs, preference and confidentiality. Patients/clients should not be discriminated on grounds of age, gender, marital status, education, medical condition, national or ethnic origin, physical or mental disability, political affiliation, tribe, race, religion or social status."*<sup>197</sup>

The obligation to ensure a patient's informed consent is emphasised as is the obligation to give appropriate advice and information to the patient.<sup>198</sup> The Code considers breaches of trust between practitioner and patient to be professional misconduct<sup>199</sup> which includes the improper disclosure of information obtained in confidence from the patient, exerting improper influence on a patient, and entering into an emotional or sexual relationship with a

<sup>193</sup> Republic of Zambia: Ministry of Health *Zambia Consolidated Guidelines for Treatment Prevention of HIV Infection* (2013), 9.

<sup>194</sup> PEP is short-term ART that reduces the likelihood of HIV infection after potential exposure to HIV.

<sup>195</sup> Zambia Consolidated Guidelines for Treatment Prevention of HIV Infection, notes 173, 44 above. At 45, the Guidelines indicate "substantial risk for HIV exposure" as including genital exposure to sexual fluids where the source is known to be HIV-infected. Penetrative sexual abuse is considered a "high risk" category.

<sup>196</sup> The Code was last reviewed in 1995. Guidelines for healthcare practitioners' professional misconduct are not stipulated in the Health Professions Act or Health Professions (General) Regulations. Section 61 of the Health Professions Act, does, however, determine contraventions of the Act and breaches of the Code of Ethics as professional misconduct.

<sup>197</sup> Health Professions Council of Zambia *Professional Code of Ethics and Discipline: Fitness to Practice*, at para 5.1.

<sup>198</sup> As above, 4, at para 5.1(c)

<sup>199</sup> As above, 5, at para 5.2(b).

patient.<sup>200</sup> Quite distinctly, the Code of Ethics also deals with the obligation on practitioners not to refuse to treat a patient merely for presenting with a stigmatising condition:

*"A health practitioner should not refuse to treat or attend to a patient/client if the condition is within the health practitioner's competence, solely on the grounds that the patient/client is or may be having a stigmatising medical condition."<sup>201</sup>*

### **Guidelines for Good Practice in the Health Care Profession**

The HPCZ has developed a number of Guidelines for Good Practice in the Health Care Profession. The Guidelines on informed consent<sup>202</sup> state that healthcare users have a right to information about their condition and treatment options<sup>203</sup> and about healthcare services, to be presented in a way that they understand.<sup>204</sup>

The Guidelines on patient confidentiality<sup>205</sup> state the understanding of a healthcare professional's duty of confidentiality as meaning they "may not disclose any health care information revealed by a patient or discovered by a practitioner in connection with the treatment of a patient".<sup>206</sup> This is stated to include all information "disclosed to a physician during the course of the patient-physician relationship".<sup>207</sup>

Exceptions to the obligation of confidentiality are framed in a somewhat contradictory manner:

On the one hand, the only permissible exceptions are noted to be where the healthcare user consents to disclosure, or if the healthcare professional is required to disclose information by law. The concept of a "breach of confidentiality" is further described as any disclosure to a third party of the healthcare user's information without consent or a court order.

However, the Guidelines state that healthcare users' personal information may be disclosed without consent if the benefits of a disclosure to the public or another person outweigh the public and private interests in keeping the information confidential.<sup>208</sup> The example of HIV-status disclosure to a healthcare user's spouse or partner is noted.

### **[Nurses and Midwives] Professional Code of Conduct**

In addition to the Nurses and Midwives Rules described above, the General Nursing Council of Zambia has developed a Professional Code of Conduct, 2013. Among other things, the Code of Conduct requires that all nurses and midwives

*"[r]ecognise and respect the uniqueness and dignity of each client and respond to their need for care, irrespective of their ethnic origin, political affiliation, religious beliefs, gender, traditional beliefs, values and practices, personal attributes and the nature of their health problem or any other factors."*

<sup>200</sup> As above, 6, at para 5.2(b).

<sup>201</sup> As above, 11, at para 5.6 (i).

<sup>202</sup> Health Professions Council of Zambia *Guidelines for Good Practice in the Health Care Profession: Obtaining Patients' Informed Consent: Ethical Considerations*, March 2016.

<sup>203</sup> As above, at para 3.1.1.

<sup>204</sup> As above at para 6.1.

<sup>205</sup> Health Professions Council of Zambia *Guidelines for Good Practice in the Health Care Profession: Maintaining Patient Confidentiality*, March 2016.

<sup>206</sup> As above at para 1.0.

<sup>207</sup> As above.

<sup>208</sup> As above at para 9.

Nurses and midwives are further required to protect “all confidential information concerning clients obtained in the course of [their] professional practice”. A nurse or midwife may only disclose confidential information with the consent of the healthcare user, by order of court, by order of the General Nursing Council of Zambia, or if the disclosure can be justified “in the wide public interest.”

## 4.5 A brief overview of the criminal laws relating to sex workers and LGBT persons

### Sex workers

Sex workers<sup>209</sup> are women, men and transgendered persons who receive money or goods in exchange for sexual services and who consciously define those activities as income-generating, even if they do not consider sex work as their occupation.

Most former British colonies have similar laws relating to sex work. The legal framework in these countries, including Botswana, Malawi, and Zambia, can be described as one of partial criminalisation. Partial criminalisation refers to a situation where only the activities related to sex work are criminalised and not the actual act of selling sex. Activities related to sex work which are criminalised include living off the earnings of prostitution,<sup>210</sup> procurement,<sup>211</sup> brothel-keeping<sup>212</sup> and persistently soliciting.<sup>213</sup> Notably, the offences relating to sex work are mostly aimed at criminalising the activities of those who exploit sex workers for personal gain.

These provisions are, however, seldom enforced because proof of the commission of the offences is difficult to obtain and because police resources are required for enforcement. Instead, sex workers themselves, instead of the people who exploit them, are targeted by the police usually through the arbitrary arrest of sex workers on “rogue and vagabond” provisions.<sup>214</sup> Police often make use of specific crackdowns or sweeping exercises, where women are arrested to show that the police are “doing something”. Increasingly, however, courts have held that the arbitrary arrest and abuse by police of sex workers violate their human rights.<sup>215</sup>

<sup>209</sup> This Report refers to “sex work” and “sex workers” out of respect for the dignity of people involved in sex work. The term “prostitution” is also referred to where appropriate, since this is the legal term used in many countries. The term “prostitution” is often stigmatised within society. Instead this document prefers to use the term “sex work” when referring to commercial sexual activities taking place between consenting adults.

<sup>210</sup> Malawi: section 145-6 of Penal Code; Botswana: section 155-6 of Penal Code; Zambia: section 146-7 of Penal Code.

<sup>211</sup> Malawi: section 140-3 of Penal Code; Botswana: section 149 of Penal Code; Zambia: section 140-4 of Penal Code.

<sup>212</sup> Malawi: section 147 of Penal Code; Botswana: section 157-8 of Penal Code; Zambia: section 149 of Penal Code.

<sup>213</sup> Botswana: section 155 of Penal Code; Zambia: section 146 of Penal Code.

<sup>214</sup> Botswana, Malawi and Zambia have provisions in their Penal Codes which deem as rogues and vagabonds a “suspected person or reputed thief” who has no visible means of subsistence and cannot give good account of himself, and any person found in a public place at such time and under such circumstances to lead to the conclusion that the person is there for an illegal or disorderly purpose. The rogue and vagabond offences, which have their origin in the English Vagrancy Act of 1824, are vague and overly broad and tend to be used as catch-all offences where there is no proof of the commission of an actual offence.

<sup>215</sup> The Malawi High Court in *SM and 12 others v R*, Malawi High Court 1049/2007. Justice Nyirenda dealt with an example where women were picked up at trading centre at 3 am and charged and convicted of being rogues and vagabonds, contrary to section 184(1)(c). The Court held: “But surely the law could not have intended to criminalise mere poverty and homelessness more especially in a free and open society.” ... In the present case the ladies were found occupying rest houses and nothing more to it. There was virtually nothing more to their circumstances on the facts. Perhaps they were hoping for some stray and weak-minded

Thus, although the act of selling sex is not criminalised, sex work still takes place in a largely criminalised environment. These laws stigmatise sex workers and make it difficult for them to access services. It is in this context that calls are made for decriminalisation.

Decriminalisation<sup>216</sup> refers to an approach where no specific laws criminalise consensual adult sex work and related activities. In a decriminalised situation, child prostitution, trafficking and coerced prostitution would still be criminalised:

*“Decriminalising sex work does not mean encouraging it, but it would rather pave way for policies that protect those who have been forced into the trade ... They will be able to report men who forcibly put them at risk of contracting the virus, and in turn men who seek their services will no longer abuse them as might be the situation now.” (Festus Mogae, former President of Botswana)<sup>217</sup>*

Guideline 4 of the UNAIDS International Guidelines on HIV/AIDS and Human Rights, 2006, promotes the decriminalisation of voluntary adult prostitution:

*“[W]ith regard to adult sex work that involves no victimisation, criminal law should be reviewed with the aim of decriminalising, then legally regulating occupational health and safety conditions to protect sex workers and their clients, including support for safe sex during sex work. Criminal law should not impede provision of HIV prevention and care services to sex workers and their clients.”*

It should be noted that even if the current laws are not changed, the existing offences relating to sex work do not criminalise the status of a person. Thus it is incorrect to refer to sex workers as being criminals. **Sex workers retain all the rights of other citizens including accessing healthcare services without discrimination.**

In Malawi, Botswana and Zambia, there is often a mistaken perception that the offence of living off the earnings of sex work has the effect of criminalising sex workers and their dependents. But this is not the case. The offence is specifically aimed at criminalising those persons who exploit sex workers, not sex workers themselves.

**It is not a crime to be a sex worker in Botswana, Malawi or Zambia. Even if a person attends a health facility for a sexually transmitted infection acquired as a result of sex work, a healthcare worker is obliged to attend to that person without discrimination and judgment.**

men to come around and spend the night with them. But what offence would that be on their part? As a matter of fact this was invasion of privacy on the part of the police officers. I am afraid the convictions here at were all misconceived.”

<sup>216</sup> An example of a decriminalised approach to consensual adult sex work is New Zealand.

<sup>217</sup> R Moyo “In Conservative Botswana, a Push to Legalise Prostitution” *The Mail and Guardian* (8 November 2011), available at: <http://mg.co.za/article/2011-11-08-in-conservative-botswana-a-push-to-legalise-prostitution>.

## LGBT persons

The terms lesbian, gay, bisexual and transgender refer broadly to the sexual orientation and/or gender identity of persons:

- Sexual orientation refers to a person's enduring pattern of emotional, romantic, and/or sexual attractions.
- Gender identity refers to a person's deeply felt internal and individual experience of their own gender. In most societies, there is a basic division between gender attributes assigned to males and females. In all societies, however, some individuals do not identify with some (or all) of the aspects of gender that are assigned to their biological sex. A person's self-defined gender identity is integral to their personality and is one of the most basic aspects of self-determination, dignity and freedom. A person whose gender identity does not correspond with his or her biological sex at birth is referred to as a transgender person.

**A person's sexual orientation or gender identity is not an element of any crime in Botswana, Malawi or Zambia.** Statements such as "homosexuality is a crime" are inaccurate. However, criminal laws exist which prohibit consensual sexual acts between adult persons of the same sex. Such acts are difficult to prove and few cases go to court. However, the existence of these offences leads to arbitrary arrests and discrimination.

Botswana, Malawi and Zambia's offences originate from English law, as it existed in the 1800s, and refer to offences of carnal knowledge against the order of nature (anal sex)<sup>218</sup> and gross indecency.<sup>219</sup> Initially these offences applied to same-sex sexual acts between men only but Botswana, Malawi and Zambia have revised their laws to also criminalise consensual sexual acts between women<sup>220</sup> and to increase the penalties that may be imposed for these types of offences. These offences criminalise same-sex sexual acts only, not a person's sexual orientation or gender identity. The offences do not distinguish between consensual sexual acts and non-consensual acts.

Although LGBT persons are not criminalised in themselves and should not be discriminated against at health facilities, two instances arise where LGBT persons attend health facilities in the context of existing offences against same-sex sexual acts:

- When police bring men who had been arrested on suspicion of committing same-sex sexual acts to a health facility, in order to obtain medical evidence of anal penetration.
- When LGBT persons attend health facilities to attend to an illness or infection arising from same-sex sexual acts.

In both these instances, a healthcare worker remains ethically obliged to follow medical guidelines properly – including the requirement that healthcare users' medical information are dealt with confidentially and that informed consent is obtained for medical procedures.

<sup>218</sup> Botswana: section 164 of Penal Code (7 years' imprisonment); Malawi: section 153 of Penal Code (14 years' imprisonment); Zambia: section 155 of Penal Code (15 years' to life imprisonment).

<sup>219</sup> Botswana: section 167 of Penal Code; Malawi: section 156 of Penal Code (5 years' imprisonment); Zambia: section 158 of Penal Code (7-14 years' imprisonment).

<sup>220</sup> Botswana: section 167 of Penal Code; Malawi: section 137A of Penal Code (5 years' imprisonment); Zambia: section 158 of Penal Code (7-14 years' imprisonment).

### Botswana Court of Appeal judgment on the rights of LGBT persons

On 16 March 2016, in the case of *Rammoge and 19 Others v Attorney General*, the Botswana Court of Appeal held that the refusal to register the organisation Lesbians, Gays and Bisexuals of Botswana (LEGABIBO) was not only unlawful but a violation of the right of LGBT activists to freely assemble and associate. The Court of Appeal emphasised that “all persons, whatever their sexual orientation, enjoy an equal right to form associations with lawful objectives for the protection and advancement of their interests”, and that fundamental rights applied to “every member of every class of society”. Significantly, the Court of Appeal recognised that members of the gay, lesbian and transgender community, while a minority, “form part of the rich diversity of any nation” and are fully entitled to the constitutional protection of their dignity.

The Botswana Court of Appeal’s judgment signifies the first time an apex court in Africa has provided an authoritative interpretation of the effect of criminal laws affecting lesbian and gay individuals, and clarified the common misconception that “homosexuality” itself is a crime. Referring to the offence of “carnal knowledge against the order of nature”, the Court observed that while the offence has the practical effect of limiting sexual activity, “it is not, and never has been, a crime in Botswana to be gay”. The Court emphasised that such criminal provisions do not extend to criminalising LGBT persons themselves and it is contrary to the principles of criminal law to criminalise a person’s status as opposed to their actions.

## 4.6 Conclusion

The constitutions of all three countries protect against discrimination. While in none of the countries is there a clear and explicit constitutional prohibition against discrimination in healthcare, and while none make explicit the prohibition against discrimination on the basis of health or HIV-status, occupation or sexual orientation, these protections should be understood as accommodated in the generous language afforded in the relevant constitutional protections.

The policy environments in all three countries protect against stigma and discrimination in the emphases on equitable and quality healthcare. It is noted, however, that few of the policies and plans analysed provide for particular strategies to ensure that discrimination does not occur in healthcare or to provide mechanisms for accountability and redress when it occurs.

The regulatory and ethical standards that govern the conduct of healthcare workers differ in the level to which they make explicit that discriminating between healthcare users is prohibited. However, it is clear from the nature of the conduct deemed unethical in all these frameworks that discriminatory practices are incorporated as forms of unprofessional conduct or misconduct by healthcare workers.

- Legally healthcare users in all three countries enjoy the right not to be discriminated against in terms of accessing healthcare.
- Policy frameworks in all three countries embody commitments by the Botswana, Malawi and Zambian governments to deliver healthcare services without discrimination.
- Healthcare workers are ethically and legally bound not to discriminate against healthcare users unfairly in delivering healthcare services, and to treat healthcare users with due respect for their inherent human dignity.

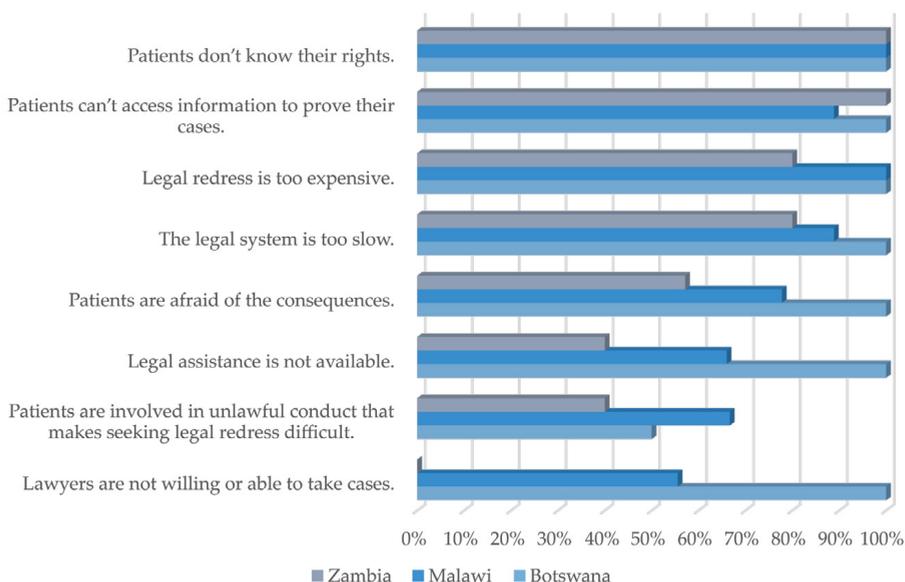
# 5. Mechanisms for accountability and redress

## 5.1 Introduction

*“The courts are only somewhat effective because the cost of litigation is high and accessibility is questionable.” (Complaints mechanisms respondent - Lusaka, Zambia)*

NGO and CBO respondents described several constraints faced by healthcare users in seeking legal redress (involving court processes or the engagement of lawyers) for healthcare users who experience discrimination in healthcare. This includes that healthcare users do not know enough about their rights to be able to enforce them, that they are unable to access information to prove cases in the courts, and that the expense, physical distances, and expertise required to litigate inhibit the use of the courts to access justice. The graph (below) represents the perspectives of NGO and CBO respondents interviewed and who completed questionnaires for the purpose of this report. The graph shows the percentage of respondents who elected particular factors as barriers, in their countries, to healthcare users accessing legal redress.

NGO and CBO perspectives on barriers to legal redress



In this chapter, various complaints mechanisms, as alternative opportunities for accountability and redress, are described and assessed in Botswana, Malawi and Zambia. Considering the disparate informal means in which justice is sought in these contexts, and accepting the limitations faced by many rights-holders in accessing legal redress through the courts, the analysis focuses on complaints processes that relate particularly to the prospect of addressing either healthcare complaints and/or issues of discrimination in healthcare. While efforts have been made to reflect the practices and opportunities for complaint in the three countries, the analysis does not purport to be comprehensive. The focus is therefore on facility-level complaints processes in healthcare facilities, health professions and nursing councils, and also national human rights institutions. The procedures for complaint through these mechanisms are described and analysed in the light of the principles developed in chapter 3 on the features of complaints mechanisms most capable of fulfilling the right to redress for human rights violations.

Desktop research was conducted on the complaints mechanisms detailed below. In addition, key informant interviews were conducted with health professions councils, nursing councils, and national human rights institutions, where available. Due to limitations in this research, it was not possible to interview representatives of the ministries of health in the three countries in order to gather more detailed information on facility-level complaints procedures. However, where respondents did have experiences of making complaints, focus groups, NGO and CBO respondents related experiences almost exclusively of using facility-level processes. In some instances, the complaints mechanisms themselves cited these processes as the preferred route for complaint.

The information on internal or facility-level complaints procedures is that which was obtainable through desktop research and the experiences of focus-group, NGO and CBO respondents. It is noted that researchers for this report were unable to access information on any formalised procedures detailing the facility-level processes in the jurisdictions described.

## 5.2 Botswana

### Introduction

In Botswana, focus-group participants and NGO/CBO participants were unaware of professional complaints mechanisms. Disability rights organisations and persons with disabilities noted the Office of People with Disability as a possible avenue for complaints. Most respondents, however, understood their options as either laying facility-level complaints or seeking redress through the courts, a process most deemed to be inaccessible and unaffordable. It is noted that in Botswana there is no national human rights institution available to receive complaints relating to human rights abuses.

### Facility-level complaints procedures

Amongst focus-group respondents in Botswana, none related engaging formal complaints processes. If any efforts to seek accountability or redress were sought, this was through directly confronting the healthcare workers or, rarely, by escalating a complaint to a superior within the health facility.

NGO and CBO respondents gave examples only of facility-level complaints options or litigation in the courts. The process was described as follows:

*"[Healthcare users can] complain to the person overseeing the clinical facility. This is usually the matron or senior nurse. One can complain to nurses, doctors and/or midwives. If it fails, the case goes to the District Health Team (DHT) and the person heading the DHT will handle the matter for them. Some members also go to the Headmen or village Kgosi/Chief or the Village Development Committee (VDC). We have seen in some cases where people go to the Ministry of Health or to NGO's that deal with health matters". (NGO respondent – Gaborone, Botswana)*

Information distributed by the Ministry of Health envisions a ten-step procedure for escalating complaints regarding services in health facilities. The healthcare user is advised to report complaints through the following steps:

- Step 1: Supervisor in charge
- Step 2: Public Relations Officer or call Hospital toll free number
- Step 3: Matron
- Step 4: Hospital Manager/Chief Admin Officer
- Step 5: Hospital Superintendent/Chief Admin Officer
- Step 6: [Ministry of Health] Headquarters Toll free number 0800 600 740
- Step 7: Director of relevant Department
- Step 8: Permanent Secretary/DPS
- Step 9: Minister/Assistant Minister
- Step 10: Office of the President.

Facility-level complaints were described by NGO and CBO respondents as "seldom effective":

*"All these structures mentioned are not formal complaint mechanisms that are formally acknowledged but these are structures that individual communities have identified that works for them. There are no formal legal mechanisms." (NGO respondent – Gaborone, Botswana)*

*"Once a complaint is lodged it is not dealt with. The process takes a very long time to deliver results and involves lots of bureaucracy. The mechanisms are such that it would not be easy for non-medical practitioners or individuals to be able to effectively engage with the processes." (NGO respondent – Gaborone, Botswana)*

Staff from professional bodies' complaints mechanisms in Botswana who were interviewed for this research indicated that clearly written complaints procedures *should* be available at all health facilities. The Public Relations Department of the Ministry of Health was indicated to be responsible for receiving complaints, although this could not be verified as being an established practice. Health professions bodies in Botswana described these processes as the primary system for healthcare user complaints but indicated that the process was "seldom effective."

It is noted, in addition, that bodies such as the Health Inspectorate and the Clinical Practice Committee carry out health-facility audits. The Council for Health Service Accreditation of Southern Africa (COHSASA) works with the Health Inspectorate, accrediting facilities in terms of the quality of health-service provision and practice. The role of COHSASA is understood by health professions bodies as instructive in ensuring standards of practice. In addition, the District Health Management Team is responsible for monitoring and evaluation of healthcare facilities' performance. The Health Inspectorate also has a role to play in monitoring the performance of the health sector and in ensuring adherence to norms and standards. It is unclear to what extent these bodies would receive healthcare users' complaints in their processes.

### ASSESSMENT

- ✘ These facility-level processes have low levels of **effectiveness** due to several factors, including the lack of clarity and guarantees in process. The efficiency, transparency and independence of the process is unstable and without guarantees.
- ✔ Facility-level processes perform better on **availability**, being accessible outside of urban centres and not necessarily requiring financial expenditure.
- ✘ While it does appear in practice that complaints can be made on behalf of others, it is unclear whether there are any confidentiality guarantees or opportunities for anonymous complaints.
- ✔ From a **sufficiency** perspective, facility-level processes appear to be well-positioned to sanction wrongdoers and to enforce those decisions and they may have the power to influence policy changes. Theoretically, since these processes constitute administrative decision, they are appealable to the courts.

## Botswana Health Professions Council

The Botswana Health Professions Council (BHPC) was established in terms of the Botswana Health Professions Act.<sup>221</sup> It is an independent regulatory body whose objectives include to promote the “highest standards in the practice of healthcare, and to safeguard and promote the welfare and interests of the Botswana public in relation to healthcare.”<sup>222</sup> In fulfilling these objectives the BHPC's duties and functions include the registration of health practitioners, monitoring standards of care and medical ethics and investigating professional misconduct and public complaints.<sup>223</sup> The BHPC is responsible for the registration of several health professionals, including medical doctors, dentists and pharmacists but not nurses and midwives.<sup>224</sup>

<sup>221</sup> 2001, Chapter 61:02.

<sup>222</sup> Section 4(1) of the Botswana Health Professions Act.

<sup>223</sup> Section 4(2) of the Botswana Health Professions Act.

<sup>224</sup> The BHPC registers the following professions: medical, dental, pharmacy, radiographers, physiotherapists, occupational therapists, opticians, optometrists, biomedical engineers, clinical psychologists, environmental health officers, laboratory scientists, speech therapists, audiologists, dieticians, paramedics, laboratory technicians, dental therapists, clinical officers, chiropodists, homeopaths, naturopaths and acupuncturists.



**Complaints** and allegations can be filed against professionals registered with the BHPC.<sup>225</sup> The BHPC's Disciplinary Committee is empowered to enquire into any complaint, charge or allegation of improper conduct of a professional nature against a healthcare professional. In addition, the BHPC Code of Conduct states that disciplinary proceedings must be taken against a practitioner if there is a contravention of the Act, the Code of Ethical Professional Conduct or a conviction for any criminal offence.

In an interview with a representative of the BHPC, the respondent described the purpose of its complaints system as: ensuring adherence to ethical standards; providing opportunities for professional misconduct and public complaints to be lodged; and protecting the rights of healthcare users. However, when asked to describe how a healthcare user should make a complaint after experiencing discrimination, the BHPC respondent did not refer to its own complaints system but to the internal processes of individual health facilities. It described these processes as "seldom effective".

The BHPC respondent stated that any person who feels they have not been treated fairly by a medical practitioner or healthcare facility can register a written complaint with the BHPC. The Botswana Health Professions Council (Professional Conduct) Regulations (Professional Conduct Regulations) state that persons who make complaints of "improper or disgraceful conduct" are required to make a written statement that sets out in precise terms the specific conduct of the practitioner.<sup>226</sup> In addition, the complainant must be willing to bring evidence of the complaint if they are requested to do so. The complaint is received by the BHPC's Executive Committee and the relevant healthcare professional is informed of the complaint. The Executive Committee determines the seriousness of the complaint. If it is considered "trivial" it is dismissed. If it is considered to be "serious", it may order that an investigation be undertaken.



**Investigations** are conducted by the BHPC Disciplinary Committee, whose investigations may include an examination of the healthcare user's medical records. The Disciplinary Committee prepares a report which is received and deliberated on by the Executive Committee. The accused practitioner is at this stage requested to provide a written statement. The Executive Committee will refer the complaint for an inquiry at the Disciplinary Committee if it considers there to be *prima facie* evidence of improper or disgraceful conduct.



**The inquiry** process before the Disciplinary Committee is detailed in the Professional Conduct Regulations as similar to a trial process before a criminal court.<sup>227</sup> The accused practitioner is asked to plead. Evidence is led by the virtual complainant and witnesses are called and may be subpoenaed to give evidence. The facts must be proved beyond a reasonable doubt for an accused practitioner to be found guilty of misconduct.<sup>228</sup>

<sup>225</sup> Available at: <http://hcp.moh.gov.bw/hprs/BHPCComplaints.aspx>.

<sup>226</sup> Regulation 33.

<sup>227</sup> Regulation 36.

<sup>228</sup> Regulation 36(1)(q).

The BHPC states that healthcare users have a right to appear before the Disciplinary Committee and make representations if they wish. Complainants are also entitled to information on the status of their complaint throughout the investigation process.<sup>229</sup> It is noted that the Regulations allow for an order to be made to protect the identity of witnesses from public disclosure but not from the accused practitioner.<sup>230</sup> In addition, statements may be made by complainants and witnesses who are not present in person at the inquiry in the form of affidavits. However, the accused practitioner may object to the use of the affidavits as evidence if they are unable to cross-examine the witness.<sup>231</sup>

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**The penalties** the Disciplinary Committee are entitled to impose if a complaint is proved are set out in the Botswana Health Professions Act: the Committee may impose a penalty as it considers appropriate.<sup>232</sup> The Act provides for the Council's power to caution and reprimand the health professional, to suspend them from the profession, to impose conditions on their practice, or to cancel their registration as a healthcare professional. There is no specific provision for ordering compensation or an apology to the complainant or victims of misconduct. Practitioners can appeal decisions of the Council to the High Court in terms of the Act.<sup>233</sup>

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The average time taken to process a complaint was stated to vary depending on the complexity of the case and whether the healthcare user concerned was deceased or alive. The BHPC respondent indicated that very few complaints were received, that funding for the BHPC complaints system was inadequate, and that the human resource capacity to handle the few complaints they received was inadequate for it to be effective and impactful. While diverse public relations and media engagements were described as efforts to raise public awareness of its complaints system, the respondent considered that healthcare users were often unlikely to complain, describing them as not being vocal about their rights and unlikely to question professional misconduct.

The Disciplinary Committee is appointed from members of the BHPC<sup>234</sup>. It comprises the following members: the Director of Health Services, the Dean of the Faculty of Medicine at the University of Botswana, fourteen healthcare practitioners elected from members of the profession, and one member of the public not associated with the medical profession who is appointed by the Minister.<sup>235</sup> A member of the Disciplinary Committee or BHPC may ask to be excused from an inquiry if the person cannot give the accused practitioner a fair hearing.<sup>236</sup>

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<sup>229</sup> The Botswana Health Professions Act provides for the right of an accused practitioner to make representations and to have legal representation before the Disciplinary Committee but does not create a similar right for complainants.

<sup>230</sup> See regulation 44.

<sup>231</sup> See regulation 36(1)(n).

<sup>232</sup> Section 14(1).

<sup>233</sup> Section 15. The Act does not specifically provide for an appeal by a complainant or aggrieved party. It is likely, however, that a party with sufficient interest in the decision (other than the accused), could take the decision on review to the High Court.

<sup>234</sup> See section 7 of the Botswana Health Professions Act.

<sup>235</sup> See section 3(1) of the Botswana Health Professions Act.

<sup>236</sup> Regulation 34(2) of the Professional Conduct Regulations.

The BHPC respondent stated that its Public Relations programme is considered an intervention to combat stigma and discrimination in healthcare in its emphasis on healthcare users' rights. In addition, the BHPC stated that it provides orientation, or induction and capacity-building training to medical professionals on a regular basis in which issues of stigma and discrimination and healthcare users' rights are addressed. The BHPC nevertheless acknowledged that further training of healthcare workers on issues of stigma and discrimination and rights-based healthcare is a continuous need.

### ASSESSMENT

- ✓ The BHPC is relatively **effective** because it ensures complainants the opportunity to make representations and because it has legislated guarantees for the independence of decision-makers.
- ✗ The **availability** of the complaints process is compromised by the limited manner in which complaints can be submitted. In addition, the requirement that complainants must be prepared to present evidence and that they can be subpoenaed are aspects that may compromise safety for vulnerable complainants.
- ✗ While rules and procedures are clear in legal terms, NGO and CBO respondents and focus-group participants showed little to no awareness of the processes.
- ✓ Finally, the **sufficiency** of the process is strong in terms of the capacity to apply sanctions against healthcare workers.
- ✗ However, the scope of redress is limited, and the prospect for the complainant to contest a decision, is likely limited to judicial review.

## Nursing and Midwifery Council of Botswana

The Nursing and Midwifery Council of Botswana (NMCB) was established in terms of the Nurses and Midwives Act.<sup>237</sup> The NMCB has powers, amongst others, to manage the registration of nurses and midwives in Botswana;<sup>238</sup> to deal with breaches of discipline or professional ethics;<sup>239</sup> and to establish and promote a code of ethical conduct for nurses and midwives.<sup>240</sup>

<sup>237</sup> Act 1 of 1995, Chapter 61:02, section 3.

<sup>238</sup> Section 7(2)(f) of the Nurses and Midwives Act.

<sup>239</sup> Section 7(2)(g) of the Nurses and Midwives Act.

<sup>240</sup> As above, section 7(2)(l).



The NMCB has a **complaints procedure**, which a respondent from the Council indicated was to ensure that nurses and midwifery practitioners embrace the highest standards of service for the protection of the public and healthcare users utilising healthcare services. Anyone can make a complaint to the NMCB about a registered nurse or midwife, including fellow registrants, colleagues in the healthcare system, healthcare users, families, the police and employers.<sup>241</sup> The NMCB respondent interviewed stated that the Council also makes use of whistle-blowers at strategic points in the health sector who assist in relating issues of concern. In addition, the respondent stated that the NMCB has a public member on its Board (selected by the Ministry of Health to represent public interests) who is also able to receive and lodge complaints from the public. Further to this, facilities are required to make reports to reflect the complaints made by the public on the conduct of healthcare workers and service provision at facility-level. The respondent stated that health facilities do not as a matter of course deliver these reports. Lastly, in a number of cases, the NMCB is alerted to professional misconduct in facilities by the media and launches an investigation on its own accord.

Complaints must be in the form of a written statement relating to a disciplinary matter of a nurse or midwife and must be lodged with the NMCB.<sup>242</sup> The NMCB has the power to make interim orders to protect the physical or mental health of any person during the conduct of an investigation into misconduct.<sup>243</sup>



Following the receipt of a complaint, the Disciplinary Officer assesses whether there is a need for an **investigation** team selected from the NMCB board.<sup>244</sup> The Investigation Team has broad powers to inspect premises and documents and to compel the production of evidence.<sup>245</sup> The Team prepares a report and recommends to the Disciplinary Committee how the complaint should be dealt with. The Disciplinary Committee can charge a nurse or midwife with misconduct following the receipt of the Investigation Team's report.<sup>246</sup> The Disciplinary Committee comprises five members of the NMCB, whose members include the President of the Nurses Association of Botswana, a member of health services appointed by the Minister, a member of the public appointed by the Minister, thirteen registered nurses elected by other registered nurses, and three enrolled nurses elected by their peers.<sup>247</sup>



Following the Committee's receipt of the accused nurse or midwife's plea on the charge, a **Disciplinary Hearing** is convened to try the accused party.<sup>248</sup> These proceedings are closed to the public.<sup>249</sup> Accused nurses and midwives have a right to be heard before the Committee, to legal representation, and to call and

<sup>241</sup> Regulation 5(1) of the Disciplinary Regulations. The complaints procedure is listed on the Ministry of Health website (<http://hcp.moh.gov.bw/hprs/NMCBComplaints.aspx>). However, there were no active links on the site to the complaint forms at the time of writing.

<sup>242</sup> Regulation 5(2) of the Disciplinary Regulations.

<sup>243</sup> As above, regulation 9.

<sup>244</sup> Regulation 7(3).

<sup>245</sup> Regulation 8.

<sup>246</sup> Regulation 10.

<sup>247</sup> Section 3(1) of the Nurses and Midwives Act.

<sup>248</sup> Regulation 13 of the Disciplinary Regulations.

<sup>249</sup> As above, regulation 13(3).

cross-examine witnesses.<sup>250</sup> The Committee has the power to summon witnesses before it.<sup>251</sup> The NMCB respondent stated that healthcare users have a right of appearance as a chief witness if they wish and are entitled to information relating to the status of their complaint.



Following a guilty finding, the Committee is empowered to impose the following **punishments**: reprimand; a fine not exceeding BP1,000; recommending suspension to the NMCB for a maximum of three months; or recommending to the NMCB that the nurse or midwife be removed from the register.<sup>252</sup> Nurses and midwives subjected to disciplinary proceedings are entitled to reasons from the Committee for reaching its decision<sup>253</sup> and can appeal the Committee's decision to the NMCB, and may further appeal the NMBC's decision to the Minister. If still aggrieved, the nurse or midwife can appeal further to the High Court.<sup>254</sup> The NMCB respondent described the responsibility of enforcement as resting with the Ministry of Health.



The time it takes for the assessment and determination of a complaint differs but was described by the NMCB respondent as representing a grey area in the delivery of its mandate. The NMBC respondent described several challenges facing its processes at the time of writing, to which the role of the Ministry of Health was indicated as the source of the challenges. Many cases were said to have been waiting to be tried and to be at risk of expiring. The cause of the delays was apparently that since December 2015 the NMCB did not have a Board, the renewal of which rests with the Ministry of Health. Without the Board in place, many cases are left pending. The NMCB respondent indicated distress at these delays, stating that "justice delayed is justice denied" in the absence of an effective governance structure at the NMBC. The respondent could not indicate the number of complaints received annually. The NMCB respondent described its own process as "seldom effective":

*"We, as a Council, attend to all the cases reported to us but facilities show a tendency to sweep issues under the carpet. However, as the Council, we make all efforts to follow the due processes for [the] issue to be investigated and if in our view there is a case to answer, we take it through due process up to the hearing stage." (NMCB respondent – Gaborone, Botswana)*

In order to inform the public of its mandate, the NMCB respondent indicated that it conducts awareness-raising activities and capacity strengthening programmes including instructing health facilities on laws, policies and regulations that regulate professional conduct.

<sup>250</sup> As above, regulation 13(6).

<sup>251</sup> As above, regulation 14. Regulation 15 makes disobedience of a summons an offence which is subject to a fine.

<sup>252</sup> As above, regulation 22.

<sup>253</sup> As above, regulations 13(7) and 22(2).

<sup>254</sup> As above, regulation 24.

## ASSESSMENT

- ✘ The NMCB rates low on **sufficiency**. While empowered to impose sanctions on respondent nurses or midwives, it has difficulty with enforcement and has no powers to order redress for complainants or meaningfully motivate structural changes.
- ✓ In terms of **effectiveness**, the NMCB can be considered to be in policy terms independent and provides opportunities for complainants to be heard.
- ✘ It is unclear however whether complainants have a right to access reasons for the disciplinary decisions made.
- ✘ The **availability** of the complaints process rates low from physical accessibility criteria and in the diversity of entry points. The process for lodging a complaint is relatively obtainable but NGO, CBO, and focus-group respondents were unaware of the processes.
- ✓ The **safety** of the complaints process is mixed. While third parties appear to be able to complain on behalf of others and the power of the NMCB to make interim orders to protect complainants are positive protections for vulnerable complainants, the NMCB's subpoena powers may inhibit vulnerable litigants from complaining if concerned about social or legal exposure following a complaint.

## Office of People with Disability

The Office of People with Disability (Disability Office) falls under the Office of the State President and works to coordinate the implementation of disability policy in Botswana through developing strategies and programmes to empower people with disabilities. It envisions a “barrier-free society for people with disabilities by 2016”. The Disability Office plays a coordinating role between government departments and ministries and persons with disabilities.



The Disability Office receives **complaints** from the public relating to persons with disabilities. The respondent from the Disability Office interviewed for this research stated that any person who has a complaint relating to disability can file a complaint in writing in either Setswana or English. Complainants can attend in person to make their complaints. In rural areas, the complaints can be made with the district Disability Committee. Social workers can assist in putting the complaint into writing and in directing it to the relevant department. Healthcare-related complaints would go to the District Health Office for investigation and redress. In urban areas, the complaints go directly to the Disability Office.



Details of the complaint are recorded and would be forwarded to the Ministry of Health for further investigation. The respondent stated that complainants can make follow ups, but there are no guarantees they will receive information on the status of the complaint. The respondent noted no restrictions on who could bring complaints to the Disability Office's attention, nor any restrictions on anonymity or parties making complaints on behalf of others.



The respondent stated that the objective of the procedure is not necessarily to punish an offender but to ensure the behaviour is not repeated, to right the wrong incurred and to ensure that persons with disabilities are treated with dignity and

respect. The purpose is to address discriminatory practices in the public service and to combat future incidences while collecting and collating data on human rights issues affecting persons with disabilities. The Disability Office does not have any particular powers to order redress nor to enforce change: its powers are those incidental to the Office of the State President.



The Disability Office respondent described that the procedure is fairly new and that it is working towards formalising protections for persons with disabilities in laws and policies. No information on the annual number of complaints received was available.

### ASSESSMENT

- ✓ The Office of People with Disability rates high on **availability**, offering diverse entry points, options for assistance of complainants and referrals, and having no requirement for complainants to expose their identities.
- ✗ The clarity of rules and procedures, however, is low considering that the complaints process has not yet been formalised.
- ✓ The Disability Office's **sufficiency** is good in terms of the breadth of interventions it can pursue when handling a complaint, including in motivating structural change and engaging other government agencies.
- ✗ The Disability Office, however, has no enforcement powers and is limited in the absence of a strong legislative and policy framework for persons with disabilities in Botswana.
- ✗ The Disability Office ranks lowest on **effectiveness** in that its transparency, independence and efficiency is either unclear or not yet prescribed. However, it does appear that the Disability Office in principle would wish for complainants and rights bodies to make representations and to engage in its decision-making process when considering a complaint.

## The Office of the Ombudsman

In Botswana, the Ombudsman is appointed by the President in consultation with the leader of the opposition party in Parliament, in terms of the Ombudsman Act 5 of 1995. The Ombudsman's mandate is to investigate complaints of maladministration against public institutions. The Ombudsman's functions are narrowly focussed on administrative action.<sup>255</sup>

Complaints relating to healthcare may feasibly fall within the Ombudsman's mandate to the extent that an administrative decision made by a healthcare institution or healthcare provider indicates behaviour such as bias, neglect, arbitrariness, or incompetence. Under the Ombudsman Act, the following complaints way not be investigated, among others:

- issues relating to private, non-governmental institutions or persons;
- any case before a court or any other tribunal;

<sup>255</sup> See section 3(1) of the Ombudsman Act.

- actions taken under order of the Botswana Police Force or Defence Force; and
- a case that concerns the investigation of a crime.<sup>256</sup>

From public information distributed by the Office of the Ombudsman, it also appears that its mandate is understood as excluded if the complaint deals with any case that has a remedy before a court of law. The Ombudsman further requires a complainant to exhaust all internal review mechanisms first, before approaching the Ombudsman.



Any member of the public or a group of people can **complain** to the Ombudsman. The Act requires complaints to be submitted to the Ombudsman in writing.<sup>257</sup> However, because the Ombudsman has the power to consider an issue on his own motion,<sup>258</sup> it is conceivable that an investigation could be prompted by informal, anonymous, or third-party complaints, should the Ombudsman elect to exercise this power.



Once the Ombudsman has determined that the complaint falls within the Office's jurisdiction and that it warrants **investigation**, broad powers exist for the Ombudsman to investigate the issue in an appropriate manner.<sup>259</sup> There are no costs associated for complainants and it is not necessary to be represented by a lawyer during these proceedings. The Ombudsman may agree to the presence of a lawyer, however, if a person is giving evidence as a witness. Complainants are entitled to information on the status and outcome of their complaint



Following an investigation, the Ombudsman may make **recommendations** to the relevant public official or body. This may include recommendations to re-examine a decision or policy, to offer an apology, or to compensate someone for financial loss. However, these recommendations are not enforceable. If the recommendations are not complied with, the only recourse available is for the Ombudsman to present a special report to the National Assembly detailing the issue for further action.<sup>260</sup> The Ombudsman's findings may be published in the Annual Report.



The Ombudsman Act creates offences relating to interference in the execution of its mandate,<sup>261</sup> which may be understood to include criminal prosecution of persons who victimise complainants.

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<sup>256</sup> As above, at section 4.

<sup>257</sup> Section 5(1).

<sup>258</sup> Ombudsman Act, at section 3(1)(c).

<sup>259</sup> As above, at section 6(2).

<sup>260</sup> As above, at section 8(2).

<sup>261</sup> As above, at section 14.

## ASSESSMENT

- ✘ The Office of the Ombudsman has a narrow mandate and functions as a “last resort” for the investigation of maladministration. For this reason, its complaints procedure would have low **availability** and **effectiveness** for the particular needs of healthcare complaints who experience discrimination, and whose complaints are unlikely to meet the strict confines of the Ombudsman’s jurisdiction.
- ✓ The guarantee for **safety** from secondary victimisation for complainants through the creation of a criminal offence under the Act, may, however, support the safety of this process for vulnerable complainants.
- ✘ In terms of **sufficiency**, while the Ombudsman may make a broad array of recommendations to provide for accountability and redress, that these recommendations are unenforceable may undermine its utility as a prospect for meaningful accountability and redress for individual complaints.
- ✓ In the context of complaints relating to healthcare discrimination, the Ombudsman may be strategically useful to deal with systemic accountability issues where the function of the complaint is aimed primarily at bringing transparency to an issue where the Ombudsman’s investigatory powers can be most usefully employed.

## 5.3 Malawi

### Introduction

In Malawi, neither service providers nor vulnerable healthcare users are aware of complaint mechanisms to report an experience of healthcare discrimination.<sup>262</sup> It is rare for healthcare users to complain to health facilities.<sup>263</sup> In the present research, none of the focus group or NGO and CBO respondents related making any complaints but through a multitude of bodies internal to the health systems and at facility level. Access to redress and accountability in healthcare in Malawi appears therefore to be most accessible through networks and diverse entry points with little clarity or predictability in process or outcome.

### Health system and facility-level complaints

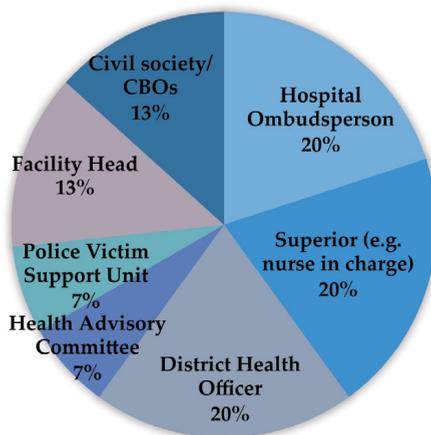
When asked how healthcare users should complain if experiencing discrimination in healthcare, NGO and CBO respondents gave different answers, suggesting low levels of uniformity or varied understandings of processes in place. Respondents variously suggested that complaints should be made through a hospital ombudsperson at each health facility, the healthcare worker’s superior (nurse or medical officer in charge), the District Health Officer or District Health Team, Health

<sup>262</sup> IJ Anderson “Sex workers’ access to health care in Lilongwe, Malawi” *Masters Thesis at Simon Fraser University* (2011), available at: <http://summit.sfu.ca/item/11649>, 45.

<sup>263</sup> Norwegian Agency for Development Cooperation (NORAD) *Local Perceptions, Participation and Accountability in Malawi’s Health Sector* (2013), available at: [http://www.opml.co.uk/sites/default/files/Norad%20-%20Local%20Perceptions,%20Participation%20and%20Accountability%20in%20Malawi’s%20Health%20Sector\\_0.pdf](http://www.opml.co.uk/sites/default/files/Norad%20-%20Local%20Perceptions,%20Participation%20and%20Accountability%20in%20Malawi’s%20Health%20Sector_0.pdf), 74 (hereinafter referred to as the NORAD Report).

Advisory Committees, the Police Victim Support Unit, the facility Head, or simply to NGOs, CBOs and support groups. These processes were predominantly described as inconsistently effective, somewhat effective, or never effective.

### Where should a patient complain? NGO and CBO perspectives



The respondent interviewed from the Nurses and Midwives Council of Malawi (NMCM) stated that healthcare users experiencing discrimination should complain to the hospital ombudsperson or the management of the particular facility. In some cases, one could complain to the Hospital Advisory Committee. These complaints procedures were described as “inconsistently effective”.

The respondent from the National Organisation of Nurses and Midwives of Malawi (NONM) similarly described that if healthcare users experience stigma or discrimination in healthcare settings, they should directly approach the facility head. The respondent described health facilities as usually having their own mechanisms, such as reporting to the management at the ward, reporting at the department level or directly to the hospital directors. The respondent indicated these processes to be “somewhat effective” depending on who handles the case and the gravity of the consequences.

A 2013 study by the Norwegian Agency for Development and Cooperation (NORAD)<sup>264</sup> identified routes through which public concerns on services could be voiced. This included:

- Direct supervisors including facility in-charge, District Health Officers and District Management Teams.
- Health Care Advisory Committees.
- Village Health Committees.

<sup>264</sup> NORAD Report, note 232 above.

- District Health Ombudsmen.
- Civil society organisations.
- Traditional leaders.

**District Health Officers** are responsible for managing primary and secondary health facilities and are often located in the district hospital.<sup>265</sup> The NORAD study, referred to above, indicated that complainants to these structures were seldom informed of the process or status of their complaint and meaningful redress was not often achieved.<sup>266</sup>

The Malawi Health Sector Strategic Plan 2011-2016 establishes **Health Centre Advisory Committees (HCAC)** at each Health Centre. The HCACs comprise health workers and community members. NGO respondents described the HCACs as working to ensure transparency and accountability on health facilities' performance and to mobilise communities' participation in accountability efforts. NGO respondents stated that the HCACs have not been particularly effective in this role due to a lack of funding and the ignorance of members of their functions:<sup>267</sup>

*"We do not know ... the [HCAC] that you are talking about. If they are there, then they do not work to protect our interests. When we complain to the hospital administrators, they do not help us adequately because in all honesty, how do you expect hospital administrators to punish their colleagues who have wronged us? Of course they will always defend each other." (Sex worker respondent – Mwanza, Malawi)*

NGO respondents recognised, however, the potential for the HCACs to be used to ensure accountability for healthcare discrimination even if not offering the possibility for redress for complainants. Respondents recognised instances where HCACs were visible and effective in the communities and where cases had been taken up by the HCACs to pursue disciplinary actions against healthcare workers.

The Health Sector Strategic Plan also establishes **Village Health Committees (VHCs)** which aim to promote health services and preventative interventions such as improving sanitation and hygiene at community level. The Plan further envisages VHCs as facilitating community involvement in planning and monitoring health services. VHCs can channel healthcare complaints. However, the 2013 NORAD study showed that the VHCs were the least functional of the accountability structures examined within the health system and many were inactive.<sup>268</sup>

**Ombudspersons** at hospital or district level are understood to have been put in place following the development of District Service Charters. These ombudspersons are seemingly able to receive and determine complaints from the public and healthcare workers. It is unclear what decision-making powers, processes and referral systems are in place for complaints processing or to what extent there is uniformity in processes. The 2013 NORAD study found that district health

<sup>265</sup> As above, 18.

<sup>266</sup> As above, 77.

<sup>267</sup> See also, NORAD Report, as above, 67, where research indicates that HCAC and VHS members indicate frustrations with not being orientated in their roles.

<sup>268</sup> As above, 80.

ombudspersons had been appointed in most but not all districts but they received little or no guidance or training on their functions and dealt with “extremely small numbers of complaints”.<sup>269</sup> Key informants interviewed for the present research noted that guidelines and terms of reference for ombudspersons were still in development.

All police stations in Malawi should provide victim support services. **Victim Support Units** are a component of the Community Policing Services Branch and their key functions are: counselling, first aid, advice, referral, interviewing of complainants in cases of sexual abuse, rape, defilement, indecent assault and other offences that require privacy and confidentiality; dealing with cases of domestic violence; helping victimised children; and conducting general sensitisation on human rights and policing.<sup>270</sup> According to the Victim Support Unit guidelines, forms of gender-based violence include: physical abuse; psychological or emotional abuse; sexual abuse (rape, defilement, indecent assault, procuring); cultural abuse (any harmful act/practice that causes suffering on the part of the victim and results in, among other things, physical, sexual, psychological harm and economic deprivation); social abuse; economic abuse; and financial abuse.

## ASSESSMENT

- ✓ Subject to limitations in available information, these processes rate well on **availability** criteria as multiple means of entry ensure physical accessibility and options for supported complaint-lodging that may enable precautions for vulnerable complainants.
- ✗ Due to the absence of any identifiable reporting chain or process for any of these systems, the clarity of rules and procedures are low.
- ✗ These processes rate relatively low on **sufficiency** – particularly because, in the absence of a formalised process and decision-making criteria, the enforceability, arbitrariness and absence of viable prospects for appeal or review by complainants compromises the process.
- ✓ However, the process rates higher in terms of the scope of redress available, in that it is possible for individualised sanctions and redress to be offered as well as for information feedback for policy reform.
- ✗ It is not apparent however that there are systems in place to ensure structured information feedback from complaints into the healthcare system.
- ✗ These complaints processes are low on **effectiveness** as there are no guarantees of complainants being given an opportunity to be heard by decision-makers, and the transparency, efficiency and independence is dependent on the individual decision-makers and is not formalised with any guarantees in place.

<sup>269</sup> As above, 73.

<sup>270</sup> Malawi Police Service & Malawi Human Rights Resource Centre *Guidelines for the Support and Care of Victims of Gender Based Violence, HIV and AIDS related abuses, and other Human Rights Violations.*

## Medical Council of Malawi (MCM)

The Medical Council of Malawi (MCM) is established by the Medical Practitioners and Dentists Act.<sup>271</sup> The MCM's aims include the promotion and improvement of the health of the population of Malawi and the exercise of disciplinary control over the professional conduct of practitioners registered under the Act.<sup>272</sup> The Malawi Health Sector Strategic Plan describes the objects of the MCM to include setting and maintaining standards of healthcare in relation to the qualifications and credentials of healthcare personnel including their behaviour and conduct towards healthcare users and clients.



The MCM respondent interviewed for this research stated that individuals can **complain** about medical practitioners' conduct to the MCM either in writing, or by phone, or by coming in person to meet the Registrar.<sup>273</sup> The respondent described the purpose of its complaints procedure as to help discipline professionals and to ensure abidance to medical ethics.



Upon receiving a complaint, the Registrar creates a confidential case file. The Registrar, Assistant-Registrar and investigators assess the complaint. Following an investigation into a complaint or allegation against a practitioner, the MCM may refer the allegation to the Disciplinary Committee for an inquiry, may dismiss the allegation, or may "take such action as it deems fit".<sup>274</sup>



**Inquiries** into professional misconduct and incompetence are dealt with by the Disciplinary Committee.<sup>275</sup> The Disciplinary Committee comprises the Chairman of the Council, two to four other practitioners appointed by the Chairman, and two other members who may or may not be members of the MCM.<sup>276</sup>

The Disciplinary Committee is empowered under the Act to regulate its own procedure.<sup>277</sup> It is obliged to afford an accused practitioner an opportunity to be heard and the accused is entitled to the assistance of legal counsel.<sup>278</sup> The MCM Chairman or Registrar can summon witnesses and compel the production of documentary evidence.<sup>279</sup> The MCM respondent stated that complainants have a right to appear before the Registrar and are usually contacted to hear their side of the story. The respondent considered that complainants are entitled to information on the status of their complaints. The Disciplinary Committee, after its inquiry, reports its findings to the MCM and makes recommendations.<sup>280</sup>

<sup>271</sup> Act 17 of 1987.

<sup>272</sup> See: section 10(a) and (c) of the Medical Practitioners and Dentists Act.

<sup>273</sup> Section 55 of the Medical Practitioners and Dentists Act empowers the MCM to make regulations to regulate the procedure for lodging complaints. At the time of writing, no regulations had been promulgated.

<sup>274</sup> As above, section 50(2).

<sup>275</sup> As above, section 47(1).

<sup>276</sup> As above, see section 46(1).

<sup>277</sup> As above, section 46(7).

<sup>278</sup> As above, section 47(2).

<sup>279</sup> As above, section 48(1). Refusal to abide by a summons is an offence punishable by a fine or six months' imprisonment, under section 48(4).

<sup>280</sup> As above, section 51(1).



The **discipline** of the practitioner is decided upon by the MCM after considering the Disciplinary Committee's findings and recommendations.<sup>281</sup> The MCM may dismiss the allegation and if the allegations are considered frivolous or vexatious, the complainant can be ordered to pay the costs of the inquiry.<sup>282</sup> The MCM is empowered upon a guilty finding to deregister practitioners and to order them to cover the costs of the inquiry.<sup>283</sup> In the alternative, the MCM may order the practitioner's suspension, impose conditions on their practice, order a penalty to be paid, or censure or caution the practitioner.<sup>284</sup> The Registrar is obliged to publish in the Government Gazette the names of any persons who have been deregistered or suspended from practice.<sup>285</sup>

The Act provides that "any person who is aggrieved" by the MCM or Disciplinary Committee's decisions may appeal the decision to the High Court within three months.<sup>286</sup> The breadth of the provision includes the option of appeal by the complainant.



In terms of section 50 of the Medical Practitioners and Dentists Act, if any allegation is brought to the notice of the Council that might be the subject of an inquiry by the Disciplinary Committee, the MCM is empowered to call for information and refer the issue for further disciplinary inquiry. This process indicates that third party and anonymous complaints to the MCM are possible and may be acted upon. It is noted, however, that under section 47 of the Act, an accused medical practitioner has the right to be heard in disciplinary proceedings, which may include the possibility of cross-examining a complainant. This may limit the potential for anonymous complainants to successfully use the MCM process.



The MCM respondent interviewed for the report indicated that it receives over twenty complaints per year. Reports in early 2015 stated that the MCM receives on average of ten complaints per month relating to negligence and incompetence of its members.<sup>287</sup>

The MCM respondent described its own complaints procedure as "very effective" and that complaints are assessed and determined "immediately". On the other hand, a media report describes the MCM's monitoring system as "porous" with inadequate adherence to ethical standards and supervision.<sup>288</sup> In the same report, the MCM's Registrar stated that in early 2015, the Council was yet to deal with 30% of the 120 cases registered in 2014, indicating a much slower process than accounted for.

When asked if the MCM has any programmes to combat stigma and discrimination, the MCM respondent indicated that the MCM "reminded professionals about the evils of stigma and discrimination." The MCM respondent, while acknowledging

<sup>281</sup> As above, section 51(2).

<sup>282</sup> As above, section 51(2)(c).

<sup>283</sup> As above, section 51(2)(ii).

<sup>284</sup> As above, section 51(2)(b).

<sup>285</sup> As above, section 53.

<sup>286</sup> See section 52(1), as above.

<sup>287</sup> A Kasakura "Complaints Choke Medical Council" *Times Malawi* (28 February 2015), available at: <http://timesmediaw.com/complaints-choke-medical-council/>.

<sup>288</sup> As above.

that a lack of information on its mandate is a principal barrier to healthcare users making complaints, stated that it engages multiple media forums (radio, television and press releases) to inform healthcare users and healthcare providers of their complaints service.

### ASSESSMENT

- ✘ In terms of **sufficiency**, the MCM process does not provide for systemic input or complainant redress – it has power only to discipline its members.
- ✓ The MCM process does, however, provide for a right of appeal of its decisions by complainants.
- ✓ The **availability** of the process is strengthened by the MCM's stated commitment to receive complaints in a variety of forms and to accommodate anonymous and third-party complaints.
- ✘ However, there are low levels of awareness of the process by NGO, CBO and focus-group respondents and it is unclear what protections could be afforded to vulnerable complainants.
- ✓ The **effectiveness** of the process is strengthened by the right of complainants to make representations before decision-makers and to access information on the status of the complaint.
- ✓ The constitution of decision-making bodies is also likely to ensure a measure of independence.
- ✘ Public reports suggest that **efficiency** of the system may be constrained.

## Nurses and Midwives Council of Malawi (NMCM)

The Nurses and Midwives Council of Malawi (NMCM) is established in terms of the Nurses and Midwives Act.<sup>289</sup> It is the sole regulatory body for nursing and midwifery education, training practice and professional conduct. Its functions include exercising disciplinary control over the professional conduct of registered nurses and midwives.<sup>290</sup>



A patient, client, professional colleague, or any other person who has a substantial interest in the practice and conduct of a registered nurse or midwife may lodge a **complaint** with the Investigations Committee of the NMCM.<sup>291</sup> The complaint must be in writing and must state in clear terms the specific acts or omissions that are being reported.<sup>292</sup> The NMCM respondent interviewed for this research stated that individuals can complain to secretaries or nursing officers at health facilities, who may in turn file the complaints at the Director's Office where the complaint is registered.

<sup>289</sup> 16 of 1995.

<sup>290</sup> Section 11(c) of the Nurses and Midwives Act.

<sup>291</sup> As above, section 52(1).

<sup>292</sup> As above, section 52(2).

It is possible to make **anonymous and third-party** complaints to the NMCM. However, the NMCM does not encourage anonymous complaints in order to ensure that investigations can be easily conducted.

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The Director and nursing officer conduct an initial assessment of the complaint which is then referred to the **Investigations Committee**. The Committee regulates its own procedure and has the power to investigate any matter referred to it by the NMCM.<sup>293</sup> If after conducting a preliminary investigation, the Investigations Committee determines that the exercise of disciplinary control is necessary, it will refer the complaint to the Disciplinary Committee.<sup>294</sup>

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The **Disciplinary Committee** will then conduct an inquiry into the allegation referred to it. Nurses and midwives who are the subject of an investigation before the Disciplinary Committee have a right of appearance and may be legally represented in those proceedings.<sup>295</sup> During its inquiry process, the Disciplinary Committee is empowered to summon witnesses and procure any record, book, document or thing.<sup>296</sup> Parties to the procedure may also call expert witnesses.<sup>297</sup> All witnesses may be cross-examined by a respondent or their legal representative.<sup>298</sup> The NMCM respondent stated that complainants have a right of appearance during the complaints procedure and that feedback on the process is given to the complainant. While the structure of the Disciplinary Committee procedure is much like that of a trial, it is not bound by strict rules of evidence and practice: its inquiry may be conducted in an informal manner.<sup>299</sup>

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Following its inquiry, the Disciplinary Committee reports its findings and recommendations to the NMCM. If the NMCM agrees that the relevant nurse or midwife has committed misconduct or is incompetent, it has several **disciplinary powers** at its disposal. This includes the nurse or midwife's removal from the Register, their suspension, the payment of a penalty or expenses relating to the inquiry, or imposing conditions on their practice.<sup>300</sup>

Any person who is aggrieved by the findings of the Disciplinary Committee or the decision of the NMCM, may **appeal** to the High Court within three months.<sup>301</sup>

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The NMCM respondent stated that complaints take three to six months to process, depending on financial resources. The NMCM respondent interviewed for this report indicated it receives 20-30 complaints per year. Healthcare users and healthcare workers are informed of the procedure through meetings and radio programmes.

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<sup>293</sup> As above, section 50-51.

<sup>294</sup> As above, section 55.

<sup>295</sup> As above, section 58(2).

<sup>296</sup> As above, section 59.

<sup>297</sup> Rule 15 of the Nurses and Midwives (Disciplinary Inquiry) Rules GN 11/2003.

<sup>298</sup> As above, rule 10(1).

<sup>299</sup> As above, rule 14.

<sup>300</sup> Nurses and Midwives Act, section 62.

<sup>301</sup> As above, section 63.

### ASSESSMENT

- ✓ The **availability** of the NMCM complaints process is strengthened by the possibility of relating complaints through secretaries and nursing officers at facility-level.
- ✗ The requirement that complaints be in writing, however, may be restrictive for some complainants.
- ✓ Even though anonymous and third-party complaints are discouraged, the possibility for their inclusion enhances the safety of the NMCM process for vulnerable healthcare users.
- ✗ Vulnerable complainants might, however, be wary of the safety consequences of being summoned to give evidence and cross-examined during the investigation process.
- ✓ The **efficiency** of the procedure is strengthened by there being legislated structures in place to in theory secure independence of the investigation and decision-making processes.
- ✗ The **sufficiency** of the NMCM process is limited by its strictly disciplinary powers against its members.
- ✓ A broad prospect of appeal to a court of law does, however, enhance sufficiency potential.

## Malawi Human Rights Commission

The Malawi Human Rights Commission (MHRC) is an independent body established in terms of the Constitution.<sup>302</sup> It is vested with the responsibility to protect against and investigate violations of rights in the Constitution and other law.<sup>303</sup> In fulfilling its mandate, the MHRC has powers to investigate issues and make recommendations on its own accord or on application of individuals or classes of people.<sup>304</sup> Complaints are sometimes related to the Commission through public inquiries.



According to the Commission's website,<sup>305</sup> **complaints** can be submitted by writing letters or filling out a complaint form, or calling or visiting the Commission's offices in Blantyre or Lilongwe. Written complaints must include the name, contact details and address of both the complainant and the respondent, and also details of the complaint and all relevant documents. Commission officers may assist complainants who are unable to read or write. In addition, complaints may be brought by representatives, third parties, NGOs, and other legal persons.<sup>306</sup>

<sup>302</sup> See: sections 129-131 of the 1994 Constitution of Malawi.

<sup>303</sup> As above, section 129.

<sup>304</sup> As above, section 130.

<sup>305</sup> Available at: <http://www.hrcmalawi.org/complaints.html>.

<sup>306</sup> Section 16(2) of the Human Rights Commission Act 27 of 1998.

Complaints may relate to any violation of a person's rights under the Constitution or other law. However, the Commission will not consider cases pending before the courts or other decision-making bodies, or issues that are frivolous or vexatious.



It is understood that generally after a complaint has been submitted the Commission proceeds to categorise it and assign officers to be in charge of it. An **inquiry plan** is then completed by the assigned officer who can proceed to consider the complaint. An investigation of the facts and merits of the case is conducted and further evidence acquired. The Commission has significant investigatory powers, including to search and also seizure powers (under a warrant)<sup>307</sup> and can subpoena witnesses.



The Commission is empowered to determine its own procedure for the conduct of hearings on matters brought to its attention.<sup>308</sup>



In terms of section 22 of the Human Rights Commission Act, following hearing a complaint or based on any investigation, the Commission has several **remedies** at its disposal. These include seeking amicable settlement, transmitting the complaint to any competent authority, compelling mediation, making recommendations to the competent authority proposing reform, and referring a matter for prosecution.<sup>309</sup> The Commission is also empowered to litigate in the public interest, affording the Commission broad standing in the context of otherwise narrow limits in legal standing for court cases to be brought in the public interest.



The Human Rights Commission Act requires the MHRC to promote a complainant's access to remedies, and to provide assistance to complainants and information on the status of a complaint and parties' rights.<sup>310</sup>

The Commission states that it treats all matters "in a confidential way". It is unclear to what extent complainants are entitled to anonymity or if they may seek that their identities are protected from respondents.

Commissioners and staff are guaranteed independence and organs of government are required to assist and cooperate with the MHRC as may be reasonably required.<sup>311</sup>



Respondents from the MHRC interviewed for this report estimated that about 300-500 individual cases are dealt with per year. However, respondents believed that the number of complaints was insignificant in relation to the extent of human rights violations. This they stated was due to accessibility constraints. Accessibility challenges were identified as knowledge deficits, geographic limitation, and restrictions on the Commission's outreach work in outlying areas due to financial constraints. The respondents explained the Commission's focus as being largely

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<sup>307</sup> See, as above, sections 19 and 20.

<sup>308</sup> As above, section 17.

<sup>309</sup> See, as above, section 22.

<sup>310</sup> As above, section 22.

<sup>311</sup> As above, section 34.

demand-driven and was interested in understanding factors that might constrain complainants to report healthcare-related violations. The respondents stated that the MHRC does not receive many complaints relating to healthcare discrimination, a phenomenon respondents described as due to low levels of service delivery making it difficult for healthcare users to complain as they would inevitably need to return to the same parties and facilities for healthcare.

The MHRC respondents related frustrations for the Commission in fulfilling its mandate due to human resource and financial constraints. Considering the breadth of its human rights mandate and the limited resources available, respondents considered that perhaps the most strategic use of the MHRC's mandate would be to focus on *systemic* issues and to pursue *structural* interventions to lessen occurrences of symptomatic individual cases, as opposed to focussing on individual issues.

### ASSESSMENT

- ✓ The MHRC rates high on **availability**, showing strong indications of physical and financial accessibility through offering diverse complaints lodging options even if having limitations in its physical localities.
- ✓ The legal obligations on the MHRC to ensure **accessibility** of its system and to support complainants, ensures diverse entry points for complaints in addition to offering flexibility in ensuring the safety of complainants.
- ✓ In terms of **effectiveness**, three aspects are positive attributes for the MHRC: its institutional independence; that complainants enjoy the rights to making representations and to information; and that the MHRC processes relatively high volumes of complaints.
- ✗ However, its **efficiency** is constrained by severe funding shortfalls.
- ✗ With respect to **sufficiency**, while it does not appear that the Commission can impose binding sanctions on respondents or redress for complainants.
- ✓ However, its processes may be useful for creating opportunities for systemic input and policy change and for broad-based public interest issues to be raised through the MHRC, including through its broad standing to litigate.

## Office of the Ombudsman

The Office of the Ombudsman is a constitutional body tasked with investigating and litigating on government abuses or legal violations on behalf of individuals who lack other means of redress. The respondent from the Office interviewed in this report described its function as assisting individuals who cannot use the courts.



In terms of sections 15(2) and 46(2)(b) of the Constitution, persons or groups who believe that their constitutional rights have been violated or threatened may approach the Ombudsman for assistance or relief. The respondent from the Office interviewed for this report understood the Ombudsman's powers as extending to ensuring that no discrimination is faced in public-health institutions. The Ombudsman's powers are limited, however, to the investigation of public facilities. The conduct of private facilities would be excluded.

**Complaints** can be sent to the Office of the Ombudsman directly or to its regional officers in Lilongwe, Balaka, Mzuzu or Blantyre. Complaints can be made in writing or orally at one of these offices. Legal officers assess and screen complaints.

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The respondent from the Office indicated that the initial assessment process usually takes about ten days. Healthcare users can make submissions to legal officers and may appear before the Ombudsman if mediation or public enquiries are pursued on the issue. Complainants are entitled to information on the status of their complaints.

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Following an investigation of the complaint, the Ombudsman has the power to recommend an action to the respondent. However the recommendations of the Ombudsman are not binding. This is acknowledged by the respondents from the Office interviewed in this report as being a major barrier to the effectiveness of the Office. Its own procedure was described as "somewhat effective" for this reason.

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The length of time taken to determine the complaint is stated to vary according to the complexity of the case and the evidence presented.

Per annum, the Office of the Ombudsman receives about 105 complaints.

Healthcare users and healthcare workers are made aware of the complaints procedure through civic education, workshops, and "Ombudsman days".

### ASSESSMENT

- ✘ The **availability** of the Office of the Ombudsman appears to be limited for persons living in rural areas.
- ✓ However, the use of regional offices and options for either oral or written complaints supports **accessibility**.
- ✓ The complaint turnaround indicates a relatively **efficient** process and there appears to be flexibility in how investigations are conducted to ensure complainant safety and input in the process. This flexibility may make the process difficult to predict for complainants but highlights the potential for the process to be **effective**.
- ✘ The **sufficiency** of the Office of the Ombudsman in fulfilling the right to redress is significantly undermined by the non-binding nature of its recommendations.

## 5.4 Zambia

### Introduction

Studies in Zambia have shown that accountability, equity and responsiveness at the primary level of healthcare is essential to achieving population health outcomes.<sup>312</sup> The same study found that there were comparatively few mechanisms for enforcement, and healthcare facilities at primary healthcare level, in particular, were marked by permissive work norms and a culture of impunity.<sup>313</sup> Internal or facility-level complaints mechanisms are identified in the present report as being largely informal but tending to be the preferred or only-known method of complaint amongst NGO/CBO and focus-group respondents.

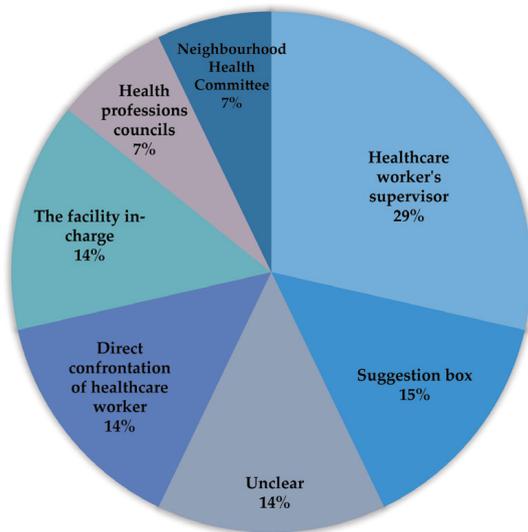
### Facility-level complaints

NGO and CBO respondents interviewed for this report in Zambia in all cases thought healthcare users should lodge complaints at health-facility level. The manner of complaint varied from use of suggestion boxes, to complaining to the healthcare worker's supervisor or the facility in-charge. Some considered that there were no complaints mechanisms available. A small proportion referred to engaging Neighbourhood Health Committees and others to a process of escalation of complaints eventually to health professions councils and courts but that initial complaints must occur at facility-level. Where respondents could identify a manner of complaint, these were universally described as "inconsistently effective".

<sup>312</sup> SM Topp et al. "Understanding the Dynamic Interactions Driving Zambian Health Centre Performance: a Case-based Health Systems Analysis" (2014) *Health Policy and Planning*, available at: <http://heapol.oxfordjournals.org/content/early/2014/05/14/heapol.czu029.full.pdf+html>.

<sup>313</sup> As above, 12.

### Where Should a Patient Complain? NGO and CBO Perspectives



**Neighbourhood Health Committees** comprise volunteer representative members of the community in which the health facility is located. These Committees were established under the National Health Services Act 22 of 1995, later repealed by the Health Services Act 17 of 2005. The committees therefore operate without a formal legal mandate but, where they exist, they operate to link the health facility to the community in its catchment area.

**Health Centre Committees** were not noted by respondents as being an avenue for complaint but may be a useful channel. Like the Neighbourhood Health Committees, Health Centre Committees were established by the 1995 National Health Services Act and were subsequently repealed under the 2005 Health Services Act. They nevertheless continue to function and operate as a high-level link between the community and the health centre. These Committees are only located at health centres and comprise the person in-charge of the health centre, volunteer representatives of the Neighbourhood Health Committee, an Environmental Health Technician, and a Maternal and Child Health Coordinator.

The respondent interviewed from the Health Professions Council of Zambia (HPCZ) stated that the appropriate response for a healthcare user complaint was to relate the concern to the **head of the facility**. The respondent nevertheless stated that there were different mechanisms at each institute. The respondent from the General Council of Nurses of Zambia (GNCZ) stated similarly that management at facility level should receive healthcare user complaints. The GNCZ respondent's view was that only if management failed to address the complaint should it be approached.

Researchers were in addition able to establish a formalised complaints procedure at the **University Teaching Hospital** in Lusaka, which is Zambia's largest hospital. Anyone who is dissatisfied with the

delivery and quality of healthcare services can complain. In a pamphlet detailing the procedures, healthcare users are advised to lodge complaints, either verbally or in writing, through:

- The sister-in-charge;
- Block nursing officers;
- Heads of departments;
- Customer Relations Offices;
- The Public Relations office;
- The Chief nursing officer;
- The Deputy managing director;
- The Managing director;
- Suggestion boxes;
- By telephone;
- By email; or
- Via the University's website.

The department management committee is nominated to handle the complaints. Healthcare users are advised that they can expect three possible outcomes:

*“Apology.*

*Explanation of what went wrong.*

*Hope that staff will recognise their short-comings.”*

### ASSESSMENT

- ✘ Researchers had difficulty obtaining sufficient information on internal or facility-level complaints processes. This dearth of information is itself an indication of low **availability** of the processes.
- ✔ Like other facility-level processes, however, these systems should have good **availability** in having the potential to be accessible to health users because they function at the point of care.
- ✘ **Safety** concerns for complainants, particularly for those who would need to return for care are, however, noted.
- ✘ In the absence of any indication of a formalised or structured complaints-management process, it appears that the facility-level processes in Zambia have low levels of **effectiveness**, being entirely reliant on the individual receiving the complaint to ensure effectiveness.
- ✔ There should be potential in the **sufficiency** of the process to determine and enforce varied redress and accountability. However, there is no indication that complaints made through these channels would necessarily result in sufficient outcomes for complainants.

## Health Professions Council of Zambia (HPCZ)

The Health Professions Council of Zambia (HPCZ) is a regulatory body established under the Health Professions Act.<sup>314</sup> The HPCZ is responsible, amongst others, for the registration and regulation of the professional conduct of registered health practitioners except for nurses and midwives.<sup>315</sup> The Council is empowered to investigate allegations of professional misconduct and can impose sanctions against practitioners if necessary.<sup>316</sup> The HPCZ respondent interviewed for this report described the purpose of the HPCZ's complaints process as being to regulate health practitioners.



Members of the public can lodge **complaints** for professional misconduct against HPCZ-registered practitioners with the Disciplinary Committee through the Registrar of the HPCZ. Complaints must be in writing. Complainants may refer any contravention of the Code of Ethics or any provision of the Health Professions Act.<sup>317</sup> The HPCZ respondent understood this to include cases relating to stigma and discrimination in healthcare, while noting that it had not ever dealt with any cases of discrimination in healthcare.

The HPCZ does not ordinarily receive anonymous complaints, in keeping with its policy of transparency. The HPCZ respondent stated, however, that in exceptional cases, and where it is in the best interests and safety of the healthcare user, an anonymous complaint may be received.



The HPCZ respondent explained that the Registrar and Legal Officer conduct an initial **assessment** of the complaint. This includes addressing correspondence to the institution in question to request a reply on the allegations and for the healthcare user's medical records. The medical practitioner is asked to explain their conduct. The Executive Committee determines whether an inquiry shall proceed on a complaint

The **Investigations Committee** meets every quarter to discuss cases and decides to either close the case or refer it to the Disciplinary Committee for determination of the allegations.



The **Disciplinary Committee** is established by the HPCZ and comprises a chairperson and vice-chairperson who are legal practitioners qualified to hold high judicial office, the chairperson of the HPCZ, a peer of the health practitioner accused of misconduct, and a lay member of the HPCZ.<sup>318</sup> The HPCZ respondent stated that the Committee meets twice every quarter due to the backlog of cases on file.

A Disciplinary Committee's **hearing** is deemed to be a judicial proceeding.<sup>319</sup> The respondent stated that complainants have a right to appear before the

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<sup>314</sup> 24 of 2009. See Part II, Section 3.

<sup>315</sup> Section 4 of the Health Professions Act.

<sup>316</sup> As above, section 4(1)(h).

<sup>317</sup> A guideline to the complaints procedure is available at: [http://hpcz.org.zm/download/?file=1442646766aints\\_Submission\\_Procedure.pdf](http://hpcz.org.zm/download/?file=1442646766aints_Submission_Procedure.pdf).

<sup>318</sup> Section 63 of the Health Professions Act.

<sup>319</sup> As above, section 66(4).

Disciplinary Committee during a hearing of a case and are entitled to information on the status of their case. All parties are entitled to legal representation at the Disciplinary Committee proceedings.<sup>320</sup> However, all proceedings are closed to the public.<sup>321</sup> During the hearing, the Disciplinary Committee may hear and receive evidence and has the power to summon witnesses and to compel the production of evidence.<sup>322</sup>



The standard of proof required to find a practitioner guilty is not specified in the Act. On a guilty finding by the Committee, several **sanctions** may be imposed.<sup>323</sup> This includes cancelling the healthcare worker's license to practice, imposing conditions on the person's practice, censuring or cautioning the practitioner, imposing a fine payable to the Council, ordering payment of the costs of the hearing or of parties to the hearing, and ordering the payment of restitution to an affected party or complainant.<sup>324</sup> The Committee is obliged to give a reasoned judgment of its decision and all parties and affected persons must be given a copy of the judgment.<sup>325</sup> The Disciplinary Committee may publicise the facts relating to a practitioner found guilty of misconduct but is not obliged to do so.<sup>326</sup> Factual findings of the Committee are not appealable;<sup>327</sup> however, any person aggrieved by the Committee's decision (including a complainant) may appeal its decision to the High Court within 30 days.<sup>328</sup>



The HPCZ respondent stated that complainant confidentiality is protected in line with patient confidentiality rights. Some facts around a complaint may be published with the Committee's decision, however, the names of patients are concealed.



The HPCZ respondent estimated that complaints take on average six months to process and that the HPCZ receives 30 cases of professional misconduct per year.

The HPCZ has a Public Relations Unit that uses multiple channels to inform the public of its work, including print, radio and television media, and events at agricultural trade shows and traditional ceremonies.

<sup>320</sup> As above, section 65(5).

<sup>321</sup> As above, section 65(3).

<sup>322</sup> As above, section 66. Failure to abide by a summons is an offence in terms of section 66(2), and is punishable by a fine.

<sup>323</sup> As above, section 66(5).

<sup>324</sup> As above, section 66(5).

<sup>325</sup> As above, section 65(6).

<sup>326</sup> As above, section 64(2).

<sup>327</sup> As above, section 66(6).

<sup>328</sup> As above, section 68(1),

## ASSESSMENT

- ✘ The HPCZ disciplinary process is relatively formalised, which may limit the **effectiveness** and availability of the process for healthcare users who lack legal support in pursuing a complaint against a health professional. The limited recognition of anonymous complaints may also be difficult for vulnerable complainants.
- ✓ However, the HPCZ's stated commitment to preserving patients' confidentiality is an important safety guarantee for vulnerable complainants.
- ✘ The **sufficiency** of the process is limited by the narrow focus of its remedial powers in disciplining health professionals and in the apparent absence of a system for capturing information on the content of complaints to feedback into the health system or professional training.
- ✓ That decisions of the HPCZ are appealable by any aggrieved person, and the formality of the process may, however, stand as guarantees for the independence and transparency of the process, at least in principle.

## General Nursing Council of Zambia (GNCZ)

The General Nursing Council of Zambia (GNCZ) is a statutory body that was established in terms of the 1970 Nurses and Midwives Act,<sup>329</sup> which has since been repealed. The Nurses and Midwives Rules,<sup>330</sup> promulgated in terms of the 1997 Nurses and Midwives Act,<sup>331</sup> detail disciplinary procedures that can be taken against nurses and midwives registered with the GNCZ. The GNCZ respondent interviewed for this report understood this process as being aimed at healthcare users who had failed to obtain relief at the hospital or clinic facility level and defined the purpose of the process as regulating nurses and midwives, and protecting the public from malpractice.



Any person who is aggrieved by the conduct of a registered nurse or midwife can make a **complaint** in writing to the GNCZ or in person as a "walk-in client". The GNCZ also accepts anonymous complaints. An inspector is positioned to investigate anonymous complaints. The GNCZ also follows up on allegations against nurses and midwives' professional conduct in the media.



The GNCZ respondent explained that, on receiving a complaint, the Monitoring and Evaluation Officer and the Standards and Compliance Officer **assess** the complaint. The Registrar then prepares a statement on the complaint received. These are then presented to the Professional Conduct Committee comprising a legal officer from the Ministry of Justice, the Board President of the GNCZ and five other board members appointed by the Ministry of Health. The Committee meets every quarter. The Committee compiles a report on each complaint which is sent to the full Council, which also meets once a quarter.

The Nurses and Midwives Board is established in terms of the Nurses and Midwives Act.<sup>332</sup> It is the body that decides whether disciplinary proceedings should be

<sup>329</sup> 55 of 1970.

<sup>330</sup> 1981.

<sup>331</sup> 31 of 1997, Chapter 14:05.

<sup>332</sup> As above, section 3.

pursued against a nurse or midwife. The Board is constituted by the Chief Medical Officer, the Matron of the Public Hospital and three other members appointed by the Minister of Health.<sup>333</sup> If a decision is made to hold an enquiry or to dismiss a complaint, the complainant and respondent must both be notified.<sup>334</sup>



In a disciplinary **enquiry**, an accused nurse or midwife is entitled to legal representation.<sup>335</sup> Accused persons are entitled to make presentations to the Board, to present evidence, to call witnesses and to cross-examine them.<sup>336</sup> The Board is also empowered to call and question witnesses.<sup>337</sup> During this process, the Zambia Union of Nurses Organisation may participate in the interests of its members.

The GNCZ respondent stated that complainants do not have a right of appearance or a right to make representations before the Committee. A complainant is, however, entitled to information on the status of their complaint, in the respondent's view.



If the Board is satisfied that the "evidence is insufficient", charges can be dismissed. If the Board finds the nurse or midwife guilty of professional misconduct it is empowered to impose sanctions. Outcomes of the complaints procedure can include the issuing of a warning to the nurse or midwife, temporary or permanent removal<sup>338</sup> from the register or suspension.



The GNCZ perceives its own complaints system as being very effective. The respondent estimated that it receives twelve complaints per year, each which takes on average of 3 to 13 months to determine.

The public are made aware of the GNCZ's complaints mandate through public relations activities that include distributing brochures, agricultural shows and the use of its website.<sup>339</sup>

<sup>333</sup> As above, section 3(1).

<sup>334</sup> Rule 31(6) of the Nurses and Midwives Rules.

<sup>335</sup> As above, rule 31(7).

<sup>336</sup> As above, rule 31.

<sup>337</sup> As above, rule 31.

<sup>338</sup> In terms of section 13 of the Nurses and Midwives Act, the Nurses and Midwives Board can remove a nurse or midwife from the register or roll, if they are shown to be incompetent or negligent, incapable of discharging their duties, convicted of any felony, misdemeanor, or other serious offence, or are of "bad character". Persons removed from the register or roll may appeal their removal to the Appeals Tribunal. Removal from the register or roll results in a prohibition against practice as a nurse or midwife.

<sup>339</sup> General Nursing Council of Zambia website (2016), available at: <http://www.gnc.org.zm/>.

## ASSESSMENT

- ✘ The GNCZ process does not have structured means in place to ensure the system's **availability** to diverse users and particularly to ensure the safety of vulnerable complainants.
- ✓ The GNCZ's willingness to accept anonymous complaints does, however, offer **safety** prospects for vulnerable complainants.
- ✘ The low number of complaints received per annum signals inaccessibility of the systems and low **efficiency** prospects.
- ✘ Efficiency is further limited by the absence of a complainant's right of appearance or a right to make representations before the Committee
- ✓ A measure of **effectiveness** is, however, provided in the relatively formalised guarantees for independence and transparency in the complaints process.
- ✘ **Sufficiency** is limited by the GNCZ's mandate to regulate professional conduct.
- ✘ That the GNCZ respondent perceived the GNCZ process as secondary to failure at facility-level processes is perhaps a worrying indication of the extent to which the GNCZ perceives the importance of its mandate in regulating the professional standards and conduct of nurses and midwives in Zambia.

## Human Rights Commission (HRCZ)

The Human Rights Commission of Zambia (HRCZ) was established subsequent to amendments to the Zambian Constitution in 1996. Its mandate under the 2016 Constitution of Zambia (Amendment) Act is to “ensure that the Bill of Rights is upheld and protected”.<sup>340</sup> To this end, the 2016 amendments to the Constitution empower the HRCZ to investigate and report on the observance of rights and to “take necessary steps to secure appropriate redress where rights and freedoms are violated”.<sup>341</sup> Further to this, section 241(d) of the 2016 constitutional amendments states that the Commission “shall take measures to ensure that State institutions and other persons comply with its decisions”. The HRCZ respondent interviewed for this report stated that the purpose of the Commission's complaints system was to provide redress for victims of human rights violations.



The respondent explained that **complaints** could be made by any person to the Commission by phone, in writing by email or letter, or in person at any of their offices. Because complaints must be in writing, if a complainant relates a complaint telephonically or in person, staff at the Commission are required to assist those who cannot write. The HRCZ is in the process of developing an electronic filing system for complaints, noting that members of the public sometimes make use of social media such as Facebook to note complaints to the HRCZ.

<sup>340</sup> Section 230(2).

<sup>341</sup> Section 230(3)(a) and (b).



The HRCZ does accept anonymous complaints of a general nature, where it is possible to independently investigate the complaint. For investigations that require investigations into a particular set of facts, a complainant would need to be identified in order to be interviewed.



Lawyers in the Commission's legal department **assess** complaints. Complainants have a right to appear before the Commission, to make representations, and are also entitled to receive information on the status of their complaints.



The HRCZ respondent indicated that complaints take on average 60 days to assess and determine. The determination of a complaint can result in a **recommendation** made by the Commission to the relevant public institution. The case can further be referred to the Legal Aid Board for litigation. The HRCZ respondent indicates the system as "somewhat effective" on the basis that its recommendations can be accepted or rejected by the respondents to a complaint. However, under the 2016 constitutional amendments noted above, new opportunities have been created for the Commission to improve its effectiveness under provisions that appear to create enforcement powers for the Commission.



The HRCZ respondent stated that the Commission receives on average 700 cases per year, dealing with human rights generally.

The HRCZ respondent noted that the Commission is accessible and affordable for complainants. In order to make the public aware of its activities, the Commission conducts general sensitisation programmes on equality and fundamental rights but does not have any specific programmes on discrimination in healthcare.

A Zambian transgender focus-group respondent noted distrust, however, of the Commission's capacity to deal with discrimination-related complaints for transgendered persons, indicating a need for the HRCZ to make its stance on LGBT issues clear:

*"I am sceptical about the Human Rights Commission. The Human Rights Commission does not carry out their own research on the stigma and discrimination we experience. They have not engaged the transgender community. I would like to see them take a lead so we can trust their complaints mechanism." (Transgender respondent – Lusaka, Zambia)*

In response to an enquiry regarding these concerns, a respondent from the HRCZ stated that the Commission would not turn away a complainant simply because they were a member of the LGBT community but thus far they have not been formally approached with a complaint based on discrimination against members of the LGBT community.

## ASSESSMENT

- ✓ The HRCZ is open to receiving information and complaints through varied media and appears to be committed to expanding its accessibility and **availability**.
- ✗ The availability of the HRCZ is in practice constrained for certain vulnerable persons to the extent that there is a sense of distrust. The HRCZ need to show a willingness to embrace the particular **safety** needs and interests of key populations such as LGBT persons.
- ✓ The HRCZ is in structure independent but **effectiveness** appears to be limited by funding restrictions.
- ✓ The HRCZ receives the highest volume of complaints in comparison with all the other complaints bodies interviewed for this report across the three countries.
- ✓ The **sufficiency** of the HRCZ has great potential under the constitutional amendments. The extent to which it exercises and enjoys compliance with these expanded powers remains to be seen.

## 5.5 Conclusion

A variety of options exist for persons in the three countries analysed to relate complaints on stigma and discrimination in healthcare outside of the formal court process. However, these processes provide for varying levels of availability, effectiveness and sufficiency in holding healthcare workers and systems to account and in providing healthcare users with the right to redress.

### Internal and facility-level processes

- All three countries have some version of facility-level or health system complaints procedures and, usually, a number of avenues for relating a complaint can be pursued internally. These were the processes most frequently referred to by all research participants when asked how a healthcare user should make a complaint.
- These processes generally have higher levels of availability, being closer to communities with no formal complaints-lodging process. They also have the potential to be sufficient forms of redress in that they offer the prospect of system-level information feedback and policy input, of individual disciplinary action against offenders as employees, and of direct redress to victims.
- This potential is undermined by the absence of predictable processes for complaints management in all three countries, which makes these processes unreliable for complainants.
- Where examples have been related of successful outcomes following complaints being laid through these processes, this has usually been through the vigorous support of NGOs or

## Health professions and nursing councils

- Health professions and nursing councils exist in all three countries and have, in most instances, some level of formalised process through which complaints can be handled.
- These systems focus exclusively on the management of their respective professions and so offer a narrow range of redress in the professional discipline of a particular healthcare worker. While most of these bodies have mandates that would include some level of systemic input and, in the least, systemic input through the management of professional training, there have not been any indications that these bodies capture data from complaints or provide health-systems-information-feedback from the complaints received.
- The councils interviewed generally handle very few complaints per annum and appeared in some examples to lack a willingness to engage with concepts of discrimination in the context of professional misconduct.
- While comparatively lower on availability and sufficiency, these complaints processes do appear to have better efficiency prospects in the existence of more formalised processes that typically allow for complainant input. Efficiency is however compromised by the lack of clarity on the standard of proof required for a complaint to succeed against a healthcare worker. In the BHPC the standard is specified as requiring proof beyond reasonable doubt to succeed with a claim against a healthcare professional. This high standard of proof required, particularly when healthcare users may struggle to access evidence of abuses and where no more reconciliatory processes are offered within the complaint system, may in effect exclude healthcare users from being able to use the process effectively.

## National human rights institutions and ombudspersons

- Human rights commissions exist in Malawi and Zambia. In Malawi, it would also be possible to relate a complaint to the Office of the Ombudsman. Botswana has no national human rights institution but the Office of the Ombudsman may deal with healthcare discrimination complaints to the extent that they meet its narrow mandate.
- These systems tend to have better availability than health professions and nursing councils in terms of being more flexible to the ways in which information reaches the bodies and in which complaints can be made and determined.
- Because these bodies are not prosecutorial in nature, the manner in which they engage with complainants can vary, potentially allowing for better accommodation of security concerns for vulnerable complainants.
- Having high levels of institutional independence, these complaints processes have the potential to be effective options for lodging discrimination complaints in healthcare.
- These bodies are limited, however, from a sufficiency perspective and are likely best placed to deal with issues concerning more systemic and policy-based complaints than with individual grievances. With the exception of the Zambian Human Rights Commission's expanded powers under the 2016 constitutional amendments, these bodies lack enforcement powers to sanction offenders or to deliver direct redress to victims.

- However, the litigation-powers of the commissions in Malawi and Zambia may prove a useful resource for NGOs and CBOs to work with the commissions to pursue individual remedies in the public interest, particularly for vulnerable persons.

## Specialised bodies

- Only one specialised body was examined in this report – the Office of People with Disability in Botswana.
- To the extent that specialised bodies are financially sustainable to run, they may offer prospects for ensuring more tailored access to accountability and redress for vulnerable persons, depending on the nature of their powers and the process.

While having some potential to be used by healthcare users to lodge complaints on healthcare discrimination, these processes all require significant investment and improved procedural clarity and consistency to be able to ensure that States are complying with their obligations to fulfil the right to redress for victims of discrimination. As will be illustrated in chapter 6, greater sensitivity to the needs of key populations and vulnerable populations needs to be guaranteed within these systems to ensure that the processes in themselves are not discriminatory by excluding certain persons from meaningful, safe and effective access.

# 6. Experiences of stigma and discrimination in healthcare

## 6.1 Introduction

This chapter analyses experiences of stigma and discrimination in healthcare of four groups of persons understood as either *key populations* or persons who are *vulnerable* to HIV and/or discrimination.<sup>342</sup> The outcomes of fourteen structured focus-group discussions held in Botswana, Malawi, and Zambia are reflected below in an effort to understand these experiences and to give context to the need for accountability and redress for discriminatory conduct. Discussions were held separately with persons who self-identified as sex workers, women living with HIV, LGBT persons, and persons with disabilities.

Focus-group discussions were conducted through facilitators asking open-ended questions. Participants were asked to describe experiences of stigma or discrimination in healthcare and their experiences, if any, of laying complaints or seeking redress. Certain examples of discriminatory conduct in healthcare were raised by facilitators to engage participants to discuss whether they had experiences of these types of conduct.

The analysis below is largely reflective of the participants' own words and experiences, as translated where necessary. Where possible, effort has been made to categorise the various types of discriminatory behaviour raised by the participants.

The experiences of sex workers, women living with HIV, LGBT persons, and persons living with disabilities, are described in turn including their experiences, if any, of accessing complaints processes. In addition, poverty and location in rural areas, as grounds of discrimination, are briefly discussed to highlight strong perceptions of systemic discrimination in healthcare against persons who are economically disempowered and living outside urban centres. Lastly, the chapter describes the perceptions of respondents from complaints mechanisms, CBOs and NGOs of behaviours perceived as discriminatory.

<sup>342</sup> See the definitions of “key populations” and “vulnerable populations”, notes 2 and 3 above.

## 6.2 Sex workers

*“We are intimidated especially by the police when they are in uniform. [It is the] same as the nurses. Often because of the long queue they do not usually pay attention to you and will quickly attend to you without understanding your concerns. This is why people opt to get over the counter medicine and now they are even buying [ART] without going to the clinic. Also nurses are very rude.” (Sex worker respondent – Lusaka)*

### Introduction

Sex workers in southern Africa are marginalised, face human rights violations, discrimination, harassment, and numerous other barriers to accessing healthcare.<sup>343</sup> The perpetuation of indirect criminalisation<sup>344</sup> of sex work not only exposes sex workers to abuse but adds to barriers in accessing healthcare in its own right.

### Focus groups

Focus groups were held in Botswana, Malawi and Zambia with persons who self-identified as sex workers.

In Botswana, HIV prevalence amongst sex workers is high at an estimated average of 61.9%.<sup>345</sup> While government has initiated programmes to enhance sexual and reproductive health services and access to HIV treatment and testing for sex workers, there remains a significant treatment gap, particularly among migrant/non-citizen sex workers.<sup>346</sup> In Botswana, a focus group with sixteen participants who self-identified as sex workers was held in Selebi Phikwe, a mining town located in Botswana’s Central District. Although official estimates are inaccessible, Selebi Phikwe has reportedly high numbers of commercial sex workers,<sup>347</sup> particularly non-citizen sex workers, for whom access to healthcare services is additionally constrained.<sup>348</sup> Selebi Phikwe has the highest HIV prevalence in Botswana at 27.5%.<sup>349</sup>

<sup>343</sup> F Scorgie et al. “‘I Expect to Be Abused and I Have Dear’: Sex Workers’ Experiences of Human Rights Violations and Barriers to Accessing Healthcare in Four African Countries” (2011) *African Sex Worker Alliance*, available at: [http://www.plri.org/sites/plri.org/files/ASWA\\_Report\\_HR\\_Violations\\_and\\_Healthcare\\_Barriers\\_14\\_April\\_2011.pdf](http://www.plri.org/sites/plri.org/files/ASWA_Report_HR_Violations_and_Healthcare_Barriers_14_April_2011.pdf).

<sup>344</sup> In Zambia, sections 144-149 of the Penal Code indirectly deal with offences relating to sex work, including crimes of living off the earnings of prostitution, soliciting for immoral purposes, and operating facilities for immoral purposes. Sex workers are frequently targeted through the use of loitering laws (M Mwendela et al. “Legal, Policy, and Socio-Cultural Barriers to HIV-Related Prevention, Treatment, Care and Support for Key Populations in Zambia” *National Alliance of State and Territorial AIDS Directors* (2015), available at: [https://www.nastad.org/sites/default/files/Zambia\\_Law\\_Review.pdf](https://www.nastad.org/sites/default/files/Zambia_Law_Review.pdf)).

<sup>345</sup> Republic of Botswana *Botswana 2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of Commitments on HIV and AIDS* (2013), available at: [http://www.unaids.org/sites/default/files/country/documents/file\\_94425.es..pdf](http://www.unaids.org/sites/default/files/country/documents/file_94425.es..pdf), 19.

<sup>346</sup> Republic of Botswana: Ministry of Health *2012 Mapping, Size Estimation and Behavioral and Biological Surveillance of HIV/STI Among Select High-Risk Sub-Populations in Botswana* (2013), available at: <http://www.fhi360.org/sites/default/files/media/documents/BSS%202012%20Final.pdf>, 29 at para 3.2.1.1.

<sup>347</sup> See, for example, M Duve “Phikwe Suffocating under Volcanic Sex Trade” *Mmegi Online* (20 November 2008), available at: <http://www.mmegi.bw/index.php?sid=1&aid=9&dir=2008/November/Thursday20/>.

<sup>348</sup> A Raw “Legal Barriers to Healthcare for Zimbabwean Sex Workers in Botswana” (2015) 6 *BUWA! A Journal on Women’s Experiences* 80. See, also, Botswana 2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of Commitments on HIV and AIDS, note 303 above, 29 at para 3.2.1.1.

<sup>349</sup> Botswana 2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of

In Malawi, most stakeholders (including sex workers) report an intolerant attitude of healthcare workers towards sex workers and difficulties accessing care from service providers.<sup>350</sup> Two focus group discussions were held with fifteen women who self-identified as sex workers in Mwanza (a border town near Mozambique in Malawi's Southern District) and with twenty participants in Blantyre (Malawi's commercial capital and second-largest city, located in the Southern District). Instances of abuse against sex workers by healthcare workers and government officials have been reported in Mwanza, including coercive HIV testing of women presumed to be sex workers, which was the subject of a 2015 High Court decision.<sup>351</sup> In Blantyre, commercial sex workers face significant police abuse without access to redress, including the arbitrary enforcement of vagrancy laws to arrest and detain sex workers.<sup>352</sup>

In Zambia, while there has not been any systemic monitoring of HIV prevalence amongst sex workers, estimates indicate a high prevalence at around 65-69%.<sup>353</sup> Sex work in Zambia appears to be concentrated in Lusaka, tourist locations, major highways, and in border and trading towns.<sup>354</sup> A focus group was held in Lusaka with 21 participants who self-identified as sex workers.

### An example of discrimination against sex workers in Malawi: *S v Mwanza Police, Mwanza District Hospital*

#### The Facts

In 2009, eleven women suspected of being sex workers were arbitrarily arrested in Mwanza, Malawi, during sweeping exercises conducted by the police. The women were detained overnight at the Mwanza Police Station and taken to Mwanza District Hospital the following day. At the hospital, the women were subjected to blood tests without their informed consent. The medical officers noted the women's names and test results on pieces of paper and handed these over to the police. Thereafter, the women were taken to the Magistrate's Court where some were charged with spreading venereal diseases, in contravention of section 192 of the Penal Code. In the courtroom, the particulars of the offence were read out loud including that the women were HIV-positive. This was the first time some of the women became aware of their HIV status. Notably, all these actions took place without the women having committed any offence and without there being any evidence of wrongdoing apart from a presumption that they were sex workers.

Commitments on HIV and AIDS, notes 303, 15 above.

<sup>350</sup> J Anderson note 262 above, 45.

<sup>351</sup> See, A Meerkotter and I Southey-Swartz "Malawi High Court Rules that Mandatory HIV Testing is Unconstitutional" *Southern Africa Litigation Centre*: Blog (20 May 2015), available at: <http://www.southernafricalitigationcentre.org/2015/05/20/malawi-high-court-rules-that-mandatory-hiv-testing-is-unconstitutional/>.

<sup>352</sup> "No Justice for the Poor: A Preliminary Study of the Law and Practice Relating to Arrests for Nuisance-Related Offences in Blantyre, Malawi" *Southern Africa Litigation Centre* (2013), available at: [http://www.southernafricalitigationcentre.org/1/wp-content/uploads/2013/07/09\\_SALC-NoJustice-Report\\_Use-of-Vagrancy-Laws-Against-Sex-Workers.pdf](http://www.southernafricalitigationcentre.org/1/wp-content/uploads/2013/07/09_SALC-NoJustice-Report_Use-of-Vagrancy-Laws-Against-Sex-Workers.pdf), 86-100. See, also, indications of the prevalence of sex work in Blantyre, in: R Mthenga Chizimba & G Tikambenzi "Counting the Uncatchables: Report of the Situation Analysis of the Magnitude, Behavioural Patterns, Contributing Factors, Current Interventions and Impact of Sex Work in HIV Prevention" *Family Planning Association of Malawi* (2011), 40.

<sup>353</sup> Republic of Zambia and National AIDS Council *Zambia Country Report: Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access Biennial Report* (2014), available at: [http://www.unaids.org/sites/default/files/country/documents/ZMB\\_narrative\\_report\\_2014.pdf](http://www.unaids.org/sites/default/files/country/documents/ZMB_narrative_report_2014.pdf), 16.

<sup>354</sup> As above, 29.

The women subsequently filed an application in the Blantyre High Court challenging their subjection to mandatory HIV tests, the admission of the HIV test results as evidence in criminal cases against them, and the public disclosure of their HIV status in open court. The Blantyre High Court delivered judgment in favour of the women in May 2015. The Court held that the mandatory HIV tests violated the women's constitutional rights to privacy, dignity, non-discrimination, and freedom from degrading treatment.

The case highlights the systemic discrimination faced by sex workers, where the police and healthcare facility jointly acted in a manner that showed poor regard for the women's rights. The case shows that it is possible for vulnerable populations to hold the government accountable when their rights have been violated but it also illustrates the lengthy process of litigation and the need for less formal and accessible complaints mechanisms.

## Experiences of stigma and discrimination in healthcare

In all four focus groups, clear examples of healthcare workers **refusing to treat healthcare users** were described, including examples of outright refusal to treat (sending the healthcare user away) and refusal to provide particular types of treatment, such as contraceptive care:

*"I was refused to be given [ART] at Queens when I went there to get more drugs when I had only a few pills left. The nurse there told me that they will not assist me because I sleep with their husbands." (Sex worker respondent - Blantyre, Malawi)*

*"I had gone to Mzuzu for business, whilst there I ran out of my [ART]. I went to Mzuzu Hospital and met one doctor who also happened to be my client. Since he knew who I was, he refused to give me the drugs." (Sex worker respondent - Blantyre, Malawi)*

In Zambia, several examples were described by sex worker respondents of refusing sex worker healthcare users access to PEP.<sup>355</sup> The respondents stated that nurses explained this was to discourage reckless behaviour and that the treatment was only offered to "rape patients", behaviour which the respondents described as "unfair":

*"I had sex [with a client] and the condom broke. And in the morning I went to the clinic, [because] I knew about PEP because a few years ago I was raped by a taxi driver ... and when I went to the clinic, they put me on meds to protect me from getting sick. So when I went this time around, I had hoped I would be assisted with the same treatment. Yet the nurse said that was only for rape cases: 'we don't give it to people like you because you decided to put yourself in that situation and all.' ... She said they don't encourage people to know about PEP because they can become careless." (Sex worker respondent - Lusaka, Zambia)*

Sex worker respondents in Lusaka related difficulties accessing PEP even following rape, largely as a consequence of the perceived criminalisation of their work and police abuse:

<sup>355</sup> See note 194 above for an explanation of PEP.

*“For me it’s the police. When you are moving, let’s say at night to another club, the police will catch you and tell you, ‘if you don’t want to be arrested give us some sex’ and they threaten you and so you agree, which I think is rape. But when you go to the clinic, the people there ask you to go back to the same police to get the report from them [to prove you have been raped]. So you are scared to go back to the police and so you end up not getting any treatment.” (Sex worker respondent – Lusaka, Zambia)*

*“I had a client. ... We negotiated everything but the condom broke. I asked him for my money but he even slapped me ... and he said he would finish me. When I went to the clinic to get some sort of protection for being exposed, they asked me what happened. They said they could only attend to me if I came back with a police report. They could not attend to me without it. That’s how I ended up at the police station. The police also were cruel. They asked me to mention the person I was with. When I told them (because the guy is a government official) they were scared and were like, ‘manje wenze kuchita chani na abo bamuna, ndiwe hule ka.’ [Facilitator’s translation: ‘What were you doing with that man? You must be a prostitute.’] That is how they threw me in cells. But I called a lawyer friend the following day who came and spoke to them. They called the man who I gave that service to and he agreed to pay me even more to go to a private clinic. The people at those government clinics are really mean and they don’t care about treating you even when the issue could be an emergency. I don’t have any trust for government clinics or even the police.” (Sex worker respondent – Lusaka, Zambia)<sup>356</sup>*

**In Botswana and Malawi, sex workers described instances where they had been denied access to healthcare in the absence of being accompanied by a male sexual partner:**

*“One respondent in Mwanza narrated her ordeal that took place in 2009 when she contracted [a sexually transmitted infection]. She was told to bring a man whom she had slept with when she sought help at Mwanza District Hospital. Knowing that there was no way she could get hold of the man, she revealed that she was a [sex worker]. In spite of her explanation, she was still asked to bring the man, failing which she could not access the healthcare services. After all attempts had failed, she finally decided to pay for healthcare services at a private clinic.” (Facilitator – Mwanza, Malawi)*

**In both Botswana and Malawi (in Mwanza), sex worker respondents gave examples of their children being denied treatment, either due to the mother’s status as a sex worker or as a result of the mobile lifestyles inherent to their mother’s work. In Selebi Phikwe, for example, respondents noted that if their children had been registered elsewhere, they could not access healthcare when travelling in a different district.**

<sup>356</sup> As explained in Chapter 5, PEP is recommended under Zambia’s 2013 Consolidated Guidelines for Treatment Prevention of HIV Infection, following a determination of the need for PEP based on the risk of transmission and the risks and benefits of taking or not undertaking the intervention. There is no explicit limitation of its application in the case of rape or that healthcare users are required to prove rape in order to access the treatment.

In some cases, refusal of treatment is described as being coupled with **sexual coercion**:

*“Yes, I went to the hospital because I had stomach pains and I was told by a doctor that he will not assist me because I had the previous day refused to sleep with him.” (Sex worker respondent – Blantyre)*

Multiple, disturbing examples of **sexual abuse** were described by sex worker respondents in Blantyre, Malawi and Lusaka, Zambia. No examples were offered by sex workers in Botswana, however, no explicit questions were asked relating to sexual abuse by healthcare workers.

*“At one point I had gone to a clinic to terminate a pregnancy. The doctor asked me to sleep with him before he did the procedure. He paid me money and had unprotected sex with me in the examination room and proceeded to do the procedure after.” (Sex worker respondent – Blantyre, Malawi)*

*“I was also sexually abused by a doctor. He told me that the hospital had run out of [ART] but that he knew where he would get them for me only if I could sleep with him. I had unprotected sex with him in the examination room and he only gave me three pills.” (Sex worker respondent – Blantyre, Malawi)*

*“At one point I went to the hospital with a friend who had a similar problem to mine. When she went into the examination room, she was told to pull her dress half up for examination. But when I went in for examination, I was told to take off all my clothes and be naked. There were three doctors in the examination room and all three were just touching me. I did not understand why they treated me differently from my friend who had gone in earlier with a similar problem. They were just taking advantage of me.” (Sex worker respondent – Blantyre, Malawi)*

In all three countries, sex worker respondents related being **ignored by healthcare workers**, which they understood to be on the basis of their status as sex workers. In Botswana, sex worker respondents stated they were ignored for long periods of time – especially if they were HIV-positive and particularly when presenting repeatedly for treatment of sexually transmitted infections.

*“A friend of mine, who is also a sex worker, was involved in a car accident, the doctors did not attend to her in time because they were notified that she is a sex worker. They kept ignoring her the whole night until she died.” (Sex worker respondent – Blantyre, Malawi)*

Sex worker respondents described instances in all three countries of healthcare workers **not examining them before prescribing or administering medication**:

*“Sometimes when the doctors know that you are sex worker, they will just write down a prescription without taking time to examine you. When you go back to the hospital after some days of taking the medication and noticing that there are no changes, the doctors will still not examine us. Sometimes when we ask to be examined when it’s a sexually transmitted disease, they will say sarcastically that we love taking off our clothes.” (Sex worker respondent – Blantyre, Malawi)*

The **refusal of healthcare workers to communicate** with healthcare users or to undertake proper informed consent procedures was described in all three countries and met with strong concurrence amongst participants. In Botswana, sex worker respondents bemoaned in particular the commencement of invasive examinations without explanation or forewarning. This included, for example, the insertion of a speculum or the use of a spatula for internal examinations without forewarning or explanation when testing for sexually transmitted infections.

*“Another thing is that doctors and nurses don’t tell you anything. ... So you go in there and they scribble on your file, ask you to go to the lab and come back, they scribble more things and then tell you to go collect your medicines. They never interact with you or keep you in the loop for you to know what is going on. Even when, as me, I am a very inquisitive person and I will ask these questions. But the reaction you get, it’s like they are shocked that you are interested to know what is going on with your health. ... I think this is wrong. The patient ... deserves to know what is wrong with them.”*  
(Sex worker respondent – Lusaka, Zambia)

Sex worker respondents in all three countries most frequently related dissatisfaction with healthcare workers’ use of **harsh or abusive language** as discriminatory conduct. In Botswana, respondents strongly shared the perception that female healthcare workers were less courteous and helpful than their male counterparts. Some respondents acknowledged that when receiving care from doctors who were foreign nationals and who did not speak Setswana, they may wrongly assume the doctors are speaking poorly of them.

Sex worker respondents in all four focus groups referred to healthcare workers **blaming the healthcare users** for their health conditions due to their status as sex workers:

*“[Nurses say], ‘Selo ke wena...hane o itshireletsa, o kabo o sa tsenwe ke malwetse a dikobo!’ – meaning, ‘You thing, had you protected yourself through condom use, you would not have contracted a sexually transmitted infection (STI) again!’”* (Sex worker respondent – Selebi Phikwe, Botswana)

*“I have experienced discrimination by a nurse. I was assaulted at a drinking place and I went to Queen Elizabeth Hospital for treatment. The nurse there told me that since my case occurred at a drinking place and I looked to be a sex worker, I had brought that upon myself and that the hospital only assists serious cases, not mine. I was told to go to a private hospital.”* (Sex worker respondent – Blantyre, Malawi)

Respondents in Botswana related examples of healthcare workers’ sense of disgust towards them as healthcare users. Sex worker respondents stated that doctors seldom make eye contact with them and nurses turn on the fans in examination rooms during the winter, inferring the healthcare users smell bad.

Experiences of **confidentiality breaches** were common amongst sex worker respondents:

*“For us to access [ART] we usually go to a hospital which is out of Blantyre, because we know that if we go to Queens in Blantyre or any clinic in Blantyre,*

*the medical personnel, who in most cases are our clients, will spread the news to our other potential clients that we are on [ART] and then we lose out on business. In order to avoid that, we go to the clinics outside Blantyre. The problem comes when we have run out of the drugs and we need the drugs urgently and we have no money to travel to the district where we get our [ART]. When we go to the hospital, like Queens, they will refuse to give us the drugs; they will insist we get a transfer from the district. This leaves us without medication for days.” (Sex worker respondent – Blantyre, Malawi)*

*“[T]he health workers will call out in the public waiting area, that all those that have this and that STI, stand in a particular line. This becomes so embarrassing for everyone to know that you have come with an STI problem.” (Sex worker respondent – Blantyre, Malawi)*

*“Sometimes when you go into the examination room with an STI, the health workers will start calling each other in the examination room while you are on the examination table, for them just to see how the disease has affected your private parts. A number of health workers will just be walking in and out which can be very embarrassing.” (Sex worker respondent – Blantyre, Malawi)*

Sex worker respondents did not offer many examples of **segregation of healthcare users** or the use of **identifying practices** as instances of discrimination. When direct questions were imposed, some examples were described in all three countries. In Botswana, sex workers noted the requirement that persons with tuberculosis receive their medication outdoors, which was perceived as discriminatory. Further examples related to the use of different-coloured hospital cards for healthcare users on ART and patterns of patient-processing that respondents were concerned disclosed their HIV-status inadvertently:

*“As HIV-positive members of society on [ART], our hospital cards are a different colour from ‘normal’ cards that are pink for females and blue for males. Our cards stand out and tell the world that we are on [ART].” (Sex worker respondent – Selebi Phikwe, Botswana)*

*“I went to Matero clinic, when you go from the VCT centre, so you are all sitting in one room and you go into the counselling room. If you are negative you were asked to go just after getting your result, but if you are positive they asked you to stay back to attend a second counselling. And it was so easy for all of us to tell who was positive or who was not and I thought the treatment wasn’t fair.” (Sex worker respondent – Lusaka, Zambia)*

*“Again in the ART clinics, like at Kalingalinga Clinic, when you sit at the bench for people awaiting to receive their [ART], everyone will know that you are sick. And it is in such a space that anyone who is going into the clinic sees you seated on that bench waiting to collect your meds.” (Sex worker respondent – Lusaka, Zambia)*

*“Also there is a tendency to put the medicines, that is the [ART] in a big*

*brown folder and if you walk out with that folder then everyone who sees you will know you are from collecting your [ART] and it's in this way that gossip and rumours begin in the community. Also you find even the registry is the same in these clinics, but for HIV it's different." (Sex worker respondent - Lusaka, Zambia)*

An issue that came out strongly in Selebi Phikwe, Botswana and in Malawi as discriminatory, was the **failure to accommodate sex workers' needs** for ART in particular when their mobility or financial circumstances do not permit consistent consultations at the same points of care. In Selebi Phikwe, sex worker respondents stated that they were denied refills of their ART prescription if they were late for collection. They stated that if they were turned away, they were unlikely to return for care.

*"The health workers do not understand our needs at all. We are always mobile, looking for clients in different districts. So when you are in a particular district and you explain to the health worker that you have run out of [ART], they still refuse to give you more drugs without a transfer letter. This makes us sometimes stay for days without taking medicine." (Sex worker respondent - Blantyre, Malawi)*

Only in Blantyre did a respondent describe an example of being sent for **HIV testing or treatment without counselling**. In Botswana, sex worker respondents universally related positive experiences of receiving adequate counselling before HIV testing and treatment.

*"Ba e tshwere gotlhe HIV counselling ba botsogo mo Botswana!" [Facilitator's translation: "When it comes to counselling, health human resources in Botswana hospitals have it all!"] (Sex worker respondent - Selebi Phikwe, Botswana)*

## Why are we discriminated against?

*"Normally, we are discriminated against in health facilities because of our status. For instance, I myself was once denied treatment because of my status as a [female sex worker]. At the STI department, the situation is even worse. I remember one healthcare provider who used to play with our genitals and calling us prostitutes in the process." (Sex worker respondent - Mwanza, Malawi)*

Sex worker respondents related a variety of reasons why they thought they experienced stigma and discrimination in healthcare settings. Some respondents sympathised with the stress experienced by healthcare workers stating that "they are also human", and acknowledged that nurses experience work and home-related stresses, work long hours and get overwhelmed.

Most frequently, respondents understood that they were perceived as carriers of disease, undeserving of care and reckless because of their status as sex workers:

*"The health workers think that we deliberately look for diseases and as such we should not be treated like any other patient." (Sex worker respondent - Blantyre, Malawi)*

Sex worker respondents in Botswana felt that the religious beliefs of some healthcare providers cause them to discriminate against sex workers and others like LGBT persons.

The role of perceived criminalisation of sex work was also seen as contributing to stigmatising attitudes:

*“Illegality of sex work leads to discrimination, as healthcare providers cannot accept us as we are and treat us as a special group that demands specific interventions.” (Sex worker respondent – Selebi Phikwe, Botswana)*

Other accounts included that healthcare workers were not held accountable and did not respect healthcare users generally, perceiving themselves as superior.

## Access to accountability and redress

In Selebi Phikwe, Botswana and Blantyre, Malawi, none of the respondents related ever making a complaint following mistreatment or discrimination by healthcare workers or institutions. In Botswana, some respondents noted having seen suggestion boxes but none had ever used them.

On being asked why redress or accountability was not pursued, sex worker respondents variously related a lack of knowledge of where or how to complain, and a sense that their complaints would not be taken seriously, strengthened by related experiences of secondary victimisation and indifference when seeking to report violence or abuse to police:

*“We do not know where to go to lay our complaints. Even if we report to the police, the police also abuse us a lot. A friend of mine was raped by four police officers who also took away money from her.” (Sex worker respondent – Blantyre, Malawi)*

Examples of proactive complaint efforts given by sex worker respondents in Mwanza described experiences of secondary victimisation from the process. One respondent described discrimination she encountered when she sought antenatal services when she was pregnant. She was called names by healthcare workers because she was a sex worker. She was asked to get a letter from the chief, seemingly in order to access services. The chief similarly also used derogatory language towards her. The result was that the respondent was significantly delayed in terms of accessing antenatal services. When asked why she did not report the discriminatory behaviour, the respondent said she did not know to whom she could turn, as she was discriminated against by the chief himself.

In Lusaka, Zambia, sex worker respondents gave both successful and unsuccessful examples of direct confrontation with healthcare providers who discriminated against them. One respondent gave an example of escalating a complaint to more senior staff:

*“[A sex worker friend] noticed that she was having problems with her anal area and had a serious infection in that area. She was admitted just there in Livingstone. The nurses refused to clean her up. It took me when I got there to clean her mess up and wash and change her linen. The nurses called her names and said she had brought it on herself because she is a ‘Hule’ [Facilitator’s translation: derogatory term for sex worker]. The nurses*

*were going there to change her drip and give her medicine, but for days they did not change or clean her and the dirt just accumulated. I confronted the nurses but they just shut me up saying if I thought I could do a better job. When it was better I took her away and took care of her on my own. I shouted at her. These nurses need to be taught what their job is.” (Sex worker respondent – Lusaka, Zambia)*

*“I have [complained] in a way. My first born, I had her when I was about 18. I was still young, and being the first pregnancy I didn’t know what to do. And I was going to Chainama for antenatal [care]. My labour started in the morning and I went to Chainama, but they sent me home. When I got home the pains became unbearable and I told my sister I am not going back to that place and so I went straight to [the University Teaching Hospital]. When I got there the nurses refused to attend to me saying I didn’t have a referral. I was in so much pain that I just started to scream and asked for a higher person to talk to. That’s how this doctor came and he directed the nurses to attend to me. Even though they were bitter, they made sure not to do any of those stupid things they do because they were afraid that I would report them.” (Sex worker respondent – Lusaka, Zambia)*

A sex worker respondent in Mwanza, Malawi, related an example of complaining through the District Health Officer but was dissatisfied with the outcome of the complaint. In that case, a sex worker had been knocked over by a motorcycle at night. She fell unconscious and was rushed to Mwanza District Hospital by onlookers and a police officer. At the Hospital, a nurse on duty recognised her as sex worker. The nurse treated her with just two pain-killer tablets and discharged her. The sex worker was taken home where she bled until the morning when she was brought back to the Hospital where she died. Thereafter, sex workers took up the issue by informing the District Health Officer. The District Health Officer took up the issue with the nurse who was on duty. The nurse refused to write a statement on what happened and sought protection from the Nurses and Midwives Council. It appears that the complaint against the nurse was not pursued further. The motorcyclist who caused the accident was, however, arrested and taken to court where he was sentenced to a fine of MWK10,000.<sup>357</sup> The sex worker respondent said her fellow sex workers were not satisfied with the sentence but felt they did not have capacity to appeal the case further.

In Selebi Phikwe, Botswana, sex worker respondents stated that ideally they would want an effective complaints process to deliver a range of possibilities for redress. This included change in policy and laws where appropriate, changes in behaviour and attitudes of healthcare workers, punishment and discipline of responsible healthcare workers, and an apology to victims of mistreatment. Respondents noted that compensation could also be important when a healthcare user loses opportunities following discrimination or neglect by healthcare workers.

357 Estimated to be equivalent to US\$14 on 19 May 2016.

## What is needed for change?

When asked how change could be achieved, sex worker respondents strongly drew links to the punitive legal regime governing sex work and their capacities to be active citizens capable of demanding fair services. In Botswana, for example, it was expressed that without full legal recognition of sex work, engaging effectively in complaints processes would be difficult. When discrimination occurs, respondents felt they could not engage procedures as a group (as sex workers) but had to engage procedures set for all citizens. Although the act of selling sex is not illegal in Botswana, Malawi or Zambia, presumptions about the unlawfulness of sex work result in many sex workers feeling that their complaints would not be taken seriously, whether by police, traditional courts or senior hospital staff.

In Malawi and Zambia, sex worker respondents strongly expressed a need for having NGO partners or sex worker-led advocates supporting the process of reporting complaints and pursuing accountability. The importance of legal recognition for sex worker advocacy groups was noted:

*“I think as we are doing this work, we need backup. Because with the current law, we are not safe. We will be arrested and we need some protection and we can do this but it should be calculated.” (Sex worker respondent - Lusaka, Zambia)*

## Conclusion

- Experiences of sex workers of discrimination in healthcare settings are closely linked to abuse by police and other persons in positions of authority, both in the cause of the abuse and in the inhibitions to accessing justice. The examples cited illustrate how police abuse and anticipated abuse bars sex workers from seeking PEP and sexual and reproductive health services when needed. Experiences of police abuse similarly create distrust for authority among sex workers, while fear of arrest and secondary victimisation inhibit sex workers from accessing justice when abuses occur. It is in this context of abuse by authorities that sex workers experience criminalisation of their work as a citizenship issue, a status that disenfranchises sex workers from seeking accountability and redress as members of a legal community.
- In many of the examples cited, sex workers actively sought out healthcare to ensure safe sexual practices and health. Sex worker respondents also could clearly identify issues that constrain their effective health access, including the refusal of certain health systems and healthcare workers to accommodate for the mobility of sex workers to ensure sustained and effective access to HIV services.
- Ensuring the protection of healthcare users’ confidentiality extends to presumptions that healthcare workers may make about healthcare users’ occupations and was indicated by respondents as being vital to enable sex workers to access healthcare sustainably close to home when they need it.
- Indirect discrimination is experienced by sex workers as significant inhibitions to care through policies or practices of healthcare workers refusing to provide STI or HIV testing

or treatment in the absence of healthcare users' sexual partners. These practices, while potentially neutral in abstract, have disproportionate effects on women and persons particularly vulnerable to HIV such as healthcare workers.

- STI treatment was narrated as being particularly stigmatised among sex worker respondents who described habits of denial of care and verbal abuse, particularly when seeking treatment for STIs.
- Finally, it is distressing to note the experiences of sexual abuse and coercion related by some sex workers in Malawi. These abuses are occasioned in contexts of significant vulnerability of the sex workers as healthcare users. Many of these accounts related experiences of high-risk sexual contact, which aggravates the individual abuse and negatively impacts on public health outcomes.

## 6.3 Lesbian, gay, bisexual and transgender persons

### Introduction

LGBT persons are recognised as vulnerable to HIV. Men who have sex with men (MSM) are particularly vulnerable to HIV. MSM are nineteen times more likely to be living with HIV than the general population and only 5% of MSM worldwide have access to the prevention, care and treatment service they need.<sup>358</sup> The WHO defines MSM as “all men who engage in sexual and/or romantic relations with other men.”<sup>359</sup> Sex between men and sex between women are criminalised in Botswana, Malawi and Zambia.<sup>360</sup>

The WHO employs “transgender” as an umbrella term for “people whose gender identity and expression does not conform to norms and expectations traditionally associated with the sex assigned to them at birth.”<sup>361</sup> The term is inclusive of people who are transsexual, transgender or otherwise gender non-conforming. The WHO further states that the high vulnerability and specific health needs of transgender people necessitate a distinct and independent status in the global HIV response. The United Nations Development Programme (UNDP) has stated that transgender persons face systemic discrimination in trying to access general health services and are highly vulnerable to ignorance or prejudice in seeking healthcare and fear of violent reprisals if healthcare workers breach confidentiality.<sup>362</sup> Furthermore, violence, stigma, social exclusion, and discrimination harm transgender persons' health and wellbeing, which deters people from seeking HIV prevention, treatment, care, and support services.<sup>363</sup>

<sup>358</sup> “Advancing the Sexual and Reproductive Health Rights of Men who have Sex with Men Living with HIV: A Policy Briefing” *Global Forum on MSM and HIV & Global Network of People living with HIV* (2010), 4.

<sup>359</sup> Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, note 2 above.

<sup>360</sup> Botswana, Malawi and Zambia have identical provisions in their respective Penal Codes, which criminalise unlawful carnal knowledge (anal sex between men), gross indecency between men, and gross indecency between women.

<sup>361</sup> Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, note 2 above.

<sup>362</sup> United Nations Development Programme Discussion Paper: *Transgender Health and Human Rights* (2013), available at: <http://www.undp.org/content/dam/undp/library/HIV-AIDS/Governance%20of%20HIV%20Responses/Trans%20Health%20&%20Human%20Rights.pdf>, 17.

<sup>363</sup> As above, 18, citing J Godwin *Legal Environments, Human Rights and HIV Responses Among Men Who Have Sex with Men and Transgender People in Asia and the Pacific: An Agenda for Action* (2010); S Khan et al. “Living on the Extreme Margin: Social

Ensuring that MSM and LGBT persons broadly are able to access appropriate healthcare safely and without discrimination is therefore vital to ensuring effective responses to HIV. In Botswana, Malawi and Zambia, there are minimal verifiable data on LGBT persons, including on stigma and discrimination faced in healthcare.

A 2012 Study by the Government of Botswana sought to assess the population size, HIV and STI prevalence and incidence and risk profiles of MSM.<sup>364</sup> HIV prevalence amongst MSM is estimated by government at 13.1%.<sup>365</sup> The Botswana government has recognised that stigma and discrimination place HIV-positive MSM at increased risk of HIV.<sup>366</sup> In Botswana, transgender activists list a variety of challenges in accessing healthcare in primary healthcare institutions, which includes discrimination and a lack of understanding from service providers.<sup>367</sup>

In Malawi, a medical professional who was perceived to be MSM, was attacked and reported being fearful of seeking medical attention in the facility where he worked.<sup>368</sup> Civil society in Malawi has called on the Minister of Health to issue instructions to personnel in charge of health training to design and implement a curriculum to address discrimination by healthcare workers.<sup>369</sup>

In Zambia, MSM are repeatedly neglected in government-funded studies despite an acknowledgment of the absence of information on MSM in the context of the HIV epidemic. For example, the Joint Mid-Term Review of the National HIV/AIDS Strategic Framework 2014-2016 does not include MSM in its definition of key populations thereby failing to speak to MSM in its priority interventions and strategies. In Zambia, transgender activists state that there are “no safe spaces for transgender people to interact” and stress the importance of documenting human rights abuses.<sup>370</sup>

## Focus groups

A total of five focus-group discussions were run with persons who self-identify as LGBT. In Botswana, two focus groups were held with LGBT participants – one in Palapye with six LGBT participants and one in Gaborone with seven LGBT participants. In Malawi, one focus group was held with LGBT participants in Lilongwe. In Zambia two focus groups were held: one in Kitwe with 23 LGBT participants and another in Lusaka with twelve transgender participants.

Exclusion of the Transgender Population (Hijra) in Bangladesh” (2009) 27 *Journal of Health Population and Nutrition* 441; “HIV and the Law: Risks, Rights and Health” *Global Commission on HIV and the Law* (2012), available at: [www.hivlawcommission.org/index.php/report](http://www.hivlawcommission.org/index.php/report), 53.

<sup>364</sup> Republic of Botswana: Ministry of Health *2012 Mapping, Size Estimation and Behavioral and Biological Surveillance of HIV/STI Among Select High-Risk Sub-Populations in Botswana* (2013), available at: <http://www.fhi360.org/sites/default/files/media/documents/BBS%202012%20Final.pdf>, 29 at para 3.2.1.1.

<sup>365</sup> Republic of Botswana *2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of Commitments on HIV and AIDS* (2013), available at: <http://www.unaids.org/sites/default/files/countrydocuments/file,94425.es..pdf>, 20.

<sup>366</sup> As above.

<sup>367</sup> “Report of the Southern Africa Transgender Advocacy and Capacity Building Summit, 15-17 August 2014, Johannesburg, South Africa” *Transgender and Intersex Africa* (2014), available at: <http://transgenderintersexfrica.org.za/wp-content/uploads/2014/10/summit-report.pdf>, 12.

<sup>368</sup> “Human Rights Violations on the Basis of Real or Perceived Sexual Orientation and Gender Identity in Malawi” *Centre for Human Rights and Rehabilitation & the Centre for the Development of People* (2014), available at: [http://iranti-org.co.za/content/Africa\\_by\\_country/Malawi/2014\\_CEDEP\\_Human\\_Rights\\_violations\\_report.pdf](http://iranti-org.co.za/content/Africa_by_country/Malawi/2014_CEDEP_Human_Rights_violations_report.pdf), 16.

<sup>369</sup> As above, at 22.

<sup>370</sup> As above, at 13.

## Experiences of stigma and discrimination in healthcare

The most common form of discriminatory behaviour LGBT participants complained of was the use of harsh and abusive language by healthcare workers. Several respondents noted that gay men in particular experienced **verbal abuse**. In many of the descriptions, LGBT respondents stated that healthcare workers had related religious convictions that indicated the healthcare user to be sinful:

*“A friend asked me to escort him to get tested; he had makeup on. People were staring at him at the hospital. When we went into the doctor’s office, the doctor asked him whether he was a girl or a boy. My friend answered that he was both. I intervened and asked whether they could just test him so we could leave. The doctor went to call another doctor and they started mocking us by their questions and comments. They insisted that both of us should be undressed and checked, but we refused and that’s how we left without testing.” (LGBT participant – Lusaka, Zambia)*

*“One participant who is feminine presenting said he went to a clinic with general chest pains. As he was explaining to the attending nurse, she was looking at him strangely at first. She then called in another nurse and started talking rudely about him right there in his presence, laughing about his appearance and ‘gay’ behaviour, his health issue totally forgotten. He told them to mind their business and demanded treatment. She in turn became rude and rough with him. All the time while she was treating him she lectured about God and sin of Sodom.” (Focus-group facilitator – Gaborone, Botswana)*

**Blaming healthcare users** for their health status was frequently related by respondents when recounting dissatisfactory interactions with healthcare workers. In Palapye, a respondent described a nurse blaming him for becoming infected with HIV, by saying that it was punishment for engaging in anal sex. Following the interaction, the respondent ceased using government facilities and only accessed healthcare at private facilities. Due to financial limitations, the respondent no longer accesses healthcare services but claims to “self-medicate” instead.

LGBT respondents, particularly transgender respondents, complained of an **unwillingness by healthcare workers to accommodate their particular healthcare needs**.

*“It is difficult to get prescriptions for certain medicines if you are a transgender person. For example, one cannot not buy testosterone. If we cannot get services from one place we try another provider.” (LGBT respondent – Lusaka, Zambia)*

Several respondents discussed **concealment of their identities** when seeking healthcare as necessary to access services, but as inhibiting appropriate treatment and prevention services.

*“The problem is that we don’t even go there. If we do, we don’t go as our authentic self. We go there under an umbrella of someone else. ... It has to do with the fact that we are attended to, but not in the way we would want to. ... I would give an example of a situation where you’ve got anal warts,*

*you don't even know how to explain that to them, so you end up giving them some form of things for them to give you some medication that is closer. ... Others do not go there, but opt to self-medicate.” (LGBT respondent – Kitwe, Zambia)*

*“I had an STI in 2012 and I went to the clinic to seek help. But I was told I would not be treated until I went with my partner. And so, here I was in pain and yet the clinician was busy asking for my partner. So I ended up lying so I could get the help I so desperately needed. So now I think, for me it felt like the structures in these institutions, the doctors themselves, it makes me question the kind of training that they have. I understand why they have to ask for a partner for them to treat you, I get that these are public resources and they want to have the most impact with the limited resources. But at what cost will they optimise resources, at the cost of losing a life?” (LGBT respondent – Kitwe, Zambia)*

It is noted in this context that in all focus groups, LGBT participants raised treatment-avoidance behaviours, indicating a preference to avoid accessing treatment for fear of the disclosure of their sexual orientation or gender or other forms of discrimination. In Lilongwe, Malawi, some participants described this behaviour as a form of self-stigmatisation.

Several respondents related difficulties in relation to the insistence of healthcare workers that HIV and STI testing or **treatment is conducted together with one’s sexual partner**. Some related examples of healthcare workers refusing to test or counsel homosexual partners together. In Gaborone, for example, an LGBT participant described asking for an HIV test at an HIV testing centre. The respondent asked if he would be permitted to bring his (male) partner, so that they might receive counselling together. He was refused.

*“My friend and I are both transgender persons. We decided to go and each test for HIV. The counsellor assumed we were a couple and insisted on doing couple counselling and testing. We told him that we were not a couple but he insisted, stating that he could not attend to one of us but both of us since we were a couple. We both got counselled and tested as a couple.” (LGBT respondent – Lusaka, Zambia)*

*My friend and I went to Kabwata Market to test for HIV at a VCT booth. We told them we were a couple and they refused to test us, stating that they cannot test people in a same-sex relationship.” (LGBT respondent – Lusaka, Zambia)*

A number of NGO and CBO respondents interviewed described concern for LGBT persons accessing healthcare, in that there was a tendency for healthcare workers to **report LGBT persons to the police**. In Malawi, a transgender respondent related that he feared accessing care at state-owned facilities being under the impression that the healthcare workers would call the police. The respondent stated that he prefers instead to access private care, but conceals his sexual orientation even when accessing private care. While no examples were given by LGBT respondents of being reported to the police by a healthcare worker, some had experienced threats of being reported to the police:

*"I asked [the sister in charge], 'Do you serve the key population?' and I also asked her what she meant by key populations. She said, 'children, women and old people'. And I was like, 'Let me more specific. Do you treat lesbians, gays, transgender or bisexual people?' And she was like, 'If a thief who came to my house to steal come here to seek a service, I would serve them. And afterwards, I would hold them by the hand and hand them over to the police. I would do the same with those people you are talking about.'" (LGBT respondent - Kitwe, Zambia)*

Some respondents had experienced being **refused treatment** by healthcare workers on the basis of their actual or perceived sexual or gender orientation. In other cases, particular services were denied to respondents, such as sexual and reproductive healthcare services, when healthcare users' gender identities did not match the healthcare worker's expectations:

*"I had a fight with my brother after he found out that I dated boys. He was hitting me and kicked me on the testicles so I had to go to the hospital when the pain wouldn't go away. I explained to the doctor what had happened and as soon as I disclosed that the fight was over my sexual preference the doctor's attitude changed. He stopped listening and started lecturing me, saying that I deserved the beating, that in fact my brother should have cut my testicles off. He stopped treating me right there and then and told me to leave him, telling me I deserved worse for doing 'unnatural things'. I left and went to a pharmacy and was given painkillers." (LGBT respondent - Gaborone, Botswana)*

*"I went to hospital for treatment and I was told to go home and change my clothes. I was told to put on clothes that reflect my sex." (LGBT respondent - Lusaka, Zambia)*

*"I identify myself as a male person. I escorted two of my female friends to UTH for cervical cancer screening. I decided to also screen for cervical cancer. But because of the way I was dressed and probably the way I carried myself, the nurse refused to screen me. She said I do not have penetrative sex, and therefore there was no need to screen for cervical cancer." (LGBT respondent - Lusaka, Zambia)*

A significant concern that emerged for LGBT respondents, was not only the **failure to observe confidentiality** by healthcare workers with regard to their health status, but also the failure to observe confidentiality with respect to their gender identity or sexual orientation following healthcare access:

*"[O]ne of my trans sons had ulcers. ... I found he was in very bad shape. I could not afford to take him to a private clinic as I was broke, so I took him to Chainda clinic. There wasn't a long queue. The issue then was how do you identify this person because he was using his chosen name and his gender? Apparently when he went for check-up, the clinical officer asked him to take off his shirt, and because he was pre-op there were still breasts. So, because of that, the conversation in the clinic became about his gender identity and*

*not that he was sick. The clinical officer came out of the treatment room and started sharing his details carelessly so that the whole clinic now was wondering who this person was.” (LGBT respondent – Kitwe, Zambia)*

*“I went to the clinic to get some medication. Later on I met the counsellor and the nurse that attended to me at a local drinking place/bar and they started discussing my status with their friends.” (LGBT respondent - Lusaka, Zambia)*

Some respondents related experiences of healthcare workers **refusing to properly examine** them, or to touch them, or conducting themselves in a manner that indicated a sense of disgust towards them, including refusing to make eye contact and using what were felt to be excessive precautions when undertaking examinations.

In relation to HIV-specific services, one respondent related being given **inferior counselling** services following the revelation of their sexual preference. A transgender respondent was refused treatment in the **absence of HIV testing**:

*“I went for HIV test. I wasn’t counselled, but was asked a few questions about my sexuality and sexual practices e.g. if I was sexually active and if I use condoms. When I asked whether the counselling is over, the counsellor said to me, ‘We don’t counsel people like you.’ The person who went in before me had spent about 25 minutes, but I went through everything in less than 10 minutes.” (Transgender respondent – Lusaka, Zambia)*

*“I went to the University Teaching Hospital (UTH) and I was told they couldn’t treat me until I underwent an HIV test. The counsellors started talking to me about same-sex relationships and counselled me on this basis although I’m not in a same-sex relationship.” (Transgender respondent – Lusaka, Zambia)*

## Why are we discriminated against?

Respondents were asked to reflect on why they thought they were discriminated against. Most explained that social patterns of discrimination in the community were reflected in the attitudes of healthcare workers. These attitudes were described as caused by ignorance, fear and prejudicial attitudes founded in religious and traditional, cultural beliefs.

## Access to accountability and redress

When asked if any respondents had complained about discriminatory treatment, a few instances of direct confrontations with healthcare workers were related, none with satisfactory outcomes:

*“I remember when I was at university going to the CBU clinic and telling the nurse ‘bane nshili bwino’ [‘I am not well’] and she started asking me funny questions, ‘ala nail shouta nukuba trainesha’ [‘I shouted at her and taught her a lesson’]. But the end result was that I did not receive the service that I needed. So I ended up scared to go to the next clinic because of fear of being discriminated against. The moral of the story is that all I needed*

*was health care, and here I was having someone wanting to preach to me.”*  
(LGBT respondent – Lusaka, Zambia)

A few respondents related examples of escalating a complaint to a healthcare worker’s superior, with varying levels of satisfaction with the outcomes:

*“My friend was admitted to hospital for 3 days. During medical examination by the nurse, the nurse forced my friend to move from the male ward to the female ward. We had to call the doctor, who intervened and directed that the patient should remain where he was.”* (LGBT respondent – Lusaka, Zambia)

*“I explained to the person in charge but my issue was not addressed. He was also biased. At first he reassured me that he would address the matter but when I went back for feedback, he passed the same comments as the counsellor I had complained about.”* (LGBT respondent – Lusaka, Zambia)

When asked why respondents did not complain about discriminatory healthcare, several reasons were related. In Zambia, in particular, respondents were frustrated with the suggestion of making a complaint, relating that in the context of criminalisation of same-sex sexual acts, the prospect of complaining was unfeasible:

*“But for us, that is a far-fetched conversation that may be irrelevant right now. So I go and report that I am a gay man who got anal warts through anal sex with a man and when I went to Chamboli Clinic the doctor refused to attend to me? That sounds ridiculous coming from my lips, unless I want to end up more than sick but also end up in prison.”* (LGBT respondent – Kitwe, Zambia)

Other respondents described that they did not know where or how to complain:

*“We don’t know what healthcare providers are expected to do by law and we don’t fully know our rights. Sometimes family and friends discourage us from complaining.”* (LGBT respondent – Lusaka, Zambia)

In addition, respondents gave examples of failed efforts to complain in the past by themselves or others making them reluctant to complain because it would not have any meaningful result:

*“[A] testing centre in Palapye refused to test a lesbian couple together. The participant said that they made a decision to test together and went to the centre, disclosed their sexual orientation and the fact they wished to be tested together as partners. The testing officer declined, saying that the Botswana law did not recognise them (lesbians), so they could not be tested as partners. They complained and in the end the coordinator of the centre tested them herself after much discussion where everyone in the centre got involved, including other patients. Confidentiality about their sexual orientation was compromised but none in the centre seemed to be even aware that ethics were being breached. The coordinator tested them together reluctantly and did not even bother to offer pre-testing counselling.”*

*Both of them went away feeling angry and abused, but did not take the matter further. They never went back to test with their partners. Participant said she didn't feel that making the report would make a difference, in any case they both had no idea where else to go to make a complaint." (Focus-group facilitator – Palapye, Botswana)*

Significantly, many respondents raised concerns over the confidentiality of their health and sexual and gender orientation as inhibiting accessing redress. Respondents in Palapye stated that a consequence of complaining about inadequate healthcare could include, for example, losing one's job if one's sexual orientation was revealed in the process. Other respondents feared their sexual orientation being revealed to family members or the community if they complained:

*"I didn't report the incident to anyone, because as soon as my father found out he went to the hospital and started asking the doctors to find a cure to convert me from being gay. I had thought that by not reporting I would be spared the public humiliation, but after that it became common knowledge as the whole hospital talked and gossiped about me. I was even afraid to go to any clinic after that. I was insulted and confronted about my sexual orientation by complete strangers on the streets. I also didn't report the doctor because I didn't know where to go. I knew little about my rights and so I let it go. I, however, felt angry, and disillusioned for a long time." (LGBT respondent – Gaborone, Botswana)*

Respondents gave ideas of what they would need in order to enable them to access complaints processes. This included:

- Guaranteed confidentiality from the complaints mechanism;
- Immunity from criminal prosecution when laying complaints of human rights violations;
- Improved access to legal aid services for the LGBT community;
- A complaints mechanism that specifically deals with the issues faced by the LGBT community;
- Secret complaints options through suggestion boxes and helplines;
- Clear guidelines on how to report a complaint and what to expect from the process;
- Information on the ethical and legal responsibilities of healthcare workers; and
- Clear sanctions for discriminatory behaviour by healthcare workers to ensure the complaints process can work as an effective deterrent.

When respondents were asked what the desired outcomes would be from an effective complaints process, the unanimous response was a process that resulted in behaviour change and/or, where necessary, changes in policy and law. For some respondents this was expressed as wanting to see improved access to healthcare services and seeing changes in the attitudes of healthcare workers. Some respondents stated that they wanted clear and enforceable consequences to result for healthcare workers, which should include the prospect of the healthcare worker apologising to the victim of discrimination. Lastly, some respondents stated merely that they wanted to assert their rights, suggesting that the process of complaining was an end in itself.

## What is needed for change?

When asked what was needed to change the prevalence of stigma and discrimination in healthcare, focus-group respondents stated clearly that legal and policy reform, particularly in the decriminalisation of consensual same-sex sexual conduct was the indispensable first step. Respondents noted that having complaints mechanisms with clear processes and enforceable outcomes would also assist. Some respondents noted the need for NGO and CBO partners to be strengthened in their capacities to respond to instances of discrimination in healthcare.

Sensitisation and training were stated to be required on three levels: for healthcare workers, for healthcare users, and for the broader community. Respondents stressed in particular that healthcare workers need to have ethics and human rights and the particular needs of the LGBT community built into professional training. Some respondents stressed the need for training to enable healthcare workers to better deal with issues of privacy and confidentiality of healthcare users.

Some respondents suggested that the solution to discrimination in healthcare was to assist LGBT healthcare users to better censor the information shared with healthcare workers to ensure that accessing care does not result in harm.

## Conclusion

- A worrying pattern of discrimination described by LGBT respondents manifests in the repeated statements by respondents of treatment avoidance – either in respondents not seeking healthcare at all or in concealing treatment and counselling needs in order to ensure their sexual orientations and gender identities are not exposed.
- Respondents described accessing healthcare in terms that indicated significant hostility and threat of social persecution and legal prosecution. The threat of healthcare workers reporting LGBT healthcare users to the police was identified by respondents as a significant concern.
- LGBT respondents described, in examples of denial of care and verbal abuse, repeated instances of healthcare workers moralising to them as healthcare users and also gender-policing respondents' conduct (for example by insisting on clothing changes that match the healthcare user's biological sex) at points of care.
- Like sex workers, the social context of criminalisation of same-sex sexual contact, inhibits LGBT persons not only from accessing treatment in the form, time and manner that is required in order to be effective, but also from accessing accountability and redress when violations occur in healthcare.
- The importance of healthcare workers observing not only confidentiality with respect to healthcare users' health status, but also their sexual orientation and gender identity is therefore closely linked to ensuring those most vulnerable to HIV are able to access healthcare equitably.
- Lastly, it should be strongly stressed that LGBT respondents had significantly limited expectations about accessing healthcare or justice in the context of criminalisation of same-sex sexual acts. Even if immunity from prosecution or confidentiality was secured

for complainants experiencing healthcare discrimination in a particular system, it is likely that, in this context, that LGBT persons will remain underserved and excluded from effective healthcare access and also from holding violators to account for breaching lawful entitlements to appropriate care.

## 6.4 Women living with HIV

### Introduction

Some studies show that women in sub-Saharan Africa are significantly more likely to experience HIV-related interpersonal discrimination than men.<sup>371</sup> In Botswana, studies indicate that entrenched gender inequities perpetuate the HIV/AIDS epidemic.<sup>372</sup> In Malawi, gender inequality, harmful gender norms and economic vulnerability, amongst others, are recognised as exposing women to heightened risk and vulnerability to HIV.<sup>373</sup> Discrimination in healthcare is commonly reported amongst women living with HIV in Malawi.<sup>374</sup> Zambia's gender equality index rates at 0.623 – ranking it 136 out of 148 countries in terms of gender equality.<sup>375</sup>

### Focus groups

Two focus groups were held with women living with HIV: one with fifteen participants in Chiradzulu, Malawi, and another with twenty participants in Kabwe, Zambia.

Chiradzulu is a town in the Southern District of Malawi, where approximately 90% of the population subsists on farming.<sup>376</sup> Chiradzulu has benefitted from years of enhanced HIV interventions by Médecins Sans Frontières.<sup>377</sup> Women living with HIV respondents in Chiradzulu expressed concern about the imminent departure of Médecins Sans Frontières from its work in the district, being worried that the Ministry of Health would not be able to take over services effectively.

Kabwe is Zambia's second-largest city, and is located in the Central Region in the Copperbelt area. Formerly a zinc and lead mining town, Kabwe retains high levels of soil and water contamination.<sup>378</sup>

<sup>371</sup> M Neuman et al. "Experiences of Stigma, Discrimination, Care and Support among People Living with HIV: A Four Country Study" (2013) 17 *AIDS Behav* 1796.

<sup>372</sup> "Epidemic of Inequality: Women's Rights and HIV/AIDS in Botswana and Swaziland – An Evidence-Based Report on the Effects of Gender Inequity, Stigma and Discrimination" *Physicians for Human Rights* (2007), available at: [http://www.essex.ac.uk/armedcon/story\\_id/botswana-swaziland-report.pdf](http://www.essex.ac.uk/armedcon/story_id/botswana-swaziland-report.pdf).

<sup>373</sup> UNDP *Assessment of Legal, Regulatory and Policy Environment for HIV and AIDS in Malawi* (2012), 31.

<sup>374</sup> As above, 32.

<sup>375</sup> Zambia Country Report: Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access, as note 311 above.

<sup>376</sup> Médecins Sans Frontières, Malawi, and the Ministry of Health and Population, Chiradzulu District, Malawi *Antiretroviral Therapy in Primary Health Care: Experience of the Chiradzulu Programme in Malawi Case Study* (2004), available at: <http://apps.who.int/iris/bitstream/10665/43063/1/9241592427.pdf>.

<sup>377</sup> See, for example, "Antiretroviral Therapy in Primary Health Care: Experience of the Chiradzulu Programme in Malawi Case Study, as above; "Malawi: Ten Years Ago, MSF Launched ARV Treatment for its HIV patients" *Médecins Sans Frontières* (2011), available at: <http://www.msf.org/article/malawi-ten-years-ago-msf-launched-arv-treatment-its-hiv-aids-patients>.

<sup>378</sup> See: "The World's Worst 2013: The Top Ten Toxic Threats" *The Blacksmith Institute* (2013), available at: <http://www.worstopolluted.org/docs/TopTenThreats2013.pdf>, 16.

## Experiences of stigma and discrimination in healthcare

A prominent feature of discriminatory conduct described by women living with HIV was the **failure of healthcare workers to obtain proper informed consent** before administering treatment, including **failing to explain treatments and diagnoses**. Respondents were particularly distressed about changes in ART regimes without explanation, involuntary HIV testing when accessing antenatal care, and women living with HIV being placed on contraceptives without their knowledge:

*“There are many times that I have gone for review and the doctor just writes a prescription without finding out how I am. Sometimes, I am asked how I’m feeling and I explain the discomfort that I experience and the doctors don’t explain what’s causing certain illnesses. They just write a prescription.”*  
(Woman living with HIV respondent – Kabwe, Zambia)

*“I was on certain [ART]. The clinic changed this drug combination which was working well. They said everyone with a CD4 count above 400 were supposed to change their drugs. I got the new drugs, but I reacted badly to them. I went to the hospital to complain about the new drug, but I was told that I must just continue with the drugs and that side effects would go away. I don’t understand why the drugs I was on before were changed.”*  
(Woman living with HIV respondent – Kabwe, Zambia)

*“Some HIV-positive expecting mothers are put on family planning without their full knowledge or consent. I have a deaf friend who was put on family planning without her full and informed consent.”* (Woman living with HIV respondent – Kabwe, Zambia)

*“Although this practice has reduced in some places, in other places it is still rampant. Pregnant women are forced to test for HIV in order to receive antenatal services.”*

*“Yes. At Kasanda Clinic, they test you for HIV before providing family planning to you. Anyone who wants to receive family planning services has to test for HIV.”* (Women living with HIV respondents – Kabwe, Zambia)

In Zambia, the practice of providing **preferential treatment** to relatives and socio-economically empowered members of the community was described as commonplace:

*“The system in our clinics in Kabwe is that [ART] drugs are only given on selected days and they are only given to the first 20 or so people to arrive at the clinic. We wake up very early, around 03:00 hours on the days we are scheduled to collect our medicines. But the clinics have a habit of allowing their friends or relatives to jump the queue and collect their drugs, which means we have to wait the following week to try again. This practice is very bad at Kabwe General Hospital.”* (Woman living with HIV respondent – Kabwe, Zambia)

Instances of being ignored or healthcare workers refusing to treat healthcare users were typically related by respondents in relation to **intersectional grounds of vulnerability**, including socio-

**economic status and disability:**

*“My friend, who is HIV-positive and a wheel-chair user, went for review to Kitwe General Hospital, but she was late by a few minutes. She was then referred to Wusakile Hospital. She didn’t have an appointment but she had missed the slot for getting drugs by one. She was number 21. It was so sad because they refused to make an exception for her and yet they make for their friends and relatives and it’s so difficult for her to move from one place to another.” (Woman living with HIV respondent – Kabwe, Zambia)*

*“People with money or some high social status like members of the defence forces always get attended to immediately. The rest of us are ignored despite waking up early to try and be in the queue on time. They don’t even care to explain why other people are skipping the queue. (Woman living with HIV respondent – Kabwe, Zambia)*

Also in Zambia, women living with HIV respondents described frustrations with general processes implemented by healthcare facilities, ostensibly to manage health-service delivery in the context of personnel shortages:

*“Some hospitals have started a practice that can be classified as inferior. At Mahatma Ghandi and Kasanda Clinics for example, they have formed six groups of ten people to collect [ART] drugs for everyone in their groups. Only one person can collect the drugs in that month and they distribute them to the others. Then they rotate the person to collect drugs. This is a group of patients and not caregivers who are offered no prior training. If a member of the group is sick, the team leader at the time must accompany this person to the clinic for examination. The clinics have therefore cut down on the number of patients they are seeing for review and only see patients when they are sick.” (Woman living with HIV respondent – Kabwe, Zambia)*

In a 2013-2014 Zambian government study, 34% of women respondents cited “rude attitudes among health workers” as a problem inhibiting access to healthcare.<sup>379</sup> Women living with HIV respondents in both Chiradzulu and Kabwe, described experiencing **aggressive attitudes and derogatory language** used by healthcare workers. A respondent in Chiradzulu, Malawi, described going to a health facility to get medical attention and overhearing a healthcare worker stating: “Let her get treated first for she is a dead person walking.” Another respondent was shouted at by a healthcare worker to go away, exclaiming that he (the healthcare worker) is not the one who infected the respondent with HIV.

In Kabwe, Zambia, respondents had experienced healthcare workers **refusing to touch** them, and conducting themselves in a manner indicative of disgust towards women living with HIV:

*“I worked for Kara Counselling for 13 years as a caregiver. A nurse came to work with us for one year. She separated the mugs in the kitchen and*

<sup>379</sup> Central Statistical Office Zambia: *Demographic and Health Survey 2013-2014* (2015), available at: <https://www.dhsprogram.com/pubs/pdf/FR304/FR304.pdf>, 133.

*labelled the ones for nurses as 'for nurses only'. When she was asked why she did this, she said many caregivers were HIV-positive and she did not want to risk contracting HIV." (Woman living with HIV respondent – Kabwe, Zambia)*

Women living with HIV respondents did not complain directly of **non-consensual status-disclosure** or healthcare workers **gossiping**, but instances of this were apparent from respondents' descriptions of their frustrations with the attitudes of certain healthcare workers.

*"At the Kabwe General Hospital there is a nurse who brags about how she has saved many lives and mentions people's names; particularly names of people who are known in the community. When she meets a patient in the corridors of the clinic, she announces to others who are waiting to be attended to that she counselled that person and they are alive today because of her." (Woman living with HIV respondent – Kabwe, Zambia)*

Lastly, in both Malawi and Zambia, women living with HIV respondents described the **segregation of HIV-related health services** as a stigma and discrimination risk that in some cases inhibits community members from accessing services. Respondents from Chiradzulu reported that a day was set aside once a week for the ART clinic. This practice, they explained, has exposed them to stigma and discrimination. Respondents suggested that there should not be a specific day for the ART clinic and that HIV services should be offered as "primary health care under one roof." Through this method, the respondents felt they could also access other services or treatment on the same day, and with the same healthcare provider, instead of getting appointments to come again for other services. Respondents were concerned that the treatment they were receiving was not as comprehensive as possible and essential services were sometimes left out such as taking blood pressure and weight measurements.

*"Our clinic, Nkungu Clinic, is divided into segments where those of us on ART have our own section for ART. When my friend tested positive and was due for ART, I encouraged her to come with me to the clinic to get her drugs. She refused to come because the ART clinic is a stand-alone building at the clinic and it is open for everyone to see those who accessing its services." (Woman living with HIV respondent – Kabwe, Zambia)*

## Why are we discriminated against?

When asked why healthcare workers might discriminate against women living with HIV, respondents acknowledged that a contributing factor was the overburdened health system, which may overwhelm healthcare workers and compromise the quality of the care they receive. In addition, they identified ignorance-driven fear of both healthcare users and healthcare providers as being a contributing factor.

## Access to accountability and redress

The women living with HIV respondents in Chiradzulu said they would not know where to complain except through Health Advisory Committees. The respondents said they did not know what their rights were so found it difficult to know when their rights were being violated.

In Kabwe, respondents stated that in general they did not complain about mistreatment and discrimination because some of the conduct is simply routine and respondents feared being victimised by being ignored or denied treatment:

*“If we complain about the segregated ART centres, we may not have ART services as they may completely stop offering them or there would be delays in order for them to restructure their services.” (Woman living with HIV respondent – Kabwe, Zambia)*

Some instances of seeking redress and accountability were related. A Malawian woman living with HIV respondent described an example of seeking accountability for mistreatment as a collective of people living with HIV who were accessing ART services. The respondent, who was actively involved at an ART clinic in Chiradzulu, was denied treatment together with other ART clients for no apparent reason. The respondent, together with other ART clients, mobilised themselves and went to complain to a village headman who referred them to the Traditional Authority. The Traditional Authority, together with local Health Advisory Committee members, called the healthcare provider to a round-table meeting. The healthcare provider was allegedly rude and dismissive towards the complainants, the Committee and the Traditional Authority. Following the meeting, the healthcare provider started victimising the respondent who had mobilised others to report her to the authorities. No further consequences resulted from the complaint.

In both Malawi and Zambia, respondents related isolated instances of direct confrontation with healthcare workers. A respondent from Chiradzulu gave an example of a successful direct confrontation with the healthcare worker. The respondent was concerned that her HIV viral load was increasing, which was confirmed after testing. In seeking to address the increase in her viral load, the respondent sought medical assistance. She related that the clinician told her to “just accept her medical condition as [you are] already dead.” The respondent said that she continued to demand treatment and was eventually provided with appropriate treatment.

Other examples of direct confrontations were less successful:

*“I went to the hospital to collect my [ART]. The nurses were late in reporting for work and when they finally came, they were sitting in the nurses’ room chatting. They later started allowing their friends to skip the queue and they attended to them. I went to complain that I have been waiting too long and the nurse told me in local language that the medication I’m on is confusing me, and making me insane.” (Woman living with HIV respondent – Kabwe, Zambia)*

In one example from a respondent in Kabwe, the escalation of a complaint at facility-level was successful in achieving behaviour change from an individual healthcare worker:

*“I complained at a health centre. They were asking personal and health issues of patients in the queue, in the presence of other patients. Patients were not free to respond to some of their questions as they were not asking them in a private space. I told the nurse that what they were doing was wrong and she ignored me. I called the Clinical Officer in charge of the clinic*

*and the nurse who was collecting this information from patients and I asked the Clinical Officer to speak to her about my concerns in my presence. I later followed up to see how the nurse was doing and she apologised to me. My complaint was verbal, but the clinic was able to address my concern.”*  
(Woman living with HIV respondent – Kabwe, Zambia)

When women living with HIV respondents were asked what they wanted to achieve from a functioning complaints process they stated that they wanted to see a change in attitude from healthcare providers and to receive respectful treatment as healthcare users. Where possible, they wanted to receive apologies for mistreatment and changes in policies where needed. Lastly, they stated that compensation would be appropriate in cases of serious abuse.

### What is needed for change?

Respondents were asked to reflect on what was needed to change patterns of stigma and discrimination in healthcare settings. In Kabwe, respondents stated that a well-disseminated complaints procedure for healthcare institutions which is accessible by community members was needed. They suggested in addition that support groups must report to a central place, which follow up the complaints on healthcare users’ behalf. People living with HIV should be empowered to advocate for their rights in support groups. Respondents from Kabwe stated in addition that the suggestion boxes in some clinics could be better used to lay complaints and that healthcare facilities need to review the contents of the boxes regularly and take action on complaints. Respondents in Chiradzulu expressed a desire for a special committee to be put in place to address issues when their rights were violated.

In both Chiradzulu and Kabwe, respondents stressed the importance of educating and sensitising all stakeholders on healthcare users’ rights, legal systems and complaints processes.

### Conclusion

- Access to information and the integrity of the informed consent process emerge as important features of experiences of discrimination related by women living with HIV. Respondents were slow to offer examples of non-consensual treatment or failure to provide information as examples of what they thought was discrimination. But when asked directly on these experiences, women living with HIV respondents appeared to have many experiences of healthcare workers presuming that women living with HIV lack the capacity to decide on their healthcare needs, or lacked the need for information on their health status.
- Many of the examples cited by women living with HIV respondents highlight the intersectionality of women’s vulnerability to discrimination. Women who are disabled or socio-economically marginalised appear to be far more susceptible to abuse.
- In addition, women living with HIV described several instances in Zambia and Botswana of segregating and identifying practices by healthcare institutions and healthcare workers. These were described to exacerbate stigma against people living with HIV and inhibit health-seeking behaviours. Respondents’ strongly voiced preferences for integrated healthcare services and more holistic treatment options.

## 6.5 Persons with disabilities

*“This happens all the time, the assumption that you are not able to do anything just because of one’s disability. We value our independence and like to manage our own lives where we are able to but healthcare workers disregard this and do not support our differently able/disabled bodies. I can make all of life’s choices if I am given adequate information about my body.”*  
(Person with disabilities respondent – Gaborone, Botswana)

### Introduction

In Botswana, 2011 figures estimate that persons with disabilities account for about 2.92% of the population.<sup>380</sup> The prevalence of disability in Malawi is by some estimates indicated at 4.18%.<sup>381</sup> Several surveys indicate that significant portions of the population in Malawi are not able to access the health services they need<sup>382</sup> and that people with disabilities face heightened vulnerability to HIV.<sup>383</sup> In Zambia, persons with disabilities experience discrimination and restrictions in access to HIV treatment and care.<sup>384</sup> Persons with mental disabilities experience pervasive discrimination and stigma in healthcare settings in Zambia.<sup>385</sup>

### Focus groups

Three focus groups were held with persons with disabilities. One focus group was held in Gaborone, Botswana with nine participants. In Zambia, two focus group discussions were held with persons with disabilities in Ndola, comprising eight and nineteen participants respectively.

While the facilitators sought to identify and include persons with mental disabilities, in the end only persons with physical disabilities were available to participate in the discussions.

### Experiences of stigma and discrimination

*“Where we live, when going to Kabushi clinic, one side has stairs and the other side which is accessible is locked, so stairs are a barrier. They lock the accessible part of the building. When we go to the clinic they do not consider that a disabled person needs to be attended to quickly ... We rarely have strength to stand. When you look at hospitals we know our women have the right to family life but they face a lot of difficulties when they are expecting.*

<sup>380</sup> “Decent work country programme for Botswana 2011-2015” *Report of the Republic of Botswana* (2011) 12, available at: <http://www.ilo.org/public/english/bureau/program/dwcp/download/botswana.pdf>, 3.

<sup>381</sup> Malawi Health Sector Strategic Plan 2011-2016: Moving towards Equity and Quality, as notes 142, 27 above.

<sup>382</sup> As above, 27. See, also, AC Munthali et al. “Non-Use of Formal Health Services in Malawi: Perceptions from Non-Users” (2014) 26 *Malawi Medical Journal* 130.

<sup>383</sup> Assessment of Legal, Regulatory and Policy Environment for HIV and AIDS in Malawi, as notes 331, 37 above.

<sup>384</sup> “We Are Also Dying of AIDS: Barriers to HIV Services and Treatment for Persons with Disabilities in Zambia” *Human Rights Watch* (2014), available at: [https://www.hrw.org/sites/default/files/reports/zambia0714\\_ForUpload\\_1.pdf](https://www.hrw.org/sites/default/files/reports/zambia0714_ForUpload_1.pdf).

<sup>385</sup> A Kapungwe et al. “Attitudes of Primary Health Care Providers towards People with Mental Illness: Evidence from Two Districts in Zambia” (2011) 14 *Afr J Psychiatry* 290; A Kapungwe et al. “Mental Illness – Stigma and Discrimination in Zambia” (2010) 13 *Afr J Psychiatry* 192.

*They are discriminated against as if they should not have children and they should not fall pregnant. A lot of them do not even go to antenatal for fear of how the nurses will speak to them.” (Person with disabilities respondent – Ndola, Zambia)*

Only one example was raised (in Ndola, Zambia) of a **refusal to treat** healthcare users with disabilities. However, respondents recognised that some healthcare workers were “intimidated” by their disabilities and so would delegate their treatment to other healthcare workers:

*“Once I spent the whole day waiting for a doctor, when all I needed was a blood pressure test that needed no specialist. Many are intimidated by our disabilities but some just don’t care to be slowed down, or just don’t want to have to deal with us because of our disability. This is equal to denial of service but it happens frequently.” (Person with disabilities respondent – Gaborone, Botswana)*

In both Zambia and Botswana, persons with disabilities respondents strongly perceived the failure of healthcare workers to **recognise them as autonomous persons** as being discriminatory. In Ndola, Zambia, the participant group (despite exhibiting good knowledge and a habit of asserting their rights) became emotional when explaining these behaviours that they felt denied them dignity.

*“Doctors do not refuse to treat us when we are sick. The problem is that they treat us like children. The nurses are most troublesome. They usually look at the disability instead of our illness.” (Person with disabilities respondent – Ndola, Zambia)*

*“Whenever he goes for HIV testing the counsellors treat him like he is doing something he is not entitled to. And once he has an STI they blamed him for it. He told them that he is an adult man with adult sexual needs like any other man. The attitude makes him feel bad and stigmatised so he is ashamed to go for testing or even ask for condoms, which is a real shame because healthcare workers are putting his life at risk by stigmatising him about his sexuality as a man living with a disability.” (Person with disabilities respondent relating an incident experienced by a peer – Gaborone, Botswana)*

Person with disabilities respondents described struggles to have their **decisions recognised** by healthcare workers:

*“I am partially deaf, so that means I don’t need a hearing aid, but doctors always want to prescribe one for me. They ignore me when I tell them that I don’t need one especially since the volume is never adjusted to suit the partially deaf.” (Person with disabilities respondent – Gaborone, Botswana)*

Experiences of being **treated with indignity** included instances that related a sense of superstition or fear when around persons with disabilities. In Ndola, persons with disabilities respondents gave examples of healthcare workers being fearful to touch healthcare users with albinism in particular. Respondents also said that women with disabilities were often neglected during childbirth, as some nurses refused to touch the women, leaving them to clean themselves after birth despite the

women's physical limitations:

*"Some people thought they could contract the disability." (Person with disabilities respondent - Ndola, Zambia)*

Women with disabilities were highlighted in both Ndola and Gaborone as experiencing particular **discrimination when accessing sexual and reproductive healthcare**. Many respondents stated that healthcare workers frequently slapped and hit women with disabilities during labour. Respondents in Zambia stated that many women avoid accessing antenatal care in anticipation of discrimination. In Gaborone, persons with disabilities respondents said they were often presumed to be victims of sexual assault when accessing sexual and reproductive health services, not as active, consensual sexual partners. The respondents felt their needs, desires and rights to have sexual relationships and found families were delegitimised.

One person with disabilities respondent in Ndola narrated how a nurse slapped her when she went to the hospital for the delivery of her child. "How can such a woman give birth? How could you even do such a thing to yourself?" the nurse asked her. She said the nurse forced her to agree to undergo an operation for delivery. She described, however, how a doctor intervened and examined her and he reprimanded the nurse for taking her to theatre when she was fully able to deliver naturally. The respondent said she nevertheless gave birth to the child without the help of a nurse.

In relation to HIV testing, a respondent from Ndola said "Tatuyako iyo." (Facilitator's translation: "We do not even go there at all"), affirming habits of **healthcare avoidance** due to fear of being discriminated against.

*"They accuse us of being difficult, that we are troublesome and because of that we even fear to go to health facilities. [Their] attitude is bad and it tends to stop us from seeking services. We do not even go there. We fear stigma." (Person with disabilities respondent - Ndola, Zambia)*

Respondents did not describe significant instances of healthcare workers gossiping about them but did give examples of **derogatory, abusive and mocking language** being used against them by healthcare workers. In Ndola, Zambia, women with disabilities complained that the words used against them when in labour were so degrading that they refused to repeat them during the discussion.

Persons with disabilities respondents in Botswana and Zambia lamented in particular the position of blind and visually impaired persons who were treated as if "they are invisible", especially when bringing an aide with them when accessing care. Respondents related that despite being able to hear and talk for themselves, healthcare workers seldom engaged them directly. Many of these examples were described in relation to **confidentiality failures** by healthcare workers:

*"I went to the clinic with my younger sister. When I went to see the doctor I asked her to stay outside. Clearly I wanted my privacy but the pharmacist had no time for me. She could not be bothered to explain the pills to me. Instead she was talking through me as if I wasn't there. This happens a lot, and is very frustrating." (Person with disabilities respondent - Gaborone, Botswana)*

Related to this were explanations of multiple instances where healthcare workers provided **insufficient information** to healthcare users and failed to obtain proper informed consent when administering care. In Ndola, when asked on **informed consent**, persons with disabilities respondents did not know that they were even required to consent to treatment, particularly for HIV testing, accepting medication or family planning services. Visually-impaired respondents related difficulty in accessing information. Deaf and hearing impaired healthcare users gave examples of being administered treatment or given medication, without any explanation or informed consent process:

*“There are no sign-language interpreters in these health centres and posts. They expect you to write down everything for them to read. What if you are not literate? What if you can’t write because you are too weak to write? Communication with doctors is a big challenge. They end up just giving us panadol even for serious illnesses. One deaf friend of mine was given medicine for high blood pressure instead of been treated for his diarrhoea which he had suffered for three days due to a wrong diagnosis.” (Person with disabilities respondent – Ndola, Zambia)*

The failure to make **reasonable accommodation** for persons with disabilities was described by respondents as a form of discrimination. Respondents were able to distinguish “positive” and “negative” discrimination and recognised as discriminatory some healthcare workers’ refusal or ignorance to institute small accommodations to ensure that their rights are respected.

*“[They make] false generalisations: we are differently disabled and not the same!” (Person with disabilities respondent – Gaborone, Botswana)*

According to persons with disabilities respondents in Zambia, healthcare workers were not willing to explain the contents of medicines dispensed to visually impaired healthcare users:

*“For us who are blind, they just shout out the medicine to us without explaining the dosage or even the name of the medicine. They say your relatives will read it for you. But their handwriting cannot even be read by anyone. This means I have received drugs without me agreeing to them.” (Person with disabilities respondent – Ndola, Zambia)*

In Botswana, hearing-impaired respondents were frustrated by the absence of any sign language **interpreters** in public healthcare facilities: healthcare users are expected to bring their own interpreters. Hearing-impaired respondents in Ndola demanded that healthcare facilities should employ and train professional sign-language interpreters to ensure that confidentiality is observed.

In the absence of an interpreter to assist, respondents stated that they were **ignored** or not given **information** on their treatment or diagnosis. In Zambia, hearing-impaired respondents said they had never received counselling when testing for HIV and feared humiliation following communication breakdown:

*“I went to a clinic by myself and when it was my turn the nurse asked me to go get an interpreter so he could help me. I told [him] that I had no*

*interpreter and that I was able to read and write, so we could communicate that way. He immediately said it would take too long, as if that was my problem. I refused to move and told him that I was not going away until I got the help I needed. Of course his attitude immediately got rough, and he did not bother to explain what treatment he was prescribing.” (Person with disabilities respondent – Gaborone, Botswana)*

Several examples were given of simple **physical assistance being denied**, particularly for women with physical disabilities when accessing maternal healthcare.

*“When I was pregnant I was forced by nurses to get onto a very high bed. With my heavy pregnancy and my physical disability they could not give me a stool or adjust the bed. Our clinics do not have facilities that are accessible. A lot of times we have to use stairs and it is a big problem. Even the main hospital has stairs to the main foyer making it difficult to access the lift.” (Person with disabilities respondent – Ndola, Zambia)*

Respondents did not describe concerns over the segregation of healthcare users, but in Zambia, persons with disabilities respondents raised concerns about the treatment of persons with mental and intellectual disabilities, particularly their detention and forced treatment.

## Why are we discriminated against?

When asked why persons with disabilities were discriminated against in accessing healthcare, respondents in Zambia used the Bemba word “Ichifukushi”, which means “a grudge against persons with disabilities.” Respondents noted that discrimination was driven by ignorance, fear of the unknown and a general tendency to look down on persons with disabilities.

In Botswana and Zambia, respondents strongly indicated traditional and religious beliefs as driving intolerance towards persons with disabilities. Even in urban centres like Gaborone, it was explained that many people still believe disability to be a curse or the result of witchcraft:

*“Christianity [in the] Old Testament suggests that disability is an indication that one has demons or is possessed by demons or has a curse over them. All of these, it is believed, can be exorcised through prayer. All the time people start conversations with me only to suggest that I have either been bewitched or I am possessed by demons – that I should go to church to have the demons exorcised, which is ridiculous really. But this explains the stigma, the need for parents of disabled children to hide their children, sending them to the cattle posts or farms where they will not be seen.” (Person with disabilities respondent – Ndola, Zambia)*

Respondents in Gaborone inferred that the practice of families “hiding” children with disabilities was both a cause and symptom of stigma against persons with disabilities.

## Access to accountability and redress

In comparison with other focus-group participants, persons with disabilities respondents in

Zambia described rich and directly confrontational examples of seeking accountability from healthcare workers. All examples were, however, of direct confrontation of the offending party with no instances of engaging any complaints procedures as such. Zambian respondents felt they were perceived by healthcare workers as being troublesome in complaining too much but were unaware of any process external to the health facilities themselves where complaints could be made. In a number of these examples, persons with disabilities respondents were, in contrast to other participant groups, more assertive of their rights:

*“I went to a chemist and wanted condoms. This man looked at me as I specified the type of condoms I wanted, but the pharmacists kept looking at me. Then he asked if I use them. He asked about my partner. I asked him if he asks everyone about their partners and that is how he kept quiet. Attitude is bad and it tends to stop us from seeking services.” (Person with disabilities respondent - Ndola, Zambia)*

*“When I was in Monze town one lady with a disability was made pregnant. At the hospital during examination, the nurse said in Bemba, a Zambian language, ‘tamwilunfyelila uluse?’ [Facilitator translation: ‘Do you not feel pity for yourself?’. I asked the nurse whether she was married. When she said yes, I told her that the other lady also wanted to give birth like her. ‘Are you not married?’ I asked her to say ‘this woman is married just like you’ - and she did. The clinical officer agreed with me that she is human and has the same feelings and she should not be stopped from enjoying her sexual and reproductive rights. The nurse was warned.” (Person with disabilities respondent - Ndola, Zambia)*

One participant described an incident with a doctor when seeking an explanation of why his medication had been changed:

*“I told him, ‘it is because you did not ask me what drugs I am not friendly with.’ ‘I always react to that drug,’ I told him. ‘You should have asked for my consent to the drug,’ I shouted at him. I said, ‘is it because I am deaf that you wanted to kill me?’” (Person with disabilities respondent - Ndola, Zambia)*

A respondent in the Ndola focus group described frustration with this method of seeking accountability, in how persons with disabilities often end up insulting healthcare providers after experiencing mistreatment or discrimination. One respondent provided details of their experience in seeking to escalate a complaint against a healthcare worker at facility-level:

*“In 2011, during circumcision, I complained that the nurse left me without showing me where my clothes were. Yet I am blind. How was I to see them? I complained to management but they said they could not do anything as they could not know who did the circumcision. I complained to the sister in charge and got no help.” (Person with disabilities respondent - Ndola, Zambia)*

Respondents in Ndola were nevertheless able to discuss and determine together the available

procedures for how ideally complaints should be made. It was agreed that the first step in reporting a complaint would be to start with the sister in charge and then to take it to district medical office. If no help is obtained, then the complaint should be made to the provincial health office:

*“The biggest issue is that we have fear. When a medical officer speaks we develop fear. Follow the supervisor. We need to take these matters up so that our rights can begin to be addressed. They have a perception that persons with disabilities are a problem.” (Person with disabilities respondent, Ndola, Zambia)*

When respondents were asked why they might not lay complaints when experiencing mistreatment or discrimination, a common response was that of fear of retribution by healthcare workers and future denial of services:

*“I cannot take a doctor to court because I will suffer and may never seek health services ever again.” (Person with disabilities respondent - Ndola, Zambia)*

Other respondents said they did not know what their rights were or how they could complain:

*“We also do not know our rights and how to use them.” (Person with disabilities respondent - Ndola, Zambia)*

Respondents in Zambia said an effective complaints process for them could be to use civil society organisations to coordinate a mechanism for lodging complaints so that action could be taken against perpetrators. Zambian respondents emphasised the main purpose of a complaints procedure would be to change laws and policies in order to ensure that persons with disabilities are empowered and so that discrimination in healthcare is prevented:

*“We want them to be punished for wrongdoing to deter future offenders so that they develop fear. We need policies to change for the better and laws must become better so that we lead a better life. We need positive discrimination towards persons with disabilities to give them preferential treatment.” (Person with disabilities respondent - Ndola, Zambia)*

In Botswana, respondents did not relate any examples of complaining about mistreatment or discrimination. The respondents were, however, unanimous in stating that the desired outcome from a complaint would be to see a change in policy or law. The respondents noted their desire for clear and enforceable consequences for healthcare workers who discriminate against them. Disciplinary hearings should be held with the possibility of the healthcare worker being sanctioned and apologies made to the victims.

In Botswana, respondents indicated distrust about existing complaints procedures, with no confidence that redress would result even if complaints were made. Respondents expressed a sense of resignation towards social condoning of discrimination against persons with disabilities.

## What is needed for change?

Persons with disabilities respondents in Botswana and Zambia were asked what they thought was needed to change practices of discrimination in healthcare. In Botswana, respondents stressed the need for updated laws and policies on disability to ensure respect for the rights of persons with disabilities. Complaint procedures should be included in any new legislation.

In both countries, respondents said complaints processes need to be clearly articulated in policy and should provide for effective enforcement. Respondents sought a policy with clear guidelines on ethical conduct of caregivers. It was suggested that healthcare users should be given copies of rules, in a format appropriate to the healthcare user's needs and abilities. Effective access to information was also described as being important for persons with disabilities to make informed decisions on their healthcare, so reducing the reliance on healthcare workers exclusively.

Respondents stressed that information on existing complaints processes must be disseminated to persons with disabilities through representative organisations in simple or local languages, which processes should include opportunities to submit complaints to NGOs working with persons with disabilities. In addition, it was suggested that personnel in community-based mechanisms and the police should be educated on disability rights.

The need for training and sensitisation of healthcare workers, communities and persons with disabilities was strongly emphasised by all focus groups. Training should be inclusive of medical ethics, healthcare users' rights, disability rights, basic sign language, and the obligation to take time to explain issues to persons with disabilities, among others. To this extent, some participants appeared to empathise with healthcare workers who were "lost" and made mistakes.

*"It would be good to have perpetrators arrested. But we need not be treated by what I am, but by whom I am. We will die if left behind. We need the rights of persons with disabilities to healthcare to be stuck in public accessible places in the clinic and other healthcare institutions. Health centres should be sensitised on our rights." (Person with disabilities respondent - Ndola, Zambia)*

*"We need stronger advocacy and [to have] sensitisation in hospitals on disability so that their rights are respected in the healthcare system. Clear awareness raising as they are doing for HIV and AIDS." (Person with disabilities respondent - Ndola, Zambia)*

In both Botswana and Zambia, respondents envisaged improvement through the strengthening of civil society advocates on disability rights. In Botswana respondents were aware that the Botswana Council for Disabilities receives complaints as does the Disability Coordinating Office in the Office of the President. Respondents were not confident, however, that either body had sufficient capacity to follow up on complaints effectively, nor to meaningfully reach persons with disabilities in rural areas.

In Zambia, respondents identified the need for community-based organisations to be supported and trained to identify discriminatory conduct and rights violations in healthcare and to refer cases to the appropriate complaints process.

## Conclusion

- The narratives of persons with disabilities indicate that extent a failure to provide information and to apply full informed consent procedures is a form of discrimination. Respondents are aware that they are often treated as persons who lack the capacity to decide for themselves and not as autonomous persons. The challenges faced by deaf and hearing-impaired healthcare users were strongly highlighted amongst participants, who described repeatedly being ignored by healthcare workers.
- The manifestation of discrimination against persons with disabilities in healthcare is exacerbated in the context of women's access to sexual and reproductive healthcare services. This not only relates to positive discriminatory conduct but also to failures to reasonably accommodate the needs of women with disabilities to enable them to access healthcare equitably.
- In Botswana, the focus-group facilitator noted that participants were confident about their rights. Persons with disabilities respondents in both Zambia and Botswana raised and engaged in complex notions of positive and negative discrimination and concepts relating to affirmative action. It is noteworthy that persons with disabilities respondents described significantly more assertive practices of seeking accountability and redress when experiencing discrimination. While selection bias and other factors may indeed account for this, the capacity of persons with disabilities to assert their legal rights when experiencing abuses may also be understood in the absence of legal prohibitions against persons with disabilities that otherwise function to constrain other focus-group participants interviewed, such as sex workers and LGBT persons.
- However, the accounts of complaints were usually of direct confrontations with the offending healthcare workers and seldom with an outcome that meaningfully addressed the complainant's needs and frustrations. The absence of an effective, accessible and responsive framework for complaints for persons with disabilities is highlighted in these narratives.
- Finally, it is important to emphasise the absence of the perspectives of persons with mental and intellectual disabilities from the experiences described. This is noted as an issue where further research is needed.

## 6.6 Poverty and the rural/urban divide

### Introduction

*“There is also a lot of discrimination on the basis of socioeconomic status. For example, in the line, healthcare workers will be selective about who they attend to first – they assume the poor can’t do anything about it. The higher your status, the more likely you are to complain. Since I complained on behalf of someone else, they are more responsive to me in particular.”*

*(NGO respondent – Lusaka, Zambia)*

Throughout focus groups, key informant interviews and consultations with NGOs and CBOs, a repeated theme emerged on the exclusionary role of poverty and rural location as a systemically-entrenched ground of discrimination for healthcare users in Botswana, Malawi and Zambia. Some studies have shown that increased availability of treatment and services reduces HIV-related stigma and discrimination.<sup>386</sup> To the extent that healthcare accessibility is reduced in rural areas, it can be anticipated that higher levels of stigma and discrimination would prevail. To the extent that rural and poor populations are underserved in the allocation and distribution of health resources, this may be identified as a form of systemic discrimination.

The United Nations Committee on Economic, Social and Cultural Rights has emphasised the importance of the effect of conditions of impoverishment on the enjoyment of the right to health:

*“The right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.”<sup>387</sup>*

### Situation analysis

In **Botswana**, rural settings accommodate around 75% of the population where public healthcare is primarily accessed through mobile stops, health posts and clinics.<sup>388</sup> Respondents in this report identified practical limitations that made healthcare access difficult for rural populations, including distance to facilities. In Selebi Phikwe, Botswana, sex worker respondents noted in particular the difficulty of accessing healthcare if they didn’t have an identity card, which was stated to be difficult to access in rural areas or when mobile.

*“We’ve heard however about a negative practice wherein people of a certain social class are offered the private ward in our public hospitals, which is wrong. All patients are equal before our public-health facilities whether one is a government minister or street child.” (BHPC – Gaborone, Botswana)*

<sup>386</sup> S Maman et al. “A Comparison of HIV Stigma and Discrimination in Five International Sites: The Influence of Care and Treatment Resources in High Prevalence Settings” (2009) 68 *Soc Sci Med* 2271; A Farmer & P Castro “Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti” (2005) 95 *Am J Public Health* 53.

<sup>387</sup> CESCR *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)* (11 August 2000) at para 4.

<sup>388</sup> HA Akinsola “Ethical concerns in nursing practice in Botswana” (2001) 8 *Nurse Ethics* 342.

In **Malawi**, government policy explicitly acknowledges not only the discrimination in healthcare access for impoverished sectors of society but also the greater vulnerability of the poor to threats to their health. The Malawi Health Sector Strategic Plan, for example, draws a link between expanding and improving healthcare and reducing poverty:

*“The prevalence of diseases such as malaria, acute respiratory infections and diarrhoea, is higher among poor people compared to those who are rich. Therefore, the successful implementation of the [Health Sector Strategic Plan] will depend to a large extent on the reduction of poverty.”*<sup>389</sup>

The link between poverty and public health is also clearly established in the Malawi Growth and Development Strategy 2011-2016 and in the Malawi National HIV and AIDS Strategic Plan 2011-2016.<sup>390</sup> Most of Malawi’s population live in rural areas (some 80%) and experience inequitable access to healthcare:<sup>391</sup>

*“Access to [sexual and reproductive health and rights] services is worse in rural areas, as there is inequitable deployment of health personnel, which favours urban areas, [and to] the secondary and tertiary levels of care. This is aggravated by the critical shortage of health workers across the board, but especially [the] shortage of midwives.”*<sup>392</sup>

The Commission on Social Determinants of Health found in its 2008 report that one of the social determinants of health was the misdistribution and poor quality of healthcare delivery systems.<sup>393</sup>

Health systems’ failures also unequally burden the poor. Women living with HIV respondents in Chiradzulu, for example, stated that “sometimes at [ART] clinics they are told to buy medication privately when medicines are not available at the facility due to stock outs.” Most say that they cannot afford to purchase the medication.

Respondents from the Malawi Human Rights Commission, interviewed for this report raised concerns about what they felt was discrimination through the lens of resource constraints. The Commission respondents noted issues concerning the locations of health facilities and investments, disparities in rural/urban healthcare worker staffing ratios, and disparities in healthcare access between the rich and poor despite policy commitments to universal care. An example provided of the discriminatory consequences of resource constraints and misallocation was how women in Lilongwe are at times referred for caesarean sections due to the unavailability of Pitocin, a hormone commonly used to induce or augment labour.

<sup>389</sup> Notes 142, 17 above.

<sup>390</sup> Malawi National HIV and AIDS Strategic Plan 2011-2016, notes 29, 2 above.

<sup>391</sup> Gaps in Universal Health Coverage in Malawi: A Qualitative Study in Rural Communities, note 27 above.

<sup>392</sup> Republic of Malawi: Ministry of Health *Sexual and Reproductive Health and Rights Policy* (2009), 5. See, also, Malawi Health Sector Strategic Plan, note 142 above: “In particular, access to health care is low among the rural poor and the cost of maintaining better health is high.”

<sup>393</sup> WHO Commission on Social Determinants of Health *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health* (2008), available at: [http://apps.who.int/iris/bitstream/10665/43943/1/9789241563703\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/43943/1/9789241563703_eng.pdf).

In **Zambia**, the Government's Vision 2030 asserts the right of equality in access to and use of good quality healthcare for all regardless of socioeconomic status.<sup>394</sup> Despite this, studies show that the wealthy access public healthcare more than impoverished populations, despite having a lower need for healthcare.<sup>395</sup> A 2007 Department of Health study showed that while persons living in urban areas are almost twice as likely to be living with HIV than persons living in rural areas, comparisons of HIV prevalence between 2001 and 2007 by the Department show that the epidemic is contracting in urban areas (with a 3.4% decrease in urban prevalence in that time) while the rural HIV prevalence remained "virtually unchanged" between 2001 and 2007.<sup>396</sup> Studies have also indicated lower levels of accepting attitudes towards persons living with HIV in rural areas.<sup>397</sup>

NGO and CBO respondents described a dual system of care in urban public healthcare facilities where paying "customers" received preferential treatment to those who accessed free services:

*"If you don't have money, you will wait in the long queue. But if you pay those people they will treat you and take you ahead of the line." (Sex worker respondent - Lusaka, Zambia)*

*"At Kabwe General Hospital, the medical personnel have a tendency of keeping people without money for long hours without attending to them. They first attend to people with money, who are often late to come to the Hospital. Some people do not even wait in the queue for collecting [ART], they just walk straight into the doctor's office and collect their drugs; others just make phone calls." (Woman living with HIV respondent - Kabwe, Zambia)*

## Conclusion

- Whether as intersectional grounds, or independent grounds of discrimination, healthcare users who are poor and/or live in rural areas have reduced access to healthcare services, appear to have greater needs for health services, and are (based on anecdotal evidence) more likely to experience stigma and discrimination in healthcare
- It may be useful to focus advocacy efforts on identifying inequitable allocations and distributions of health resources as discriminatory when addressing policy and budgetary reform.
- In addition, poverty and rural location impacts the accessibility of complaints processes and the choices that complainants may make in using a particular complaints process. In order for complaints systems to be effective as tools for accountability and redress in healthcare, particular consideration needs to be given to the needs of healthcare users who are poor and live in rural areas.

<sup>394</sup> Government of the Republic of Zambia: Ministry of Finance and National Planning *Vision 2030* (2010).

<sup>395</sup> J Phiri and JE Ataguba "Inequalities in Public Health Care Delivery in Zambia" (2014) 13 *International Journal for Equity in Health*, available at: <http://equityhealth.biomedcentral.com/articles/10.1186/1475-9276-13-24>.

<sup>396</sup> Zambia Country Report: Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access, notes 311, 12 above.

<sup>397</sup> Zambia: Demographic and Health Survey 2013-2014, notes 337, 123 above.

## 6.7 Perceptions of discriminatory behaviour: Complaints mechanisms, NGOs, and CBOs' perspectives

*"Discrimination in Botswana's health sector is not prevalent. This finds evidence in the fact that health services are available for free to every citizen, which ensures definite access to healthcare.*

*Having said that, however, HIV-positive members of Botswana society perceive the existence of special clinics ... as discrimination. This is not fair to the government because clinics that are dedicated to specific ailments have over the years been the norm in Botswana to ensure efficiency and focus. HIV-positive members of our society rather than feel discriminated against should notice the extra mile that the healthcare sector takes for them. To avoid them being in long queues with all sick people, the government has established clinics dedicated to HIV treatment, care and support. The efficient and effective management of pandemics such as HIV calls for separation at times and HIV being the complex virus that it is that needs laboratories and specialists is no exception." (Complaints body respondent - Gaborone, Botswana)*

Key informants who were interviewed from complaints bodies had different perspectives on healthcare discrimination than those of key population and vulnerable persons from focus group discussions presented above. Health professions councils and nursing councils in particular tended to take a jaundiced view on the extent to which behaviours complained of as discriminatory by focus-group respondents were indeed discriminatory. For example, these respondents stated that disclosure of a healthcare user's HIV-status to other health professionals was not a breach of confidentiality, whether or not the healthcare users consented to the disclosure.

Health profession and nursing councils also tended to emphasise that segregation, identifying practices, and the use of excessive precautions are necessary procedures and techniques of patient-management and are important for effective data capture. For respondents who made these justifications, it was not raised as a relevant concern that healthcare users perceived these practices as discriminatory or that the practices resulted in social stigmatisation and breaches of healthcare user confidentiality:

*"No it is not discriminatory. It is the system. Certain systems must be put in place to make one's work easier. People go to all sorts of clinics - eye clinics, ART clinics, diabetes clinics, etc. These systems are for efficiency." (Complaints body respondent - Lusaka, Zambia)*

Nursing councils in particular raised at times the importance of segregation and identifying practices to ease human resource pressures in contexts of significant under-staffing. A number of behaviours identified by focus-group respondents above were justified by nursing councils as unintentional results from capacity constraints. For example, a respondent from a nursing and midwifery council stated that often ignoring a healthcare user was merely the result of implementing a "first-come-first-serve" policy.

Some respondents from health professions and nursing councils also sought to draw sharp distinction between behaviour that is discriminatory and that which is “merely” malpractice or unethical conduct. However, none of these distinctions were justified on the basis of differential treatment between groups or persons. In some instances, respondents illustrated a reluctance to engage with the concept of discrimination either as a form of aggravated malpractice or as an independent concept falling within the ethical vocabulary of their respective professions. A failure to conduct a proper informed consent process with a healthcare user was explained, for example, as incompetence and not discrimination:

*“In the healthcare setting we speak of negligence, misconduct and malpractice. Discrimination as a concept is not alive in our space.”*  
(Complaints body respondent – Gaborone, Botswana)

*“Discrimination is an attitude not a practice.”* (Complaints body respondent – Lusaka, Zambia)

However, on some issues, health profession and nursing councils expressed strong views on the importance of healthcare users’ rights, even if not engaging in concepts of discrimination and stigma directly:

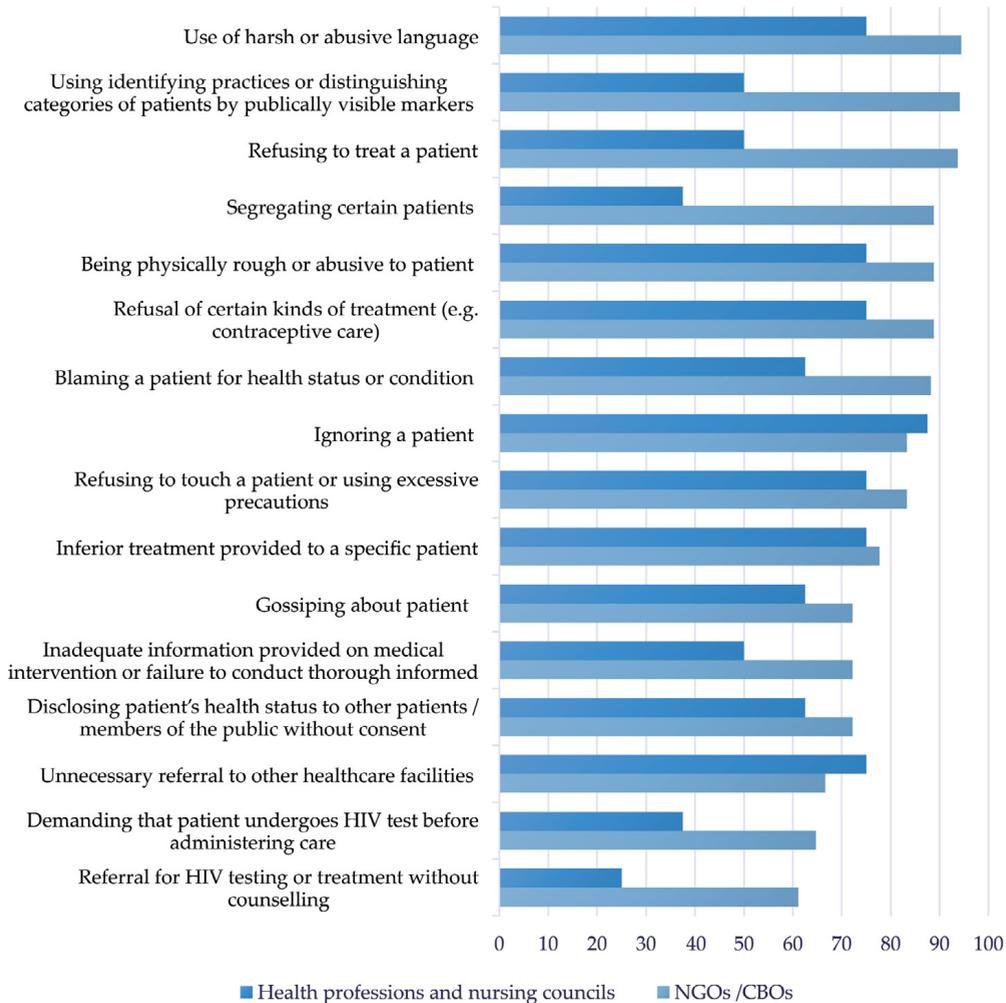
*“As long as the patient is breathing or their heart beating, they have the right to be treated.”* (Complaints body respondent – Gaborone, Botswana)

*“Health facilities are a place for care, comfort and refuge and harsh, abusive language should not be tolerated.”* (Complaints body respondent – Gaborone, Botswana)

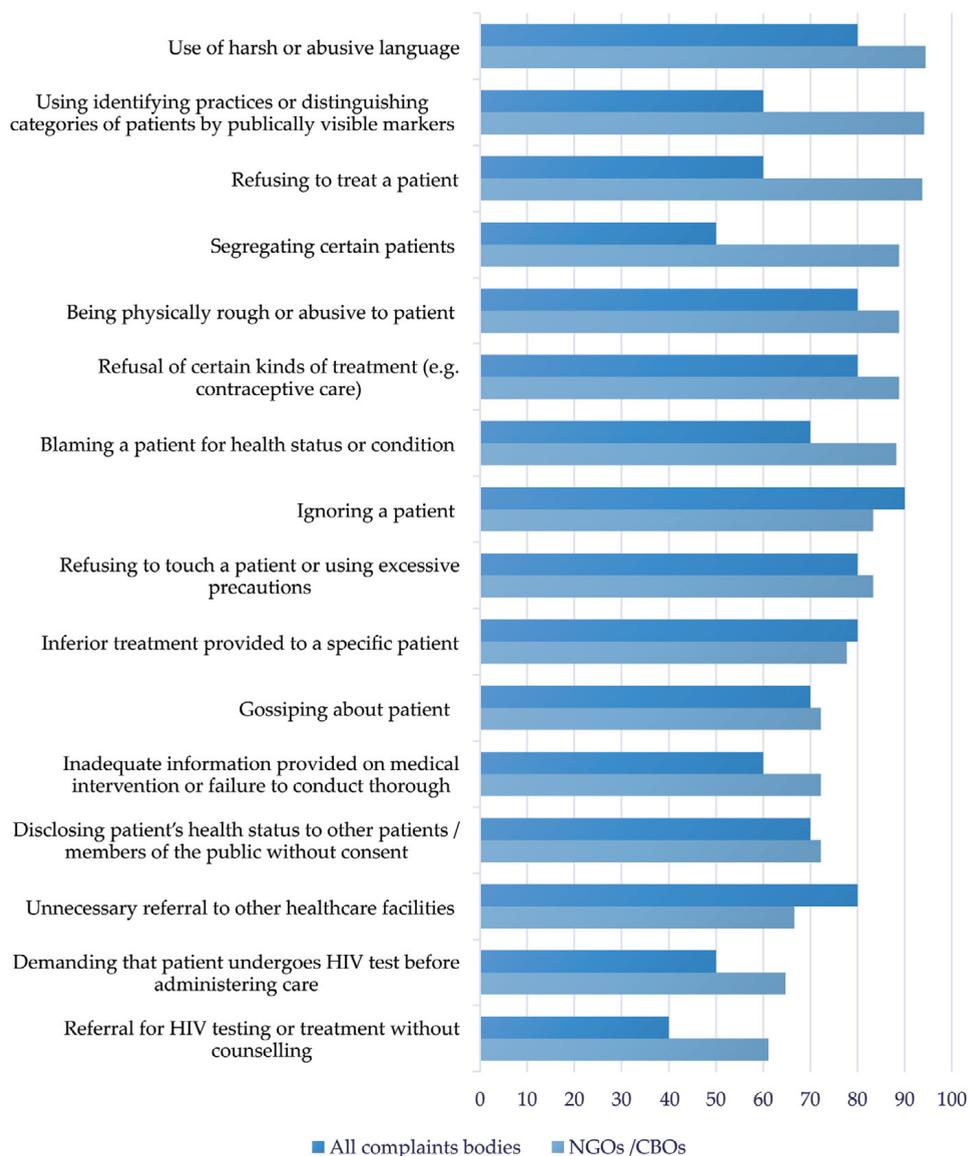
While human rights complaints bodies outside of the healthcare system (such as human rights councils and ombudspersons) tended to be more healthcare user-centred in their assessment of whether certain behaviours in healthcare amounted to discrimination, these bodies were less aware of the particularities of the healthcare environment. Some respondents highlighted the bodies’ inexperience with issues on healthcare in general.

The graphs below illustrate differences in the assessments of whether certain behaviours constitute discrimination in the context of healthcare as expressed by NGO and CBO respondents and complaints body respondents. Respondents from NGOs and CBOs and complaints bodies were asked to indicate whether certain behaviours in the context of healthcare or as enacted by healthcare providers were discriminatory. The graphs (below) show the percentage of respondents who identified the behaviours as discriminatory across the three countries. The difference in assessments of the behaviours’ discriminatory quality is more marked when considering the views of health professions and nursing councils in comparison with NGO and CBO respondents than when including the more generous views expressed by human rights complaints bodies.

## Behaviours perceived as discriminatory: Comparing health profession bodies with NGO and CBO perceptions



## Behaviours perceived as discriminatory: Comparing all complaints mechanisms with NGO and CBO perspectives



## 6.8 Conclusion

The experiences described by focus-group respondents indicate anecdotal evidence of pervasive and ongoing discrimination and stigma in healthcare in Botswana, Malawi and Zambia based on a number of grounds including health and HIV-status, gender, sexual orientation, disability, socio-economic status, occupation, and rural location. Worryingly, respondents described direct effects of discriminatory treatment on healthcare avoidance, self-medication, and social alienation.

Respondents described continuity between traditional and religious beliefs held by community members and the attitudes exhibited in conduct towards them by healthcare workers. Despite this, several respondents could relate empathetically to the constraints under which healthcare workers in the public sector function and were able to draw on these pressures as factors which exacerbated discriminatory conduct.

The use of abusive language and practices of dismissive conduct, including failures to properly examine healthcare users before providing treatment, were predominant in participants' descriptions of behaviours perceived as being discriminatory.

Healthcare-user confidentiality was also described as both discriminatory conduct and as an inhibition in health-seeking or accountability-seeking behaviours by respondents. It is important to note that LGBT and sex worker respondents in particular drew attention to the importance of not only health-status confidentiality but also healthcare user identity confidentiality (e.g. that the healthcare user is or is perceived to be an MSM or a sex worker) as central to ensuring that healthcare users can access healthcare safely, appropriate to their needs, and in good time.

Effective and respectful communication between healthcare workers and healthcare users was central to respondents' perceptions of discrimination. When healthcare workers do not conduct proper informed consent, do not accommodate healthcare users' needs to ensure they understand their health conditions and treatment options, and when healthcare workers do not communicate respectfully to healthcare users when operating under resource pressures, these behaviours are marked as discriminatory and are experienced by key populations and vulnerable populations in particular as being dehumanising. Power disparities between healthcare workers and healthcare users seeking to access public-health services, were directly noted by sex workers in particular and indirectly described by all focus groups.

Two areas of particular policy concern are noted. The first was that of healthcare workers denying healthcare users access to STI and HIV testing, counselling and treatment in the absence of (heterosexual) sexual partners. Respondents have described this conduct as functioning to deny access to testing, counselling and treatment.

The second issue, is that of segregation and the use of identifying practices for people living with HIV in Botswana and Zambia. While health professions and nursing councils were insistent on the benign managerial nature of these practices, it must be emphasised that respondents noted these as discriminatory and exacerbating social stigma while also inhibiting health-seeking behaviour. People living with HIV in particular called for integrated services.

# 7. Strengthening accountability and redress

## 7.1 Introduction

This Chapter develops perspectives on the barriers rights-holders face in seeking accountability and redress for discrimination in healthcare and discusses strategies identified by respondents for improving access to justice.

## 7.2 Barriers to accountability and access to redress

Chapter 3 highlighted the views of NGO and CBO respondents on why rights holders may be constrained in accessing legal redress through the formal court process. Chapter 6 set out how sex workers, LGBT persons, women living with HIV, and persons with disabilities felt they were inhibited in accessing accountability and redress following experiences of discrimination in healthcare. Key informant interviews with respondents from the select complaints bodies indicated their views on what some of the barriers are that healthcare users and rights-holders might face in lodging complaints relating to discrimination in healthcare. In some instances, these respondents' views corresponded with concerns raised by focus-group participants. In others, these respondents raised issues insightful of difficulties that complainants may face in accessing their particular complaints processes. However, in a few instances, the responses of complaints bodies illustrated a deficit of understanding on the diverse barriers that key populations and vulnerable populations face in accessing accountability and redress.

### Botswana

In Botswana, complaints body respondents emphasised the importance of cultural norms as inhibiting justice-seeking behaviour by healthcare users, stating that Botswana tended to display deference to medical professionals. Combined with illiteracy and a loss of faith in the effectiveness of complaints processes, the cultural inhibition to complain was emphasised as significantly inhibiting healthcare users from seeking accountability and redress. These views were confirmed by NGO and CBO respondents who emphasised that power disparities between healthcare workers and healthcare users make it difficult to challenge health professionals' authority.

Complaints body respondents also noted the social stigma that complainants may face as contributing to fear of seeking redress. Complaints body respondents did not, however, mention the impact of criminalisation or legal and policy regimes on the accessibility of accountability

processes in healthcare for key populations and vulnerable populations.

Botswana complaints body respondents stated further that complainants may have access constraints, considering the long distances they may need to travel, and the financial restrictions impeding redress.

In particular, with reference to their own processes, Botswana complaints body respondents noted that complainants may have difficulties relating to the tendencies of medical professionals to protect each other and in obtaining evidence sufficient to prove their cases. In relating the difficulties faced by complainants who experience abuse during childbirth one respondent remarked:

*“When evidence during the investigation to prove such a complaint becomes a challenge, I often encourage complainants to ‘be happy that they and their off-spring survived!’” (Complaints body respondent – Gaborone, Botswana)*

## Malawi

In Malawi, complaints body respondents most frequently stated that lack of knowledge and illiteracy were the most significant barriers to making complaints. Respondents further made repeated reference to fear of consequences as inhibiting complaints, particularly if the healthcare user would need to return to the same service-provider for care. These two factors – lack of information and knowledge on rights and complaints processes and fear of treatment withdrawal – were similarly cited by NGO and CBO respondents as being the most significant barriers to healthcare users complaining of healthcare discrimination. In addition, many NGO and CBO respondents independently stated that Malawians tend to “suffer in silence”, inferring a cultural and political disinclination to complain.

Complaints body respondents further noted accessibility constraints in terms of distances to be travelled to lodge complaints and related financial expenses. Malawi complaints body respondents were open to offering examples of barriers internal to their own processes, including that there is insufficient support for complainants from complaints bodies and healthcare institutions as well as rights bodies. The Malawi Ombudsman respondent stated that the absence of the body’s enforcement powers – that respondents simply refuse to comply with its recommendations – was a barrier to complainants.

## Zambia

Ignorance of processes and rights were cited by all complaints body respondents in Zambia as being barriers to complainants seeking redress. Accessibility constraints were identified by respondents as including the costs associated with complaining, distances from complaints bodies, and language barriers. One complaints body respondent noted that healthcare users may fear secondary victimisation by nurses if they complain. Barriers identified by the complaints body respondents as internal to their complaints processes included difficulties in proving one’s case due to healthcare workers being protective of one another and that complainants are likely to experience undue delay in their cases being disposed of.

In contrast, NGO and CBO respondents tended to emphasise structural barriers as inhibiting

access to accountability and redress for healthcare discrimination. These respondents mentioned barriers that included the absence of a legal and policy framework on healthcare complaints, narrow communication channels, and failures to equip complaints bodies with knowledge and skills sufficient to fulfil their mandates.

## 7.3 Strategies for change

### Legal and policy reform

States are obliged under international human rights law to ensure that legal frameworks are in place domestically to give effect to human rights guarantees.<sup>398</sup> In the legal and policy frameworks in Botswana, Malawi and Zambia set out in Chapter 4, discrimination is outlawed constitutionally in all three countries in broad terms. Efforts at reform may focus on the following issues:

- It may be useful to develop a direct prohibition on discrimination in the context of healthcare and to particularise the prohibition on discrimination to grounds that include discrimination on the grounds of health and HIV-status, gender, sexual orientation, occupation, socio-economic status, and rural location.
- It was strongly emphasised by sex worker and LGBT respondents that perceived criminalisation of their work and sexual orientations respectively stood as the most rigid barriers to effective healthcare access and access to justice.
- In all three countries, the obligations on healthcare workers not to discriminate against healthcare users, including on the grounds mentioned above, needs to be clarified, and which protections should extend to preserving the confidentiality of not only healthcare users' health status, but also their personal information.
- To the extent that complaints processes are inadequate, legal and policy reform must ensure that these processes are transparent, accessible, independent and capable of providing meaningful redress for complainants. Such reform should include measures to enable complainants to access information, including their own medical records, to ensure their objective prospects of success in proving their case.<sup>399</sup>
- All complaints bodies need sustainable and adequate funding, guaranteed independence, and government support in order to execute their mandates. A statement from the NMBC respondent interviewed for this study is illustrative:

<sup>398</sup> See: article 2(2) ICCPR; Articles 2 (a)-(g) CEDAW. See, also: General Comment 3, note 68 above; RC General Comment No. 31, note 66 above, at para 7; Committee Against Torture *General Comment No.2, Implementation of Article 2 by States Parties* (24 January 2008); CEDAW *General Recommendation 28, The Core Obligations of States Parties under Article 2 of the Convention on the Elimination of all Forms of Discrimination against Women* (2010); Committee on the Rights of the Child *General Comment No. 5, General Measures of Implementation of the Convention on the Rights of the Child* (27 November 2003).

<sup>399</sup> See: *Zheludkov v Ukraine* (Decision of the Human Rights Committee) Communication No. 726/1996 CCPR/C/76/D/726/1996 (October 29, 2002), 35. Individual opinion by Ms Cecilia Medina Quiroga (concurring): "A person's right to have access to his or her medical records forms part of the right of all individuals to have access to personal information concerning them. The State has not given any reason to justify its refusal to permit such access, and the mere denial of the victim's request for access to his medical records thus constitutes a violation of the State's obligation to respect the right of all persons to be 'treated with humanity and with respect for the inherent dignity of the human person,' regardless of whether or not this refusal may have had consequences for the medical treatment of the victim."

*“The power dynamics between the Ministry of Health and the NMCB ultimately impacts negatively on health service delivery which by and large means the patient. Dependency on funding from the Ministry of Health also reduces the impact, efficiency and effectiveness of the Council which literally translates into reduced health outcomes for citizens. The current state of affairs in terms of control from Ministry of Health Headquarters has meant that conflicts abound and fragmentation of critical processes is a common occurrence. A case in point is the whole issue of registration and de-registration of nurses and midwives. There have been cases in which the NMCB has felt that nursing/midwifery ethics and professionalism have been breached and refuse to register a healthcare practitioner and the concerned individual takes the issue to the Ministry of Health who give favours and allows undeserving healthcare workers to continue to practice.”*  
(NMCB respondent – Gaborone, Botswana)

In all three countries, health system and facility-level complaints options are unclear and do not appear to have structured guarantees for independent decision-making. While these systems appear to offer higher availability and accessibility to complainants, protections for the safety of vulnerable complainants and efficiency measures need significant improvements.

In Malawi and Zambia, legal development has progressed to provide for more particular protections for persons with disabilities, while in Botswana, legislative and policy reform is urgently needed, as was acknowledged by the Office of Persons with Disability:

*“There is a need for a law addressing disability and policy regulating differential treatment, stigma and discrimination in both society and the public service.”* (Office of Persons with Disability respondent – Gaborone, Botswana)

## Educating and empowering healthcare users

In focus-group discussions, respondents generally displayed rich and complex understandings of discrimination, however many could not recognise what should be expected from healthcare workers and how to complain effectively when violations occur. Healthcare users, in particular key populations and vulnerable populations, need to be empowered with knowledge of their rights in relation to healthcare and how they might safely and effectively access systems for accountability and redress:

*“Botswana has well written rules and regulations that protect the rights of patients. Botswana as patients/citizens, however, are not conscious of their rights or clued up on the action to take if they receive inappropriate, inadequate service in health facilities.”* (NGO respondent – Gaborone, Botswana)

## Challenging culture

In Botswana and Malawi in particular, a variety of respondents cited cultural impediments to seeking accountability and redress against persons in positions of authority. Some studies have drawn links to political history, structure and culture as contributing to inequalities that sustain deference to justice-seeking behaviours.<sup>400</sup> In addition, to the extent that cultural beliefs inform prejudice towards key and vulnerable groups, advocacy efforts need to include strategies to challenge these cultural impediments, in order to strengthen accountability and redress:

*“[We need] more investment into building the awareness of citizens on their rights to health and proper treatment by healthcare service providers. Although this is slowly changing, Botswana generally show a tendency of not being vocal about their rights including in the key area of health.”*  
(Complaints body respondent – Gaborone, Botswana)

*“In Malawi people fear going to healthcare centres, they either suffer in silence or go to traditional leaders.”* (Civil society respondent – Lilongwe, Malawi)

## Empowering stakeholders

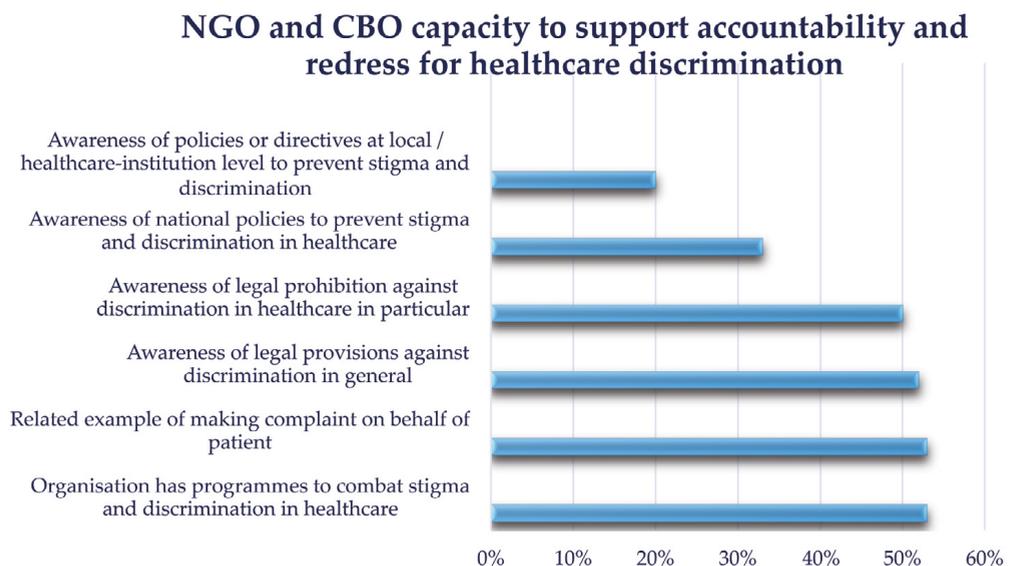
Based on interviews and questionnaires conducted with NGOs and CBOs in the three countries, over 50% had programmes in place to combat stigma and discrimination in healthcare. An equal proportion related examples of assisting beneficiaries to relate complaints of misconduct in healthcare. However, none interviewed for the present research related examples of making use of professional or human rights complaints bodies and all related disparate understandings of the processes for complaints internal to the health system or at facility level. These respondents displayed low levels and accuracy of knowledge on legal, policy, and ethical protections against discrimination in healthcare in particular whilst having generally clearer understandings of general prohibitions against discrimination. The information illustrates the value of capacity building for NGOs and CBOs to better support and assist beneficiaries to hold healthcare systems to account and to seek redress when discrimination occurs in healthcare settings.

In addition, several focus-group participants noted the importance of organisational support and having advocates who could be vocal on their interests, particularly when vulnerability to legal prosecution and abuse constrains vulnerable populations’ capacities to advocate on their own behalf. In Botswana, for example, sex worker respondents related frustrations relating to the refusal to register their sex worker organisation which makes it difficult for them to openly and effectively cooperate with health workers and the police. In Malawi, sex worker respondents stated that they needed organisational support and capacity building for sex workers to be able to represent and defend their own interests openly. NGO respondents in Botswana also stated that it is important for organisations representing the interests of key populations and vulnerable populations to work

<sup>400</sup> See, for example, NORAD Report. note 232 above, at 20, where it is described that despite a policy-level commitment to community participation and decentralisation in the Malawi healthcare system, the political imperative to maintain central control has led to implementation retreat from effective decentralisation and entrenched inequalities especially in gender and education status.

more effectively with organisations with broader healthcare mandates.

The graph below represents the results of information gathered from interviews conducted with and questionnaires sent to NGO and CBO respondents on their knowledge and capacities in relation to supporting beneficiaries to seek accountability or redress for healthcare-related discrimination:



## Educating healthcare providers and complaints body officers

The research identified a need to continue training and education for healthcare workers on stigma and discrimination in healthcare, on human rights, on the particular needs and vulnerabilities of diverse key populations and vulnerable populations, and on how ethical and legal obligations require healthcare workers not to discriminate in their work and to ensure that their conduct does not exacerbate healthcare users' vulnerabilities.

In all three countries, various respondents related the value of incorporating stigma and discrimination and key population training into the curricula of healthcare workers' training and to make these components examinable criteria, in order to ensure it is taken seriously. These recommendations came from all participants including health professions and nursing councils. Only one health professions council in Malawi stated that no further training or capacity-building was needed.

*"Ongoing training and capacity building is needed on what constitutes discrimination and stigma; some medical professionals do not take patient rights seriously." (Complaints body respondent – Gaborone, Botswana)*

*"[We] need more training of [healthcare workers] on stigma and discrimination in relation to persons with disabilities, regulated through*

*healthcare training institutes, including sensitivity to language.” (Complaints body respondent – Gaborone, Botswana)*

*“We need to have a meeting with senior medical officers to tell them the challenges that we are facing when accessing health services.” (Sex worker respondent – Mwanza, Malawi)*

*“We need more training and continuous training. [There is a] need to develop training modules on the issue and to incorporate [it] into [a] continuous professional development framework to enable nurses to gain points for their certification.” (Complaints body respondent – Lusaka, Zambia)*

National human rights institutions on the other hand illustrated good knowledge of human rights protections and concepts of discrimination. These bodies lacked experience in the healthcare sector, however. Officers may require capacity-building to enable effective handling of investigations and complaints determination on issues concerning healthcare discrimination.

## Other

In all three countries, NGO and CBO respondents working with sex workers and LGBT persons described activities to train and identify key population-friendly healthcare workers and/or to arrange for specialised health services to be provided for key populations in safe environments. These services, as an interim measure, are vital to sustain in order to ensure that key populations and vulnerable persons can sustain access to treatment and to encourage health-seeking behaviours:

*“We need our own clinic where we can be able to access all the healthcare we need as sex workers without any form of discrimination ... Pakachere has two clinics specific for sex workers which treats STIs, although they have not yet started providing [ART]. However we need more of such clinics.” (Sex worker respondent – Mwanza, Malawi)*

## 8. Recommendations

*This Report has found anecdotal evidence that key populations and vulnerable populations experience a variety of stigmatising and discriminatory behaviour in healthcare facilities and by healthcare workers in Botswana, Malawi and Zambia. Access to justice to hold healthcare institutions and personnel accountable and to seek redress for violations is restricted for those most vulnerable to abuse. The complaints bodies examined have the potential to provide some remedy to victims but certain contextual changes are vital to ensure that these systems can effectively fulfil the right to an effective remedy for persons who are discriminated against in healthcare and that healthcare users enjoy full respect for their human rights in a manner which is supportive of public-health objectives.*

### 8.1 Legislative reform

- The decriminalisation of consensual same-sex sexual acts in Botswana, Malawi and Zambia is an important step to removing barriers to access for LGBT persons.
- Criminal laws that are used to unlawfully target and harass sex workers and infringe on their basic human rights should be reviewed.
- Public health laws need to be reformed to include protections for complainants against secondary victimisation and service denial and to put in place clear procedures for handling complaints in the context of healthcare.
- Botswana should consider the adoption of comprehensive disability legislation and policy in line with the CRPD.
- Legislative reform should include the right of healthcare users to access their medical records immediately and without justification to ensure the integrity of health records and to ensure that complaints can be proven effectively where misconduct occurs.
- Botswana should consider the development of an independent national human rights institution to deal with human-rights related complaints and to conduct investigations into human rights violations.

### 8.2 Policy reform

- Policies and plans need to include commitments to end discrimination in healthcare, with particular measures to protect sex workers, LGBT persons, women living with HIV, and persons with disabilities.
- Healthcare-related policies should include budgetary and personnel commitments to enable available, effective and sufficient complaints processes for healthcare users to lodge grievances.

- Clear procedures for the referral of complaints that raise potential criminal conduct must be put in place to ensure effective and streamlined cooperation with policing.
- Facility-level policies and procedures that segregate and employ identifying practices against people living with HIV should be reviewed to ensure these practices do not contribute to stigma and discrimination and treatment avoidance.
- Policies in all three countries need to be reviewed and clarified with respect to the entitlement of healthcare users to access HIV and STI services alone or with a partner of their choosing.
- Policies with respect to accessing PEP (in Zambia in particular) need to be reviewed and/or clarified to ensure that key populations and vulnerable persons can access PEP timeously, safely and without the risk of secondary victimisation.
- At all levels of health management, policies must be developed and enforced to ensure that persons with diverse disabilities can access healthcare services independently and with due respect for their dignity, safety and right to informed consent and information.

### 8.3 Development of ethical standards and guidelines

- Professional ethical standards of conduct for healthcare workers must be updated to include concepts relating to discrimination and to address the particular forms of discrimination and healthcare needs experienced by key populations and vulnerable populations.

### 8.4 Training of healthcare workers

- Discrimination-inclusive ethical guidelines must be included in professional training and education curricula and must be made examinable to ensure trainees' commitment and capacity to uphold ethical obligations.
- Healthcare workers should be required to undergo ethical training that includes revised concepts and examples of discrimination for ongoing professional development. Curricular development should include consultations with vulnerable populations such as sex workers, LGBT persons, women living with HIV and persons with disabilities to ensure that their diverse needs and experiences are sensitively accommodated.

### 8.5 Improve the availability, effectiveness and sufficiency of complaints bodies

- Facility-level complaints processes in Botswana, Malawi and Zambia should be clarified and standardised to ensure the safety of complaints lodging for vulnerable persons, and to include measures to ensure the effectiveness and sufficiency as described in this report.
- Where facility-level or internal complaints processes are being developed, as with the ombudspersons at health facilities in Malawi, consultative processes should be held to ensure that the guidelines and terms of reference for these bodies provide appropriately for the safety of vulnerable populations, and that they are available, effective and sufficient.

- All complaints bodies should incorporate complaints-analysis processes to ensure that systemic problems are identified and that healthcare workers are supported to be responsive to concerns about discrimination.
- Information about complaints procedures and healthcare users' rights should be clearly displayed in health facilities, in a language and tone that is accessible, including to persons with disabilities. The information should include the name and contact details of the person at the facility to whom complaints can be made.

## 8.6 Capacity-building and education for healthcare users and key stakeholders

- Healthcare users and key stakeholders including NGOs, support groups, CBOs, community health networks and committees and paralegals should be trained on health rights and the use of complaints processes to support accountability and redress for discrimination in healthcare.
- Training of complaints body staff should include strategies to ensure the safety and protection of key populations and vulnerable populations.

## 8.7 Specialised health services

- To the extent that key populations and vulnerable populations are excluded from accessing health services safely and appropriate to their health needs, the provision of specialised services should be considered to ensure safe access to services in the interim. Any specialised services should be sensitive to the risk of stigma and discrimination that persons accessing such services might face and should develop operating procedures which eliminate such risks.

## 8.8 Further research

This report reveals many areas in which further research is required. A few issues in particular are noted:

- There is a need for more accurate and inclusive quantitative data on key populations and vulnerable populations discussed in this report.
- This report does not examine traditional medicine or traditional fora for complaints, and these areas require further research.
- The report reveals the need for further information from healthcare facilities and healthcare workers on issues relating to accountability and discrimination in healthcare.
- Further research and investment is required to understand the particular needs of other healthcare users not considered in this report who may be vulnerable to healthcare discrimination and difficulties accessing justice. This includes but is not limited to persons who use drugs, persons with mental disabilities, and children and the youth.

# Annexure one: Focus-group discussions' methodology

## Overview

Field work was conducted in Botswana, Malawi and Zambia between February and April 2016. During this time, 14 focus-group discussions were conducted with 211 participants.

Five focus-group discussions were conducted with lesbian, gay, bisexual and transgender (LGBT) participants with a total of 68 participants. Four focus-group discussions were conducted with sex workers with a total of 72 participants. Three focus-group discussions were conducted with persons with disabilities with a total of 36 participants. Two focus-group discussions were held with women living with HIV with a total of 35 participants. Participant recruitment was conducted through in-country NGO partners. Participant selection was based on self-identification with the relevant participant group. Figure 1 (below) shows the schedule of the focus-group discussions:

Figure 1: Schedule of focus-group discussions in Botswana, Malawi and Zambia

Location	Participant identity	Number of participants	Date	TOTAL
Palapye, Botswana	LGBT persons	6	12-Mar-16	<b>68</b>
Gaborone, Botswana	LGBT persons	7	20-Mar-16	
Lilongwe, Malawi	LGBT persons	20	1-May-16	
Kitwe, Zambia	LGBT persons	23	10-Apr-16	
Lusaka, Zambia	Transgender persons	12	12-Mar-16	
Selebi Phikwe, Botswana	Sex workers	16	18-Mar-16	<b>72</b>
Blantyre, Malawi	Sex workers	20	22-Feb-16	
Mwanza, Malawi	Sex workers	15	29-Feb-16	
Lusaka, Zambia	Sex workers	21	8-Apr-16	
Gaborone, Botswana	Persons with disabilities	9	1-Apr-16	<b>36</b>
Ndola, Zambia	Persons with disabilities	8	11-Mar-16	
Ndola, Zambia	Persons with disabilities	19	11-Mar-16	
Chiradzulu, Malawi	Women living with HIV	15	29-Feb-16	<b>35</b>
Kabwe, Zambia	Women living with HIV	20	22-Mar-16	
<b>TOTAL</b>				<b>211</b>

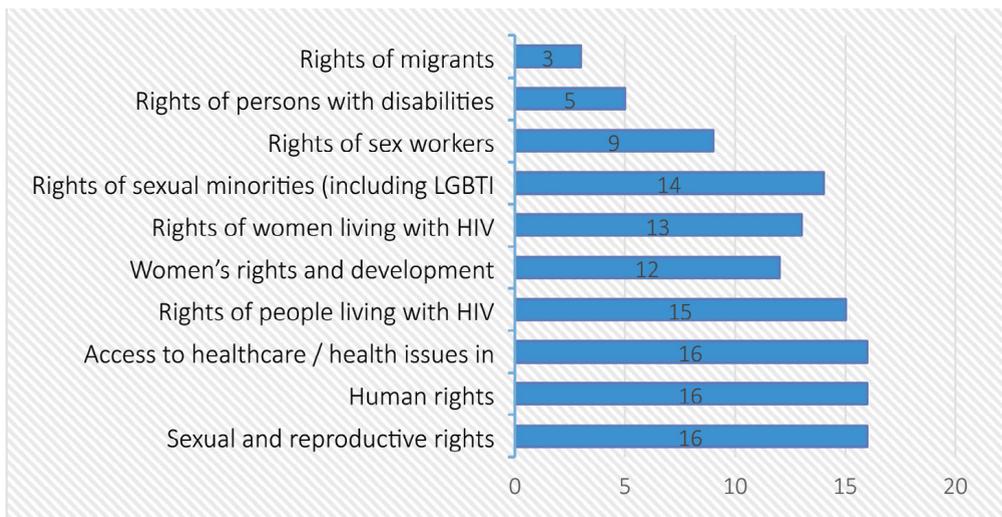
Facilitators worked off structured Focus-Group Guidelines and Terms of Reference. Informed consent was obtained from all research participants. Focus-group discussions were organised and conducted with in-country partner organisations (see acknowledgments), in order to ensure that the safety, dignity, and privacy of participants were protected. Participants were assured of the confidentiality of the information shared with researchers and were asked to respect the confidentiality of information shared by other participants in the focus groups. All researchers were required to, *inter alia*, inform research participants of the nature and purpose of the research and of their freedom to refuse to answer questions and cease participation at any stage, to protect the identities of focus-group participants, to ensure the security of data, and to destroy all personal details of the identities of participants in the research post-publication.

# Annexure two: NGO and CBO questionnaires and interviews

## Overview

A total of 16 in-person interviews were conducted with non-governmental organisations (NGOs) and community-based organisations (CBOs), and 25 questionnaires were completed by NGOs and CBOs in Botswana, Malawi and Zambia. Most of the respondents identified as national NGOs. Researchers were required to obtain informed consent from all respondents for the use of the information shared in publication.

## Issues that respondent organisations deal with<sup>401</sup>



<sup>401</sup> Some respondents indicated multiple issues, which accounts for duplications.

## Questionnaire

### Respondent Information

1. Country and region /province:
2. Your name (optional) and occupation (optional):
3. Name of organisation and department:
4. Your organisation's email/telephone number:
5. Which category best describes the sector you represent? (Please tick the relevant box).

a.	Government ministry or department	
b.	National AIDS council/coordinating body	
c.	Network or association of people living with HIV	
d.	United Nations agency	
e.	Inter-governmental organisation	
f.	Regional non-governmental organisation	
g.	National non-governmental organisation	
h.	Community-based organisation	
i.	Other (Please specify)	

6. On which of the following issues does your organisation work? (Please tick all that apply).

a.	Human rights	
b.	Access to healthcare/health issues in general	
c.	Women's rights and development	
d.	Sexual and reproductive rights	
e.	Rights of people living with HIV	
f.	Rights of women living with HIV	
g.	Rights of persons with disabilities	
h.	Rights of sexual minorities (including LGBTI and men who have sex with men)	
i.	Rights of sex workers	
j.	Rights of migrants	
k.	Other (Please specify)	

## Understanding of Stigma and Discrimination

1. Describe your understanding of “stigma” in a healthcare setting?
2. Describe your understanding of “discrimination” in a healthcare setting?
3. Do you consider the following instances of discrimination in the context of healthcare?  
(Please indicate Y for “yes” and N for “no”):

		Y/N
a.	Healthcare provider refuses to treat a patient.	
b.	Healthcare provider refuses to provide specific kinds of treatment to a patient (e.g. refuses contraceptive care).	
c.	Healthcare provider offers inferior treatment to a specific patient.	
d.	Healthcare provider refuses to touch a patient or uses excessive precautions.	
e.	Healthcare provider is physically rough or abusive to patients.	
f.	Healthcare provider uses harsh or abusive language.	
g.	Healthcare provider blames patient for health status or condition.	
h.	Healthcare provider/institution segregates certain patients.	
i.	Healthcare provider/institution employs identifying practices or distinguishes categories of patients by the use of publically visible markers (e.g. different coloured files for patients living with HIV, or separate queues).	
j.	Healthcare provider discloses the patient's status to other healthcare providers/patients/members of the public.	
k.	Healthcare provider does not adequately inform the patient of the medical intervention or does not conduct a thorough informed consent process?	
l.	Healthcare provider ignores patient.	
m.	Healthcare providers refer patient for HIV testing or treatment without counselling.	
n.	Healthcare provider unnecessarily refers the patient to other healthcare facilities.	
o.	Healthcare provider demands that patient undergoes HIV-testing before administering care.	
p.	Healthcare provider gossips about the patient to other healthcare providers, community members or patients.	

4. What are some other examples (not mentioned above) of discrimination in healthcare settings?

## Legal and Policy Framework

1. Are you aware of any legal prohibition in your country against discrimination in general? (If yes, please specify. If you don't know, please indicate.)
2. Are you aware of any legal prohibition in your country against discrimination in healthcare, in particular? (If yes, please specify. If you don't know, please indicate.)
3. Are you aware of any national policies in place to prevent stigma and discrimination in healthcare? (If yes, please specify. If you don't know, please indicate.)
4. Are you aware of any policies or directives in place at local/healthcare-institution level to prevent stigma and discrimination in healthcare? (If yes, please specify. If you don't know, please indicate.)
5. Are you aware of any government programmes (at any level) being implemented to combat stigma and discrimination in healthcare? (Please specify).
6. Does your organisation have any programmes to combat stigma and discrimination in healthcare? (Please specify).

## Complaints Mechanisms and Redress

1. If a patient experiences discrimination in healthcare, how could they make a complaint and with whom?
2. How efficient or effective are these complaints mechanisms? (Please mark with an X).

a.	Very effective.	
b.	Somewhat effective.	
c.	Inconsistently effective.	
d.	Seldom effective.	
e.	Never effective.	
f.	I don't know.	
g.	There are no complaints mechanisms.	

## Comments:

1. What are some of the barriers that patients may face in making a complaint?
2. If a patient approached your organisation complaining of stigma or discrimination in healthcare, how would you assist? Where would you direct their complaint? Or how would you advise them to seek assistance or redress?
3. What legal recourse does a patient have if they experience discrimination in healthcare?
4. What are some of the barriers patients may face in seeking legal recourse for discrimination in healthcare? (Please mark with an X).

a.	Too expensive.	
b.	Patients don't know their rights.	
c.	Legal assistance is unavailable.	
d.	Lawyers are not willing or able to take cases.	
e.	Patients are afraid of the consequences.	
f.	The legal system is too slow.	
g.	Patients can't access information to prove their cases.	
h.	Patients are involved in unlawful conduct that makes seeking legal redress difficult.	
i.	Other (please specify):	

## Addressing Stigma and Discrimination and Healthcare

1. What do you think needs to be done to effectively combat stigma and discrimination in healthcare?
2. Has your organisation undertaken any work to redress stigma and discrimination in healthcare? Please specify.

# Annexure three: Key informant questionnaires

## Overview

In-person, key informant interviews were conducted with eleven complaints bodies in Botswana, Malawi and Zambia. This included three national human rights institutions, three health professions councils, three nursing councils and organisations and one with the Office for People with Disability in Botswana. For standardisation, questionnaires were used by researchers to lead the interviews. Researchers were required to obtain informed consent from all respondents for the use of the information shared in publication.

## Questionnaire

### Respondent Information

1. Country and region/province:
2. Your name (optional) and occupation:
3. Name of organisation and department:
4. Your organisation's email/telephone number:

### Understanding Of Stigma And Discrimination

1. Describe your understanding of “stigma” in a healthcare setting?
2. Describe your understanding of “discrimination” in a healthcare setting?
3. Do you consider the following instances of discrimination in the context of healthcare?  
(Please indicate Y for “yes” and N for “no”):

		Y/N
a.	Healthcare provider refuses to treat a patient.	
b.	Healthcare provider refuses to provide specific kinds of treatment to a patient (e.g. refuses contraceptive care.)	
c.	Healthcare provider offers inferior treatment to a specific patient.	

d.	Healthcare provider refuses to touch a patient or uses excessive precautions.	
e.	Healthcare provider is physically rough or abusive to patient.	
f.	Healthcare provider uses harsh or abusive language.	
g.	Healthcare provider blames patient for health status or condition.	
h.	Healthcare provider/institution segregates certain patients.	
i.	Healthcare provider/institution employs identifying practices or distinguishes categories of patients by publically visible markers (e.g. different coloured files for patients living with HIV, or separate queues).	
j.	Healthcare provider discloses the patient's status to other healthcare providers/patients/members of the public.	
k.	Healthcare provider does not adequately inform the patient of the medical intervention or does not conduct a thorough informed consent process.	
l.	Healthcare provider ignores patient.	
m.	Healthcare provider refers patient for HIV testing or treatment without counselling.	
n.	Healthcare provider unnecessarily refers the patient to other healthcare facilities.	
o.	Healthcare provider demands that patient undergoes HIV-testing, before administering care.	
p.	Healthcare provider gossips about the patient to other healthcare providers, community members or patients.	

4. What are some other examples (not mentioned above) of discrimination in healthcare settings?

## Legal And Policy Framework

1. Are you aware of any legal prohibition in your country against discrimination in general? (If yes, please specify. If you don't know, please indicate.)
2. Are you aware of any legal prohibition in your country against discrimination in healthcare, in particular? (If yes, please specify. If you don't know, please indicate.)
3. Are you aware of any national policies in place to prevent stigma and discrimination in healthcare? (If yes, please specify. If you don't know, please indicate.)
4. Are you aware of any policies or directives in place at local/healthcare-institution level to prevent stigma and discrimination in healthcare? (If yes, please specify. If you don't know, please indicate.)
5. Are you aware of any professional standards, codes of conduct or ethical guidelines that govern stigma and discrimination in healthcare? (If yes, please specify. If you don't know, please indicate.)

6. Are you aware of any government programmes (at any level) being implemented to combat stigma and discrimination in healthcare? (Please specify)
7. Does your organisation have any programmes to combat stigma and discrimination in healthcare? (Please specify).

## Training

1. Do the healthcare workers that your organisation represents undergo any standard training relating to stigma and discrimination and/or patient rights? (Please specify details or note if not applicable).
2. Do you think that the healthcare workers require more training in stigma and discrimination and/or patient rights? (Please specify details.)
3. What needs to be done to create better opportunities for healthcare workers to learn more about stigma and discrimination and patients' rights?

## Complaints Mechanisms And Redress

1. If a patient experiences discrimination in healthcare, how could they make a complaint and with whom?
2. How efficient or effective are these complaints' mechanisms? (Please mark with an X).

a.	Very effective.	
b.	Somewhat effective.	
c.	Inconsistently effective.	
d.	Seldom effective.	
e.	Never effective.	
f.	I don't know.	
g.	There are no complaints mechanisms.	

## Comments:

1. What are some of the barriers that patients may face in making a complaint?
2. If your organisation has a complaints mechanism in place, how many complaints are received on average per year?
3. If your organisation has a complaints mechanism in place, what is its annual budget?
4. If your organisation has a complaints mechanism in place, how are patients and healthcare providers made aware of the services?
5. If your organisation has a complaints mechanism in place, how does it operate?
6. Who can file a complaint?

7. How is a complaint filed and where?
8. Who assesses the complaint?
9. Do patients have a right to appear before the complaints mechanism or to make representations?
10. Is a patient entitled to information on the status of their complaint?
11. On average how long does it take for a complaint to be assessed and determined?
12. What consequences or outcomes can come from the investigation into and determination of a complaint?
13. What is the purpose of a complaints mechanism?
14. How can accountability in the healthcare sector to practices of stigma and discrimination, be improved?





