Access to Justice for Healthcare Violations: BACKGROUND DOCUMENT

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Access to Justice for Healthcare Violations: Background Document
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About the Southern Africa Litigation Centre
The Southern Africa Litigation Centre (SALC), established in 2005, aims to provide technical and financial support 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 together with lawyers in each country who are litigating public interest cases involving human rights or the rule of law.

About the Africa Regional Grant on HIV
The Africa Regional Grant on HIV – Removing Legal Barriers is generously funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria. The grant addresses human rights barriers faced by vulnerable communities in Africa, and facilitates access to lifesaving healthcare. The grant is the first of its kind and covers 10 countries including Botswana, Côte d’Ivoire, Kenya, Malawi, Nigeria, Senegal, the Seychelles, Tanzania, Uganda and Zambia. The grant also works at continental and regional levels with the African Union and key Regional Economic Communities (SADC, ECOWAS, EAC) to promote alignment of national laws and policy with regional and international human rights commitments. UNDP is the Principal Recipient of this grant, in collaboration with four African civil society organizations – the AIDS and Rights Alliance for Southern Africa (ARASA), ENDA Santé, KELIN, and the Southern Africa Litigation Centre (SALC).

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ABBREVIATIONS

AIDS  Acquired Immune Deficiency Syndrome
AMSHeR  African Men for Sexual Health and Rights
ART  Antiretroviral treatment
AU  African Union
CAL  Coalition of African Lesbians
CBO  Community-based organisation
CEDAW  Convention on the Elimination of all Forms of Discrimination against Women
CRC  Convention on the Rights of the Child
CRPD  Convention on the Rights of Persons with Disabilities
HIV  Human Immunodeficiency Virus
ICCPR  International Covenant on Civil and Political Rights
ICESCR  International Covenant on Economic, Social and Cultural Rights
LGBT  Lesbian, gay, bisexual and transgender
NGO  Non-governmental organisation
SALC  Southern Africa Litigation Centre
STI  Sexually Transmitted Infection
UNAIDS  The Joint United Nations Programme on HIV/AIDS
UNDP  United Nations Development Programme
VCT  Voluntary Counselling and Testing
WCA  West and Central Africa
1. INTRODUCTION AND BACKGROUND

This Background Document aims to provide concrete recommendations to alternative complaints mechanisms on the ways in which they can provide safe, accessible and effective remedies for vulnerable and key populations who experience violations of their health rights. Alternative complaints mechanisms are, for the present purposes, understood as those processes identified to be able to receive and determine complaints relating to healthcare outside of formal court procedures.

These include:

- Healthcare regulatory bodies, such as health professions councils and nursing councils
- Decentralised complaints processes, such as complaints processes within ministries of health or health facility-based complaints mechanisms
- National human rights commissions and ombudspersons

This Background Document provides information on the rights to health, non-discrimination and access to remedies, the healthcare violations experienced by sex workers, gay men and men who have sex with men, transgender people, people who inject drugs and people with disabilities, and the factors which impact both on their vulnerability to abuse and their access to justice for healthcare violations.

It recognises the important role of alternative complaints mechanisms in advancing justice for vulnerable and key populations, and makes recommendations for adaptations these bodies can make in order to ensure accessibility, safety, efficacy and flexibility to address these barriers, alleviate fears and enforce justice.

This Background Document is based on the Southern Africa Litigation Centre’s (SALC) organisational experience in using legal processes to advance justice for health rights violations, as well as their more specific recent research and follow-up engagement with vulnerable and key populations, relevant non-governmental organisations (NGOs), community-based organisations (CBOs) and alternative complaints mechanisms in relation to health rights violations, during the period 2015-2017.

In 2015-2016, SALC conducted desktop research and qualitative field research in Botswana, Malawi and Zambia with selected vulnerable and key populations, namely lesbian, gay, bisexual and transgender (LGBT) persons, sex workers, women living with HIV and persons with physical disabilities, to understand their experiences of stigma and discrimination in healthcare and their experiences of seeking accountability or redress for discrimination.

The research included focus group discussions with over 200 participants across 3 countries, and around 50 questionnaires and interviews with NGOs, CBOs and key informants from institutions and organisations whose functions include the handling of complaints relating to healthcare and human rights violations.
SALC’s 2016 report of the research findings, *Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia* confirmed the findings of other pivotal research on health, HIV, human rights and key populations. Namely that vulnerable and key populations are not only disproportionately affected by HIV, they are also highly vulnerable to violations of their health rights and, by virtue of the same personal, legal, cultural, political, social and economic vulnerabilities are also less able to enforce their rights.1 Protecting and promoting human rights is not only an obligation upon all States, in terms of their international, regional and national commitments, but has also been shown to be an integral part of an effective response to HIV2.

The research findings and SALC’s subsequent follow-up engagement and capacity building with NGOs, CBOs and complaints bodies has reinforced the organisation’s understanding of the tremendous impact of healthcare violations on key populations’ access to health and the barriers they face in accessing justice. This work has confirmed the health and human rights imperatives for access to effective remedies, the vital role of alternative complaints mechanisms in promoting access to such remedies and the ways in which this is best done, to advance justice and promote health.

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2 *Id.*, *Risks, Rights and Health*. 
WHO ARE KEY POPULATIONS AND WHY ARE THEY CRITICAL TO THE HIV RESPONSE?

**Key populations:**

Key populations is a term that has arisen during the response to the HIV epidemic to identify groups who are more vulnerable or at risk of HIV infection due to their marginalised position in society and their lack of access to healthcare services. In the context of HIV, the Joint United Nations Programme on HIV/AIDS (UNAIDS) considers the main key population groups to be:

- Gay men & other men who have sex with men
- Sex workers & their clients
- Transgender people
- Prisoners & other incarcerated people
- People who inject drugs

These populations often suffer from punitive laws or stigmatising policies, and they are among the most likely to be exposed to HIV. Their engagement is critical to a successful HIV response everywhere. UNAIDS recommends that countries define the specific populations that are key to their epidemic and response, based on the epidemiological, social and legal context.

**Vulnerability:**

Vulnerability refers to unequal opportunities, social exclusion, unemployment or precarious employment (and other social, cultural, political, legal and economic factors) that make a person more susceptible to HIV infection and developing AIDS. The factors underlying vulnerability may reduce the ability of individuals and communities to avoid HIV risk, and they may be outside of their control. These factors may include:

- Lack of the knowledge and skills required to protect oneself and others
- Limited accessibility, quality and coverage of healthcare services
- Restrictive social factors such as human rights violations
- Punitive laws or harmful social and cultural norms (including practices, beliefs and laws that stigmatise and disempower certain populations).

These factors, alone or in combination, may create or exacerbate individual and collective vulnerability to HIV.

*See UNAIDS (2015) Termination Guidelines*

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HIV, HUMAN RIGHTS AND KEY POPULATIONS IN AFRICA

Sub-Saharan Africa is home to around 70% of the world’s population of people living with HIV, which amounts to around 25 million people living with HIV. Approximately two-thirds of all new HIV infections occur in sub-Saharan Africa.

Global and regional statistics show other significant disparities in who is affected across the region and within countries – differences between men and women, young and old and amongst specific vulnerable and key populations. UNAIDS estimates that key populations and their sexual partners account for more than 20% of new HIV infections in sub-Saharan Africa and more than 90% of new infections in the Middle East and North Africa. Vulnerable populations such as women, young people and people with disabilities, as well as key populations, are disproportionately affected by HIV, yet still struggle to access necessary, life-saving prevention and treatment services within many countries.

For instance, in sub-Saharan Africa, data shows HIV prevalence of more than 50% amongst female sex workers. In South Africa, for example, surveillance data published in 2015 estimated HIV prevalence among sex workers was 71.8% in Johannesburg, 39.7% in Cape Town and 53.5% in Durban. In Kenya, HIV prevalence amongst sex workers is estimated at between 29 to 47%, compared to the estimated 7% amongst the general population. In Swaziland, a cross-sectional survey of 317 sex workers showed an HIV prevalence of 70% amongst the sample.

Gay men and men who have sex with men are estimated to be 3.8 times more likely to be living with HIV than the general population. In 2012, the highest global median HIV prevalence rates amongst men who have sex with men were reported in Western and Central Africa (19%) and eastern and southern Africa (15%).

UNAIDS reports that transgender women are one of the populations most affected by HIV, being almost 50 times more likely to acquire HIV than other adults of reproductive age. Although studies in Africa are limited, research in Kenya and South Africa have confirmed higher risks of HIV exposure amongst transgender populations.

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5 Id.
7 Supra note 1, The Gap Report.
9 Supra note 6.
10 Supra note 8.
11 Supra note 8.
12 Supra note 1, The Gap Report.
13 Supra note 1, The Gap Report.
People who inject drugs are also disproportionately affected. In east Africa, in cities along the coastlines, studies from Kenya, Tanzania and Zanzibar suggest HIV-prevalence rates of over 30% in people who inject drugs. In Tanzania, people who inject drugs have HIV prevalence of 35%, despite declining prevalence rates of around 5.6% in the general population.  

Research shows that people with disabilities are at least as vulnerable to HIV, if not more so, than the general population. A 2012 survey in South Africa reported an HIV prevalence among people with disabilities of 16.7%, and a study among deaf people in Kenya indicated that nearly 7% were living with HIV. However, risk perception remained low: 78% of people with disabilities in South Africa felt that they were at a low risk of acquiring HIV.

Human rights violations are a fundamental driver of the HIV vulnerability and risk for key populations. Stigma, discrimination and human rights violations are argued to be one of the major barriers to HIV prevention and treatment, particularly where criminal laws combined with high levels of stigma, discrimination and human rights abuses marginalise key populations from society in general, as well as from crucial health services.

2. WHAT ARE THE RIGHTS OF PEOPLE LIVING WITH HIV AND OTHER VULNERABLE AND KEY POPULATIONS?

All persons have basic human rights set out in international, regional and national law.

The rights to non-discrimination and equality, dignity, privacy, health and access to an effective remedy for rights violations are all relevant to healthcare users, protecting them from acts of discrimination within the healthcare sector and promoting their health.

These broad rights are set out in various international and regional human rights instruments as well as national constitutions. These rights are also echoed in national laws, regulations, professional guidelines and codes of conduct, patient charters, government policies, strategies and plans which detail the rights of healthcare users, the duties of healthcare providers and the remedies available to healthcare users in the event of an infringement.

15 Supra note 8.
19 Supra note 1, The Gap Report.
21 Supra note 1, Risks, Rights and Health.
SOURCES OF HEALTH RIGHTS AND HEALTHCARE DUTIES

**International human rights instruments, e.g.:**

- International Covenant on Economic, Social and Cultural Rights, 1996
- Convention on the Elimination of All Forms of Discrimination Against Women, 1979

**Regional human rights instruments, e.g.:**


**National Constitutions**

**National laws, regulations, codes of conduct, professional guidelines and policies, e.g.:**

- Public health laws
- Health professions laws, regulations, guidelines and codes of ethical conduct
- Patient rights charters
- Health policies

This section examines the right to equality and non-discrimination; the right to health and the right to a remedy for human rights violations. It considers the scope and meaning of these rights for vulnerable and key populations in the context of access to healthcare and violations of the right to health. It considers issues such as:

I. the broad protection provided by non-discrimination and equality clauses which extends to vulnerable and key populations;
II. the special additional protection and prioritisation afforded to vulnerable and key populations;
III. the various elements of the right to health, which include non-discrimination, voluntary and informed consent and confidentiality; and
IV. the elements of an effective remedy for rights violations.

It should be noted that even if countries do not have the right to health within their national Constitution, the right still exists in international law. In addition, many violations within healthcare settings also violate other rights, such as the right to be treated with dignity, and the right to privacy, including the right to privacy of one’s personal information.

**KEY POINT**

Laws criminalising the actions of key populations – such as laws that criminalise soliciting for sex or laws that criminalise consensual same-sex sexual acts – do not negate the basic human rights of all citizens within a country. Vulnerable and key populations retain their rights, including their right to access healthcare without discrimination and the right to a remedy for human rights violations.
2.1 THE RIGHT TO FREEDOM FROM DISCRIMINATION

Under international law, Article 2(1) of the International Covenant on Civil and Political Rights (ICCPR) obliges States to respect the human rights of all individuals “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.”

Article 26 provides for the right to equality of all persons: “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 shall 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.”

Similarly, at regional level in Africa, Article 2 of the African Charter on Human and Peoples’ Rights (African Charter) provides for the right to freedom from discrimination and Article 3 creates a broad right to equal protection.

Although grounds such as HIV status and sexual orientation are not specifically mentioned in the non-discrimination and equality clauses, both international and regional African law have found that the prohibited grounds of discrimination are non-exhaustive. They have been held to include grounds such as health status (including actual or perceived HIV status), age, disability, marital or family status, sexual orientation and gender identity, and to apply to both direct and indirect forms of discrimination.

International and regional law also make provision for specific protection from discrimination for populations considered to be particularly vulnerable such as women, children and people with disabilities.

The Convention on the Rights of Persons with Disabilities (CRPD) provides for equality and non-discrimination for persons with disabilities. Article 5(2) states that “State Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.” Article 6 furthermore recognises that women and girls with disabilities are subject to multiple forms of discrimination and obliges the State to take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

Both the ICCPR and the International Covenant on Economic, Social and Cultural Rights (ICESCR) oblige States to ensure the equal rights of men and women to the enjoyment of their civil, political, economic, social and cultural rights. More specifically, Article 2 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) prohibits discrimination against women. CEDAW defines discrimination as “any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.”

Finally, Article 2 of the Convention on the Rights of the Child (CRC) provides young people under the age of 18 years with protection from discrimination on various grounds, including sex, disability or other status.

At regional level, the African Charter specifically protects women from discrimination in terms of Article 18(3). Furthermore, Article 2(1) of the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa (Maputo
Protocol) obliges States to “combat all forms of discrimination against women.” 31 Article 3 of the African Charter on the Rights and Welfare of the Child protects young people below 18 years of age from discrimination on similar grounds to those set out in the African Charter.32

Notably, the right to non-discrimination and the right to equality are both self-standing rights, as well as applicable to the enjoyment of all other human rights (such as the right to health and the right to an effective remedy) under regional and international law. All human rights must be enjoyed without discrimination.33

At national level, the national Constitutions of countries in Africa typically contain a non-discrimination and equality clause similar to those in international and regional human rights instruments.34

2.2 THE RIGHT TO HEALTH

All persons have the right to health. This includes, inter alia, the right to non-discrimination in access to healthcare, voluntary and confidential healthcare services and the prioritisation of vulnerable populations.

Article 12(1) of the ICESCR provides all persons with the right to “the enjoyment of the highest attainable standard of physical and mental health.” 35

In Africa, Article 16 of the African Charter provides that every person has the right to “the best attainable state of physical and mental health.” 36

Non-discrimination in healthcare

The right to health includes that healthcare services should be accessible to all people. The concept of accessibility requires States to ensure that health services are non-discriminatory, physically accessible, economically accessible, and that health information is accessible.37 Non-discrimination in access to healthcare requires that States ensure that health facilities, goods and services are “accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.” 38

International and regional law specifically provide for women’s rights to non-discrimination in access to healthcare. CEDAW provides that women and men have equal access to health and healthcare services, including equal rights to information regarding healthcare.39 Article 12(1) of CEDAW urges States to work towards the elimination of “discrimination against women in the field of healthcare in order to ensure, on a basis of equality of men and women, access to healthcare services, including those related to family planning.” 40 At regional level, in Africa the Maputo Protocol obliges States to “ensure that the right to health of women, including sexual and reproductive health is respected and promoted.” 41 Article 25 of the CRPD provides that people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability and obliges States to provide equitable healthcare, including reproductive healthcare, as well as to prevent discriminatory denial of healthcare services.42

33 Supra note 25.
35 ICESCR, supra note 27.
38 Id.
40 CEDAW, supra note 28.
41 Maputo Protocol, supra note 31.
42 CRPD, supra note 26.
Finally, it is important to note that while the right to health under international law is understood as being subject to “progressive realisation” – that is, the State is obliged to take measures within its available resources to provide healthcare services – the obligation not to discriminate in the provision of services, to provide those services equitably and to prioritise vulnerable and marginalised populations, is not subject to the same “progressive realisation”; it is immediately realisable.43

**Voluntary, informed consent and confidentiality in access to healthcare**

The right to health in the ICESCR includes the right to freely consent to medical treatment and the right to protection of confidential medical information.44 General Comment No. 14 also acknowledges that accessibility to health information should not impair the right to have medical information treated confidentially, and that all health facilities, goods and services must be designed to protect the right to confidentiality.45 The concepts of voluntary informed consent and confidentiality within the right to health, are further reinforced in both CEDAW and the CRPD. For example, Article 12(1), which includes the right to quality healthcare services under CEDAW has been interpreted to include the concept of voluntary, as well as informed consent to health services by the CEDAW Committee.46 The Committee recognised that acceptable healthcare services are “are those that are delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives.”47 Article 25(d) of the CRPD requires States to provide healthcare on the basis of “free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities.”48

### 2.3 THE RIGHT TO A REMEDY

Every person has the right to an effective remedy for violations of their rights.

The ICCPR provides for the right to an effective remedy in Article 2(3), obliging every State to “ensure that any person whose rights or freedoms as herein recognised are violated shall have an effective remedy….”49

The right to equality before the law under Article 14(1) further entitles all persons to a fair and public hearing by a competent, independent and impartial tribunal.50

At regional level, Article 7 of the African Charter provides that “every individual shall have the right to have his cause heard.”51 The Maputo Protocol requires States to “provide for appropriate remedies for any women whose rights or freedoms … have been violated.”52

The right to an effective remedy requires States to adapt remedies to take account of the special vulnerabilities of certain persons.53 States are furthermore obliged to ensure not only that remedies are available, but that they are accessible, in order to ensure that people are able to use these remedies.54 Processes must be affordable, accessible and provide sufficient information in order to enable rights-holders to enforce their rights.55

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43 Supra note 25.
44 General Comment No. 14, supra note 37, at para 8 and para 12.
45 Id. at para 12(c).
46 General Recommendation No 24, supra note 39.
47 Id at para 22.
48 CRPD, supra note 26.
49 ICCPR, supra note 22.
50 Id.
52 Maputo Protocol, supra note 31.
53 UN Human Rights Committee, General comment no. 31 [80], 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.
54 UN Human Rights Committee, CCPR General Comment No. 3: Article 2 (Implementation at the National Level), 29 July 1981.
55 Id.
3. HOW ARE THESE RIGHTS VIOLATED IN THE HEALTHCARE SECTOR?

Despite protections of the right to equality, non-discrimination and health, healthcare users report numerous experiences of stigma and discrimination in access to healthcare. This section of the Background Document reports on the stigma, discrimination and health rights violations experienced by sex workers, gay men and men who have sex with men, transgender people, people who inject drugs and people with disabilities.

3.1 WHAT IS STIGMA? WHAT IS DISCRIMINATION?

Stigma in general refers to public disapproval in society of specific groups of people or behaviours. Within healthcare settings, people face stigma and discrimination for a myriad of reasons linked either to their social status or health status.

UNAIDS describes HIV-related stigma as “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”. HIV-related discrimination is defined as 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 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.

3.2 EXPERIENCES OF STIGMA, DISCRIMINATION AND HUMAN RIGHTS VIOLATIONS IN ACCESS TO HEALTHCARE SERVICES

Denial of access to healthcare services

Vulnerable and key populations report being denied access to healthcare services altogether, as well as being refused specific healthcare services and being offered conditional access to services.

For example, SALC’s research found that sex workers, gay men and men who have sex with men, transgender people and people with disabilities reported being refused healthcare and being sent away by healthcare providers. Sex workers also report being denied access to specific services, such as access to contraceptives and to post-exposure prophylaxis in the event of an exposure to HIV, and gay men and men who have sex with men and transgender persons reported being denied treatment on the basis of their sexual orientation and gender identity.


57 Supra note 20.

58 Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia.
People who use drugs have also reported high levels of denial of access to services, including sexual and reproductive health services, impacting on their willingness to access healthcare.59 A survey in Seychelles with people who inject drugs found that 68% of respondents had been refused a service in the preceding 12 months,60 and another survey in Mauritius found that almost three quarters of people who inject drugs said that they had been refused services at some point.61

“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)62

“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)63

Sex workers, gay men and men who have sex with men and transgender persons also report being refused access to treatment for sexually transmitted infections (STIs) in the absence of a partner, making it impossible for them to access services (in the case of sex workers) or making them unwilling to access services for fear of further discrimination or being reported to the authorities (in the case of gay men, men who have sex with men and transgender people in criminalised contexts).64

Access to services is also made conditional upon various other factors. For instance, sex workers have reported that access to services is at times linked with sexual coercion.65

“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)66

59 Network of HIV Positives in Sierra Leone (2013) People Living with HIV Stigma Index Report: conducted research amongst key populations, with 60% of respondents identifying as people who inject drugs, over 50% being ex-detainees, around 15% identifying as a sex worker and 12% as men who have sex with men. The Report findings showed a persistent pattern of denial of healthcare services.


62 Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia at 59

63 Id at 98.

64 Id.

65 Id.

66 Id at 88.
Provision of inadequate healthcare services

Key populations also report that, rather than outright denial of access to treatment, they receive inadequate healthcare services at various facilities.67 SALC’s research found that violations appear to relate to intersectional grounds of vulnerability, such as sex, sexual orientation and gender identity, socio-economic status and disability, and include unnecessary delays in receiving attention, preferential treatment to certain healthcare users, failure to conduct proper examinations, undignified treatment, humiliating examinations and failure to provide adequate information. Sex workers report being ignored by healthcare workers for long periods of time in healthcare facilities. People with disabilities report being forced to wait, with no recognition of the difficulties they experience due to physical limitations. Other healthcare users describe healthcare practices of providing preferential treatment to relatives, friends and socio-economically empowered members of the community.68

Sex workers, LGBT persons and persons with disabilities also report undignified treatment, humiliating examinations or a failure to examine or communicate with them appropriately before prescribing medication. Some LGBT respondents relate experiences of healthcare workers refusing to properly examine or touch them, refusing to make eye contact with them and using excessive and humiliating precautions in their examinations.69

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)70

Persons using drugs are treated as criminals and they are sent to prison, but not given care or treatment… They are not offered HIV testing as they say they are not compos mentis.

(Civil Society Participant, Nigeria)71

Persons with disabilities complain of being treated like children or of being “invisible”, with no respect for their autonomy and sexual and reproductive health and rights. Women with disabilities report that their rights to have sexual relationships and found families are delegitimised by the discriminatory attitudes and actions of healthcare providers.72

When I was in Monze town one lady with a disability was made pregnant. At the hospital, the nurse said… [‘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.

(Person with disabilities respondent, Ndola, Zambia)73

67 Id. See also Supra note 1, Risks, Rights and Health.
68 Id.
69 Id.
70 Id at 99.
72 Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia.
73 Id at 115.
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.

(Person with disabilities respondent speaking about a peer, Gaborone, Botswana)74

Healthcare services also fail to prioritise and meet their specific needs as vulnerable and key populations. Sex workers report that their ability to access and adhere to anti-retroviral treatment (ART) varies because ART services fail to accommodate their circumstances (high mobility and variations in income), endangering their health.75 LGBT persons complain that healthcare services fail to provide specific services to meet their particular healthcare needs.76 People who use drugs are unable to access vital harm reduction services, such as needle and syringe exchange programmes, to reduce their risk of HIV exposure.77 Health information fails to accommodate the needs of people with visual and hearing impairments, resulting in limited healthcare information and treatment without adequate consent. Many services are not physically accessible to people with disabilities, nor do they receive the physical support they require from healthcare providers and facilities.78

Verbal abuse

Key populations report numerous experiences of verbal abuse from healthcare providers. They experience harsh and abusive language as well as blame for their health or HIV status. For example, sex workers, LGBT persons (in particular gay men and men who have sex with men) as well as people with disabilities report various forms of verbal abuse from healthcare workers, including mocking, derogatory and abusive language and being blamed for their health status.79

Physical abuse

Human rights violations within the healthcare sector extend, at times, to various forms of physical abuse. Women with disabilities, in particular, relate extreme forms of discrimination in access to sexual and reproductive healthcare services including physical abuse (e.g. slapping) during labour and childbirth.80

Sexual abuse and coercion

The SALC research found that sex workers experienced sexual abuse by healthcare providers as well as sexual coercion, in terms of which access to healthcare services is offered on condition of sex.81

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)82
Failure to obtain informed consent

Vulnerable and key populations report infringements of their rights to informed consent, including mandatory HIV testing, failure to conduct HIV testing without adequate pre-test counselling and a general failure to provide adequate health information in relation to testing, diagnoses as well as medical treatment.83 People who inject drugs in a Mauritius study reported instances of mandatory HIV testing.84 In SALC’s research in Botswana, Malawi and Zambia, people with disabilities report receiving inadequate health information and being treated like children, with limited respect for their autonomy and decision-making ability; sex workers have been subjected to mandatory HIV tests, and both sex workers and LGBT persons relate experiences of no, or inadequate pre-test counselling before HIV testing.85

“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)86

Failure to observe confidentiality

Key populations complain of breaches of their right to confidentiality with regard to their HIV status, health status, work, sexual orientation and/or gender identity. They also report how the practices of healthcare facilities – such as segregation of services, offering certain services at specific times, public announcements of services and other administrative practices that allow for the identification of their health issues - breach their rights to confidentiality.87 SALC’s research findings show that sex workers complained of healthcare workers talking about their HIV status within the broader community. Gay men and men who have sex with men reported breaches of confidential information regarding not only their health status but also their sexual orientation and gender identity. People with disabilities reported how the ways in which healthcare providers interact with them, both through the direct actions of healthcare providers and through their failure to accommodate the needs of people with visual, hearing and intellectual impairments, resulted in breaches of confidentiality.88

“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, Blantyre, Malawi)89

83 Id.; See also Supra note 56, Report of the Africa Regional Dialogue of the Global Commission on HIV and the Law.
84 Supra note 59.
85 Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia.
86 Id., 112.
87 Id
88 Id
89 Id., 90.
4. WHAT MAKES CERTAIN POPULATIONS PARTICULARLY VULNERABLE TO VIOLATIONS OF THEIR RIGHTS?

Research suggests that some people are more vulnerable than others to violations of their rights, including in the healthcare sector. Vulnerability impacts on the ability to access all rights in various, intersecting and mutually reinforcing ways. For instance, the factors that increase the vulnerability of certain populations, not only increase their health risks - such as the risk of HIV exposure – but also make them vulnerable to human rights violations within healthcare facilities, further deterring them from accessing their health rights.90 These same factors limit their right to an effective remedy, so that when vulnerable and key populations experience rights violations, they are also less able to access remedies for violations of their health rights.91

In this section the Background Document revisits the various factors that increase the vulnerability of populations such as sex workers, gay men and men who have sex with men, transgender people, people who inject drugs, and people with disabilities and how these factors impact on their rights to equality, non-discrimination, health and access to effective remedies.

These factors are critical to understanding why vulnerable and key populations find it difficult to access alternative complaints mechanisms, and how mechanisms can respond in order to accommodate their particular needs.

4.1 FACTORS THAT INCREASE VULNERABILITY

UNAIDS identifies a range of personal, social, cultural, political, legal and economic factors that impact on vulnerability in the context of HIV, such as:

» Personal factors
  e.g. a lack of knowledge and skills on how to protect oneself, limited access to quality healthcare and other services due to distance, cost or time required to visit healthcare facilities.

» Economic factors
  e.g. unequal opportunities, unemployment or precarious employment and poverty that limit access to quality healthcare services.

» Restrictive social factors
  e.g. stigma, marginalisation, social exclusion, discrimination and human rights violations that disempower certain populations.

» Legal factors
  e.g. punitive legal environments that criminalise the actions of certain populations or fail to adequately provide for their rights to equality and non-discrimination.

» Cultural factors
  e.g. harmful cultural norms and practices that stigmatise and disempower certain populations, increasing their vulnerability to harm.92

90 Supra note 1, Risks, Rights and Health.
92 Supra note 3, Terminology Guidelines.
4.2 **SEX WORKERS**

Sex workers 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.

Sex workers face exceptionally high levels of stigma, discrimination, violence, extortion, sexual abuse and rape in their daily lives, particularly from clients, intimate partners and law enforcement officials. In Ethiopia and Kenya, a survey found that nearly 60% and 79%, respectively, of female sex workers reported violence relating to sex work. Sex workers from Kenya, South Africa, Uganda and Zimbabwe reported how high levels of stigma dissuaded them from disclosing their occupation to health workers, thereby limiting their access to effective services, and impacted on their willingness to test for HIV.94 Submissions to the Global Commission on HIV and the Law’s (Global Commission) Africa Regional Dialogue from countries across Africa (including Botswana, DRC, Kenya, Mozambique, Namibia, South Africa and Zimbabwe) reported how other law enforcement practices, such as arbitrary detention and arrests based on condom possession, deterred sex workers from accessing condoms and placed them at risk of HIV infection. Sex workers also reported how criminal laws and harsh law enforcement practices deterred them from seeking redress for violations of their rights. These rights violations increase their vulnerability and also impact upon their health rights, placing them at increased risk of HIV.95

Aspects of sex work are criminalised in around 35 African Union (AU) Member States.96 The criminalisation of aspects of sex work is inextricably linked to the marginalisation of sex workers. The isolation of sex workers, caused by stigma, discrimination and violence, in conjunction with a criminalised environment which tends to fail to punish and even condones these human rights violations, exacerbate the barriers sex workers face in accessing legal support services and healthcare services.97

Activities related to sex work that are usually criminalised include living off the earnings of prostitution, procuration, brothel-keeping and persistently soliciting. 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 such offences is difficult to obtain and require police resources to enforce. Instead, sex workers themselves, instead of the persons who exploit them, are affected. Thus, although the act of selling sex is not criminalised, sex work in practice still takes place in a largely criminalised environment. Decriminalisation 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 will still be criminalised.

It should be noted that 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 the right to access healthcare services without discrimination. 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 dependants. This is not the case. The offence is specifically aimed at criminalising those persons who exploit sex workers, not sex workers themselves.98 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.

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93 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 and instead this document prefers to use the term "sex work" when referring to commercial sexual activities taking place between consenting adults.

94 Supra note 1, The Gap Report.

95 Supra note 1, Risks, Rights and Health; Supra note 1, The Gap Report.


97 Supra note 1, Risks, Rights and Health.

4.3 GAY MEN AND MEN WHO HAVE SEX WITH MEN

Sexual orientation refers to a person’s enduring pattern of emotional, romantic, and/or sexual attractions. One’s sexual orientation is not a choice and you do not choose to be homosexual (gay or lesbian), heterosexual or bisexual. Gay men are men who are sexually attracted to other men. Men who have sex with men is a broader term which refers to men who have sex with other men regardless of whether they define themselves as heterosexual, bisexual or homosexual.

Gay men and men who have sex with men also live in environments of stigma, discrimination and violence on the basis of their sexual orientation and sexual practices. A report by African Men for Sexual Health and Rights (AMShEr) and Coalition of African Lesbians (CAL) documented widespread homophobic violence in Africa, including physical violence (murder, beatings, kidnapping, rape and sexual assault) and psychological violence (threats, coercion and arbitrary deprivations of liberty). Violence took the form of attacks in public settings as well as abuse within families and communities, from political, religious and community leaders, media outlets and law enforcement agencies.99

SALC’s research confirmed widespread stigma and discrimination against gay men and men who have sex with men within the healthcare sector, coupled with their fear of seeking redress for rights violations within a criminalised and stigmatising context in which it is safer not to disclose information about their sexual orientation.100 These rights violations, as well as a lack of appropriate sexual health services, discourage gay men and men who have sex with men from accessing HIV prevention, treatment, care and support and place them at high risk of HIV exposure.101

"A friend asked me to escort him to get tested; he had make up on…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)102

A person’s sexual orientation or gender identity is not an element of any crime. 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. Over 30 AU Member States criminalise same-sex relationships in some way, often with penalties of up to 14 years imprisonment, life imprisonment and even the death penalty for those convicted.103 These punitive legal environments are combined with stigma, discrimination and high levels of physical, psychological and sexual violence, often committed or alternatively condoned by law enforcement officials and national authorities.104 Such acts are difficult to prove and few cases go to court but the existence of such offences lead to arbitrary arrests and discrimination. Importantly, these offences criminalise actual 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.


100 Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia.

101 Supra note 1, The Gap Report.

102 Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia, 97.


104 Supra note 1, The Gap Report; also supra note 99, Violence Based on Perceived or Real Sexual Orientation and Gender Identity in Africa.
BOTSANANA 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 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, whilst 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 whilst 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 indeed contrary to the principles of criminal law to criminalise persons’ status as opposed to their actions.

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:

1. When police bring men who had been arrested on suspicion of committing same-sex sexual acts to a health facility to obtain medical evidence of anal penetration.

2. 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 patients’ medical information are dealt with confidentially and that informed consent is obtained for medical procedures.

4.4 TRANSGENDER PEOPLE

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 the 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. Thus transgender is an umbrella term used to describe people whose gender identity and expression does not conform to the norms and expectations traditionally associated with their sex at birth.105

Transgender people face a multitude of barriers to the full recognition of their rights through the operation of the law, policies as well as the actions of their families, communities, broader society, healthcare workers and other service providers and law enforcement officials. They report being marginalised by their families and society from an early age and, later, by legal systems which fail to recognise their gender identity in personal documentation and non-official records. Research shows that the lifelong impact of this may often result in poverty, exclusion from society, homelessness and, in a significant

proportion of transgender people selling sex in order to make a living.\textsuperscript{106} Transgender people also experience high levels of harassment, abuse and physical and sexual violence throughout Africa. There are reports of extreme and vicious levels of violence directed at transgender women and lesbian women, arguably due to the multiple and intersecting layers of discrimination facing women in highly patriarchal African families and societies.\textsuperscript{107}

4.5 PEOPLE WHO USE DRUGS

Criminalisation of drug use, fear of arrest, harassment and the imprisonment of people who use drugs, accompanied by widespread societal stigma makes people who use drugs highly vulnerable to abuse within society.\textsuperscript{108} In Africa, individual drug possession and use is criminalised and highly stigmatised throughout the continent, with people who use drugs often facing discrimination on many levels.\textsuperscript{109} The legal environment also creates legal barriers to the provision of needle and syringe programmes and opioid substitution therapy.\textsuperscript{110} 68% of countries in southern and east Africa reportedly have drug laws that block the provision of harm reduction services such as clean needle and syringe exchange programmes.\textsuperscript{111} People who use drugs, in a 2013 legal environment assessment study conducted in the Seychelles, complained of brutality and extortion at the hands of law enforcement officials - making access to justice difficult, and increasing difficulties in accessing harm reduction services such as needle and syringe exchange programmes.\textsuperscript{112} The widespread stigma against drug use is further reflected within the attitudes of healthcare workers towards people who use drugs, discouraging access to healthcare services and further increasing vulnerability.\textsuperscript{113}

4.6 PEOPLE WITH DISABILITIES

People with disabilities are vulnerable due to their marginalised and stigmatised status in society as a whole, as well as due to poverty, limited access to information, education and healthcare services as well as their vulnerability to violence and sexual abuse.\textsuperscript{114} Research shows that children and adults with disabilities are at a higher risk of violence, including intimate partner violence and sexual abuse, increasing their vulnerability and risk of HIV infection.\textsuperscript{115} Barriers to access to appropriate and accessible healthcare services include the attitudes of healthcare providers towards people with disabilities (particularly in relation to sexual and reproductive healthcare), the limited accessibility of services to people with disabilities (e.g. services are physically inaccessible), as well as the limited provision for targeted services to meet their specific needs (e.g. health information for those with visual and hearing impairments).\textsuperscript{116} Research in eastern and southern Africa shows that national responses to HIV fail to effectively integrate the needs of people with disabilities,\textsuperscript{117} making them vulnerable to HIV exposure and increasing the impact of HIV on their lives, once affected. These same factors also act as barriers to access to remedies for people with disabilities.\textsuperscript{118}

\textsuperscript{106} Supra note 1, The Gap Report.
\textsuperscript{107} Supra note 99, Violence Based on Perceived or Real Sexual Orientation and Gender Identity in Africa.
\textsuperscript{108} Supra note 1, Risks, Rights and Health.
\textsuperscript{110} Id.
\textsuperscript{111} Id.
\textsuperscript{112} Supra note 60, Situation Analysis of Legal and Regulatory Aspects of HIV and AIDS in Seychelles.
\textsuperscript{113} Supra note 1, Risks, Rights and Health.
\textsuperscript{115} Supra note 1, The Gap Report.
\textsuperscript{116} Supra note 114, Disability and HIV Policy Brief.
\textsuperscript{117} Id.
\textsuperscript{118} Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia.
4.7 IMPACT ON ACCESS TO HEALTHCARE AND ACCESS TO JUSTICE

In summary, the Global Commission’s Africa Regional Dialogue found that stigma, discrimination and criminalisation placed people at increased risk of social marginalisation, violence and harassment, driving key populations underground and deterring access to healthcare services. Discrimination in healthcare was shown to inhibit or delay vulnerable and key populations from using services, taking HIV tests and disclosing important health information, impacting not only on prevention of HIV transmission but on effective treatment. Affected persons also report travelling to areas outside of their communities to access healthcare privately, resulting in breaks in treatment adherence.\footnote{119}{Supra note 1, \textit{Risks, Rights and Health}; also supra note 56, \textit{Report of the Africa Regional Dialogue of the Global Commission on HIV and the Law}; also supra note 56, \textit{Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia}.}

In addition, as a result of the context within which they live, vulnerable and key populations such as sex workers, gay men and men who have sex with men, transgender people, people who inject drugs and people with disabilities are often unaware of their rights, actions that constitute violations of these rights, and how to enforce their rights. Even where they are aware of complaints mechanisms, they may lack the capacity, ability, access to information and resources to use these mechanisms because of distance, cost, and literacy and, in the case of people with disabilities, the failure of complaints processes to accommodate their physical, sensory or intellectual impairments.\footnote{120}{Supra note 1, \textit{Risks, Rights and Health}; also supra note 91, \textit{Stigma Index Review: East and Southern Africa}; see also supra note 1, \textit{People Living with HIV Stigma Index studies}; supra note 56, \textit{Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia}.}

In addition, SALC’s research shows that key populations have a multitude of fears relating to their vulnerable position in society. They fear that confidential information (such as their sexual orientation and gender identity, their HIV status or their work as a sex worker) will be disclosed, resulting in further victimisation, violence, discrimination and even police action. They also fear harming their future access to healthcare. For instance, people with disabilities and other populations recounted fears of retribution and future denial of services from healthcare workers, particularly where there are limited available and accessible healthcare facilities. The power disparities between themselves, as healthcare users, and healthcare providers also creates a more general fear of challenging actions. This, coupled with previous experiences of limited success in using such mechanisms, engenders mistrust amongst vulnerable and key populations in the usefulness of seeking legal redress.\footnote{122}{Id.; see also supra note 91, \textit{Stigma Index Review: East and Southern Africa}.}

\begin{quote}
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)\footnote{123}{Supra note 56, \textit{Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia}, 101.} \end{quote}
Strengthened legal frameworks — including laws and policies that protect the rights of people living with HIV, vulnerable and key populations — coupled with effective systems, processes and support for accessing justice for human rights violations and enforcing rights, are thus critical to protecting the health rights of vulnerable and key populations. However, SALC found that vulnerable and key populations seldom use the court system for redress for various reasons ranging from fear and a lack of knowledge of rights, to the high costs, time delays, physical distances and expertise required to litigate cases in court.  

In addition to the courts, there are a range of alternative complaints mechanisms for health-related human rights violations in most African countries, where 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 or relate dissatisfaction in a healthcare setting. Relevant complaints mechanisms for purposes of this research include, amongst others, health system and facility-based complaints mechanisms, health professions and nursing councils, ombudspersons and national human rights institutions. This section briefly considers the location, nature, function and powers of these mechanisms, highlighting their potential to create effective remedies for vulnerable and key populations.

**EXAMPLES OF ALTERNATIVE COMPLAINTS MECHANISMS**

In Malawi, there are various alternative complaints mechanisms which may be useful for seeking redress for healthcare violations, including the following:

- **Health system and facility-level complaints mechanisms** such as
  - the head of a healthcare facility;
  - district health officers responsible for managing primary and secondary health facilities at district level;
  - Health Centre Advisory Committees made up of health workers and community members, set up with the aim of creating transparency and accountability on health facilities’ performance;
  - Village Health Committees set up to, amongst other things, facilitate community involvement in planning and monitoring health services; and
  - ombudspersons at hospital or at district level with the powers to receive and determine complaints from the public and healthcare workers.
Medical Council of Malawi, an independent statutory body with the power to exercise disciplinary control over the professional conduct of practitioners registered under the Act.

Nurses and Midwives Council of Malawi, an independent statutory body with regulatory powers over nurses and midwives, including the exercise of disciplinary control over their professional conduct.

Malawi Human Rights Commission, an independent body established in terms of the Constitution, vested with the responsibility to protect against and investigate violations of rights in the Constitution and other law. Its powers include the power to investigate issues, make recommendations of its own accord or on application of individuals and classes of people.

Office of the Ombudsman, a constitutional body tasked with investigating and litigating on government abuses or legal violations on behalf of individuals who lack other means of redress.

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 for victims of mistreatment.125

SALC’s 2016 research found that these bodies have valuable potential for improving accountability and redress for health rights violations for vulnerable and key populations. They are able to provide accessible redress for systemic violations (in the case of national bodies) as well as address individual grievances, prohibiting and deterring undesirable conduct by service providers. They may also provide an opportunity for healthcare facilities and governments to access information which is vital to improving 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 mechanisms can improve user confidence and citizen participation and improve service provider morale.126

For instance, SALC’s research found that internal and facility-level processes were best known - they were the bodies most frequently referred to all by research participants for making complaints – and were more available, being closer to communities and having less formal processes. They also offered the immediate prospect of individual disciplinary action against offenders as employees and direct redress to complainants, in addition to the prospect of system-level information and feedback and policy input.

Health professions and nursing councils were found to be less available, more formal in process with higher standards of evidence required and also narrower in scope, focusing exclusively on the management of their respective professions and tending to offer a narrow range of redress in the professional discipline of the particular healthcare worker. However, there processes appear to allow for more complainant input and participation. Given the impact of healthcare violations on the respondents’ willingness to access future healthcare services, many respondents expressed a preference for immediate and basic justice such as simply being able to assert their right to complain, a disciplinary sanction, corrective behaviour,

125 Id, 93.
126 Id.
access to health services and/or an apology from a healthcare provider. SALC’s research findings suggest that many of the types of violations experienced by individual key populations (e.g. verbal abuse by a healthcare worker) to be more appropriately remedied by these health-related complaints mechanisms rather than through a costly court process. 127

**National human rights institutions and ombudspersons** tend to be more available, in terms of their broad scope to investigate human rights violations, and the flexible manner in which information reaches the bodies and complaints can be made and determined. They also have high levels of institutional independence, which may support vulnerable and key populations in lodging complaints without fear of retribution or denial of access to services. In addition, national human rights institutions and ombudspersons are not prosecutorial in nature which may allow for better accommodation of security concerns of key populations. Additionally, where human rights violations appear to be part of a broader, systemic violation of people’s rights on the basis of particular grounds (e.g. their HIV status, sexual orientation or gender identity), national ombudspersons and national human rights institutions may have a critical role to play. Their investigatory powers to examine, report and make recommendations relating to systemic human rights violations have the potential to ensure national accountability, possibly through far-reaching changes to laws, policies and practices that impact on the rights of all key populations. A number of respondents in the SALC research noted their desire for remedies to include changes to relevant laws and policies, to strengthen a protective legal and regulatory framework.128

### 6. RECOMMENDATIONS

Strengthening access to justice for human rights violations serves both human rights and public health goals. It protects the rights of all healthcare users, encourages access to healthcare and reduces the risk and impact of health issues such as HIV and AIDS. Based on SALC’s 2016 research and other research findings, recommendations for strengthening the availability of complaints mechanisms for vulnerable and key populations, to make them accessible and safe, are set out below.

**WHAT MAKES A GOOD COMPLAINTS PROCESS?**

*The African Commission on Human and Peoples’ Rights set out 3 elements in order to realise the right to an effective remedy in Jawara v The Gambia: availability, effectiveness and sufficiency.* 129 Complaints processes are important tools to realise the right to an effective remedy when health rights are violated.

Broadly speaking, a good complaints process can be considered available if it is accessible and easy to use. Accessibility should include physical accessibility and safety concerns for vulnerable and key populations. Availability also requires accommodating user circumstances, considering factors such as literacy levels, access to telephonic communications, the diverse needs of persons with disabilities, language and cultural preferences. This requires multiple entry points for lodging complaints, including allowing for third party complaints and anonymous complaints. Ease of access also requires clear rules or processes on how reports are made.

*The effectiveness of a complaints mechanism can be measured by factors that provide a complainant with an objective prospect of success. This includes a complainant’s ability to access information about their complaint and to participate in the process. It also requires a complaints system that is transparent, independent and accountable.*

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127 Id.
128 Id.
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. The remedial powers of a complaints body are therefore important, together with the prospect of enforcement.\textsuperscript{130}

### 6.1 CLEAR, KNOWN RIGHTS, RULES AND PROCESSES

Complaints mechanisms should ensure that healthcare users have clear information on their rights as well as the rules and processes in place regarding how complaints may be made, to whom, what is required, the process that will be followed, the support that may be available during that process, and the possible outcomes of a complaint. Information about their rights, the complaints rules and processes should be available and accessible in various formats to accommodate the diverse needs of vulnerable and key populations.

**HOW DOES INFORMATION PROMOTE ACCESSIBILITY?**

Sex workers, gay men and men who have sex with men, transgender people, people who use drugs and people with disabilities are often not aware of their health rights and the actions that amount to a violation of their rights. Providing this information in a format that is accessible to all vulnerable and key populations – including people with disabilities who may need accommodation for visual, hearing and intellectual impairments – will greatly improve their knowledge of when and 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)

### 6.2 PROVISION FOR CONFIDENTIAL AND ANONYMOUS COMPLAINTS OR COMMUNICATIONS

Complaints mechanisms should make provision for both confidential as well as anonymous complaints processes. Confidential complaints allow complainants to provide personal information but to have their personal, identifying information kept safe and not to be disclosed during the course of the complaint. Their personal information should not to be shared with anyone not directly involved in handling the matter. Where complaints mechanisms require a complainant to appear in person to provide evidence, procedural rules can also provide for private, ‘in-camera’ evidence to be given to protect the identity of the complainant and create a private, safe physical environment to protect the confidentiality of a complainant.

Anonymous complaints allow the complainant to complain without providing personal information, or to provide personal information that is purposefully unlinked to the complaint itself.

\textsuperscript{130} Supra note 56, Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia.
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)

…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)

HOW DOES CONFIDENTIALITY AND ANONYMITY PROMOTE SAFETY?

Vulnerable and key populations are afraid that, by making public complaints, personal information about their health status, their sexual orientation and gender identity, their work or drug use, may be revealed during the process. They fear the possible social, economic and legal repercussions flowing from breaches of confidential information, including stigma, discrimination, secondary victimisation and police action.

For instance, people living with HIV may be afraid that their HIV status may be made public, exposing them to stigma and discrimination within their families and communities. Sex workers are may be fearful of their families finding out about their sex work or of clients finding out their health status. LGBT populations fear violence and social and economic marginalisation if their sexual orientation or gender identities are disclosed without their consent.

Sex workers, gay men and men who have sex with men, transgender people and people who use drugs may fear police action. They fear that they may be arrested, due to laws criminalising sex work, same-sex sexual acts and drug use, or subjected to harassment, violence and abuse by law enforcement officials who are in many cases themselves the perpetrators of violence.

Protecting anonymity and confidentiality will help to reduce the fears associated with laying a complaint and protect vulnerable and key populations from harm.

6.3 PROVISION FOR THIRD-PARTY COMPLAINTS OR COMMUNICATIONS

Complaints mechanisms should review their procedures to provide that an interested third party (e.g. a friend, family member, partner, community member or community support organisation) may lay a complaint on behalf of a healthcare user. This further helps to broaden access to complaints mechanisms for people who may be unwilling - due to fears for their confidentiality or safety - or unable to lay a direct complaint themselves.

131 Id, 92.
132 Id, 101.
HOW DOES THIRD-PARTY ACCESS PROMOTE SAFETY AND ACCESSIBILITY?

Vulnerable and key populations may be unwilling to make public complaints for the various reasons relating to their safety and confidentiality set out above. They may also fear reprisals from healthcare workers that limit their future access to healthcare. People with disabilities and other vulnerable populations recounted fears of retribution and future denial of services from healthcare workers, particularly where there are limited available and accessible healthcare facilities. They also referred to the power disparities between themselves, as healthcare users, and healthcare providers, as creating a more general fear of challenging actions.

In addition, vulnerable populations may be unable to lay a complaint themselves due to various barriers to access to complaints mechanisms. People with disabilities may experience physical barriers to access complaints mechanisms. For those living in poverty, literacy levels or limited access to telephonic communications may create barriers to reporting their complaints. Affected populations may experience difficulties in accessing evidence (e.g. medical records, expert evidence) to prove their complaints.

Allowing a third party to lay a complaint on behalf of another will encourage populations who wish to complain, but are afraid or unable to do so, to nevertheless register a complaint.

“I cannot take a doctor to court because I will suffer and may never seek health service again.”
(Person with disabilities respondent, Ndola, Zambia)

“The biggest issue is that we have fear. When a medical officer speaks we develop fear. Follow the supervisor.”
(Person with disabilities respondent, Ndola, Zambia)

6.4 PROVISION FOR MULTIPLE ENTRY POINTS FOR MAKING COMPLAINTS

Complaints mechanisms should provide complainants with various ways to communicate their complaints. In many cases, complaints mechanisms require a complaint to be made in writing, creating barriers for complainants who are illiterate or unable to write. Where provision is made for a range of entry points to make complaints – by telephone, in writing, in person – this extends access to complaints mechanisms.

133 Id.
134 Id., 116.
135 Id.
How Does Providing for Multiple Entry Points Promote Accessibility?

Vulnerable and key populations may experience various barriers to access complaints mechanisms caused by physical distance, low literacy levels and limited access to the means of communication. People with disabilities or those living in rural areas may find it difficult and expensive to access complaints bodies in person. Those living in poverty may not have access to telephones or the money for copies of medical records and other evidence. Populations with limited education may struggle to make written complaints. Persons with disabilities may face varied barriers in accessing complaints processes independently and confidentially. For example: hearing impaired persons may not be able to relate a complaint over the phone; visually impaired persons may not be able to put a complaint in writing in the format required and may struggle to access medical records.

Allowing for multiple avenues for reporting a complaint will enable populations to use the method which is most accessible to them in the circumstances, protecting their safety and promoting broader access to remedies. Support should be offered to assist complainants to make complaints where formal requirements for submission exist.

6.5 Interim Measures to Protect Complainants

Complaints mechanisms’ powers should allow for interim measures that act to allay fears and to protect populations from the potential negative repercussions that may arise during a complaint process. Interim measures can be undertaken as soon as a complaint is made, pending the outcome of the full investigation and decision. Interim measures may include, e.g.:

- Guaranteeing the confidentiality of personal, identifying information provided by a complainant during the course of an investigation.
- Orders barring contact between the complainant and the relevant healthcare provider alleged to be responsible for the human rights violation, if there is a risk of harm or denial of medical care to the complainant.
- Orders making it an offence to interfere with the duties of a complaints body, to prevent withholding of information or denial of access to healthcare services.
- Providing interim relief and interim remedies (e.g. access to urgent healthcare services) pending the outcome of a final decision.

How Can Interim Measures Protect Complainants’ Safety?

Research shows that fear consistently arises as a barrier to access to complaints mechanisms. Vulnerable and key populations express many fears around using complaints mechanisms. People living with HIV express fears of breaches of confidentiality with regard to their HIV status. People with disabilities express fears that they will not be taken seriously and that they will be denied urgent healthcare. Sex workers, LGBT populations and people who use drugs are afraid of arrests. Gay men and men who have sex with men and transgender people are afraid of secondary victimisation and discrimination.

The nature of healthcare complaints may also require urgent relief. For example, sex workers in Malawi have stated that they have been denied ART and post-exposure prophylaxis for preventing HIV transmission.\textsuperscript{136} If a complaint

\textsuperscript{136} Id, 84-91.
is made on such a case, it is vital that the complainant’s healthcare needs are urgently met to prevent grave harm before the issue is further investigated.

Many alternative complaints mechanisms have powers to issue interim orders or assist with interim measures that can protect vulnerable and key populations. For example, some health professions and nursing councils have powers to issue orders for interim remedies regarding access to necessary healthcare services while determining an issue. Complaints processes affiliated with the healthcare system may advise complainants and assist them to access urgent healthcare services.

In other cases, orders can be made to secure the confidentiality of a complainant. In some countries, the rules regulating the functions of ombudspersons may make it an offence to interfere with the ombudspersons’ duties, preventing healthcare workers from hiding information or from refusing healthcare to complainants.

In these ways, interim measures may help to overcome many of the fears and concerns that discourage vulnerable and key populations from accessing remedies and protect persons from immediate harm while a complaint is investigated.

6.6 BROADER ENGAGEMENT WITH VULNERABLE AND KEY POPULATIONS AND HEALTHCARE WORKERS

Over and above the practical measures complaints mechanisms can take to simplify and strengthen their procedures, broader efforts to engage with key populations and vulnerable populations are critical. This may include working with CBOs and NGOs to:

» **Create awareness** of the mechanisms and how they may be used.

» **Understand** experiences and common health rights violations of healthcare users.

» **Identify priority concerns** for accessing justice and how they may be managed within the complaints process.

» **Ensure constant feedback** and evaluation of successes and challenges with access to complaints mechanisms.

» **Build evidence** on the need for broader action beyond resolving complaints, such as strengthening education and training on the rights of vulnerable and key populations for key stakeholders (Key and vulnerable populations, alternative complaints bodies, healthcare workers) in the short term, including through mainstreaming in training curriculum in the long term, and on challenging discriminatory attitudes, reviewing ethical and professional codes of conduct and providing impetus to advocacy for the reform of punitive and discriminatory laws.

» **Promote ongoing dialogue** between populations and complaints mechanisms, to strengthen understanding of mutual concerns and to build relationships of trust.
WHY IS IT IMPORTANT TO BUILD ONGOING RELATIONSHIPS BETWEEN COMPLAINTS MECHANISMS, VULNERABLE AND KEY POPULATIONS AND SUPPORT ORGANISATIONS?

Research found that vulnerable and key populations had a range of requests for improving complaints mechanisms, beyond issues of creating safe and accessible remedies.

For example, vulnerable and key populations reported a general distrust of complaints mechanisms. This may be a result of a range of factors such as the power disparities between themselves, as healthcare users, and healthcare providers and authorities or it may stem from their experiences of limited success with previous complaints.

NGOs and CBOs noted the possible impact of power disparities, within a broader cultural context of deference to medical professionals, as impacting on the willingness of affected populations to complain about rights violations. Sex workers and LGBT persons related unsuccessful experiences with complaints mechanisms, and others related experiences of confronting healthcare workers directly regarding discriminatory treatment, with varying degrees of success. Respondents from complaints mechanisms in the SALC research furthermore noted the difficulties complainants may experience in the context of healthcare workers protecting each other. At a structural level, NGOs and CBOs have reported that complaints bodies have inadequate knowledge, skills and capacity to carry out their mandates.

Vulnerable and key populations also report that the limited support available to complainants to navigate the various complaints procedures, from support organisations (e.g. CBOs and NGOs) as well as from the complaints mechanisms themselves, creates further barriers.

It also appears that a complaints mechanism’s scope of redress is an important concern for vulnerable and key populations who wish for both immediate forms of redress as well as broader change. For example, LGBT populations argued for changes to discriminatory and punitive laws on same-sex relationships, and people with disabilities noted the need for training for healthcare workers to address discriminatory attitudes towards disabilities. Creating ongoing relationships with vulnerable and key populations and with healthcare workers will support broader engagement and promote mutual support and trust, beyond improving immediate access to redress.

7. CONCLUSION

Alternative complaints mechanisms are critical to advancing access to health and to justice for vulnerable and key populations. By taking measures to strengthen their procedures and practices, they can create safe, accessible and effective remedies to provide direct and immediate relief for healthcare violations. They can also support fundamental changes to discriminatory laws, policies and practices at facilities, health systems and even at national level, thus protecting and promoting the health and human rights of those most vulnerable to abuse.
RESOURCES


For further information and resources, please refer to:

Access to Justice for Healthcare Violations:
A GUIDANCE NOTE FOR COMPLAINTS BODIES

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