

POSITIVE HEALTH, DIGNITY AND PREVENTION IN MALAWI:

FINDINGS AND RECOMMENDATIONS FROM STUDIES
LED BY PEOPLE LIVING WITH HIV



Acronyms

ANC	ante-natal care
ART	anti-retroviral treatment
ARVs	anti-retrovirals
GIPA	the greater involvement of people living with HIV
GNP+	the Global Network of People Living with HIV
ILO	International Labour Organisation
MANET+	Malawi Network of People Living with HIV
M&E	monitoring and evaluation
NAC	National AIDS Commission
NACP	National AIDS Control Programme
NAF	National AIDS Framework
NSO	National Statistical Office
PLHIV	people living with HIV
SADC	Southern African Development Community
SRH	sexual and reproductive health
STI	sexually transmitted infection

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Overview

Malawi is a landlocked country with an economy highly based in agriculture. It is among the world's least developed countries and depends heavily on aid to meet development needs. Malawi is composed of three regions (the Northern, Central and Southern regions) which are divided into 28 districts and further into approximately 250 traditional authorities and 110 administrative wards.

Our people

- Almost 85 percent live in rural areas
- Average household size is 4.6¹
- Life expectancy is 54.2 years
- 46 percent of the population below the age of 15 years²
- Over 50 percent live below the national poverty line

The epidemic

Data from the 2010 Malawi Demographic and Health Survey (MDHS) shows that HIV prevalence in Malawi is still high and close to one million people are living with HIV. In 2010, 10.6% of adults aged 15-49 in Malawi were infected with HIV and HIV prevalence was also higher among women at 12.9% compared to men at 8.1%. HIV prevalence in urban areas is twice that of rural areas; with women in urban areas having an even high prevalence of 22.7% compared to their rural counterparts, with a prevalence of 10.5%. HIV prevalence in the southern region is twice that of the central and northern regions. There are approximately 600,000 children orphaned due to AIDS.

Progress

According to the *2012 Malawi Country Report*³ the period 2004 to 2010 saw a decline in the national HIV prevalence from 12% to 10.6%, however the number of new infections remains quite high. HIV prevalence among young people (aged 15-24) has been on the decline over the period 2004-2010 though for young people aged 15-17 HIV prevalence has increased. ANC data shows that prevalence of HIV in pregnant women has declined from 16.9% in 2001 to 10.6% in 2010. Substantial progress has been made in the provision of antiretroviral therapy (ART). In 2006, a total of 59,980 people had been started on ARVs. By the end of 2011, 67% of all adults and children in need of ART were receiving ART. AIDS mortality has decreased dramatically to 43,000 in 2011 and this is due to the success in the scale-up of the ART program that Malawi has been implementing since 2004 with support from the Global Fund.

Challenges

The 2012 Malawi Country Report also lays out some critical challenges. About 88% of all new HIV infections in Malawi are acquired through unprotected heterosexual intercourse and 10% via mother-

¹ Integrated Household Survey, 2010-2011-Malawi Statistical Office

² Malawi Population Data Sheet - USAID

³ 2012 Global AIDS Response Progress Report: Malawi Country Report for 2010 and 2011

to-child transmission. This has serious implications for women's vulnerability given the fact that due to issues of disempowerment and constructions of femininity and masculinity women are often unable to initiate, let alone negotiate, for safer sex.

In 2006 a Behavioural Surveillance Survey was conducted by the National Statistical Office (NSO) and it targeted high risk groups namely truck drivers, sex workers, fishermen, young vendors, male and female school teachers, male and female police officers and female border traders. All these high risk groups had much higher HIV prevalence than the national average of 14%, with sex workers having the highest prevalence of 70.7%. Another, smaller survey conducted among men who have sex with men (MSM) in Blantyre in 2007 found an HIV prevalence of 21.4%. However, recent studies looking at HIV prevalence among high risk groups are not available and there is no system which routinely collects such prevalence data. Overall, 17% of children aged below 18 years were either orphans and/or vulnerable.

National Laws and Policies

Malawi has actively responded to HIV since 1985, when it implemented a short-term strategy after the first AIDS case was reported. In 1988, the government created the National AIDS Control Program (NACP) to coordinate the country's HIV and AIDS education and prevention efforts. Initial responses were slow, however, as public discussion of sex and sexuality issues were limited. In 2000, a five-year national strategic framework to combat AIDS was implemented. The policy was slow to take effect, as financial and organisational difficulties within the NACP persisted. In 2001, the National AIDS Commission (NAC) was created. It has since overseen a number of prevention and care initiatives, including programmes to provide treatment, increase testing, and prevent mother-to-child transmission of HIV. A national HIV and AIDS policy was developed in 2003, laying down the guiding principles for all national HIV and AIDS programmes and interventions. The Extended National Action Framework 2009–2013 followed a National Action Framework for 2005–2009.

More recently, Malawi has also produced a comprehensive National HIV Prevention Strategy (2009–2013) with an implementation plan that seeks to consolidate all prevention interventions in one single coherent framework with clear management and implementation mandates. A number of key documents have been reviewed and developed: the HIV and AIDS Policy that has been reviewed and finalised and is awaiting approval; the National HIV and AIDS Strategic Plan (2011–2016); the Male Circumcision Policy; and, the new M&E Plan (2011–2016).

The money

The national health budget for 2012, announced at the end of 2011, is 45% higher than the 2011 budget in absolute terms.

The total annual budget dedicated to HIV and AIDS also increased from US\$98.1 million in 2010 to US\$113.51 million in 2011. The bulk of the annual budget goes to treatment, care and support which covered 46% in 2010 and increased to 66% of the total funding in 2011 based on the high ART levels with the change in initiation of ART from a CD4 of 250 to CD4 of 350. This was followed by prevention: in 2010 14% of the total expenditure was on prevention and this slightly decreased to 11% in 2011.

The national response to HIV and AIDS remains highly dependent on international funds. The donor partners to the Pool Funding Mechanism contributed 98% of the total value of receipts to NAC.

Human rights

As the *Human Rights Count*⁴ study states, Malawi does have laws that address specific human rights-related issues that arise in the context of HIV and AIDS. Notwithstanding some deficiencies, the Constitution of

⁴ Human Rights Count! Malawi: Country Assessment 2013, MANET+, 2013

the Republic of Malawi has guarantees on the human rights of persons infected and affected by HIV and AIDS. Section 20 of the Constitution guarantees the right to equality and non-discrimination on various grounds. Although HIV is not listed as one of the grounds for non-discrimination, section 20 has an all encompassing clause that proscribes discrimination *“on any other status”*. HIV status can be inferred as one of the grounds. Sections 16 and 19 of the Constitution provide for the rights to life and human dignity respectively. Section 30 of the Constitution provides for the right to health. There are also a number of laws that are crucial in the context of HIV and AIDS and human rights. These laws include: the Employment Act, the Penal Code, the Prevention of Domestic Violence Act, and the Deceased Estates (Wills and Inheritance) Act etc. Significant law reform activities are also ongoing, including, the development of the HIV and AIDS (Prevention and Management) Statute and the Gender Equality Statute and the review of the Prevention of Domestic Violence Act, and Laws relating to Marriage. In addition, Malawi has ratified critical international human rights instruments.

The proposed draft HIV and AIDS (Prevention and Management) Bill has provisions that protect persons infected or affected by HIV and AIDS from discrimination. Further, the provision guarantees the following human rights for persons infected or affected with HIV and AIDS: *“the right to a respectful and humane attitude on the part of society, entailing no humiliation of his right to dignity of his person, physical, integrity, life or health; the right to practice a profession of choice; the right to compensation associated with the restriction of his enjoyment of rights; and, the right to free medication, at the expense of the State at any State medical institution, necessary for the treatment of any HIV related disease ...”*.

The study concludes that Malawi has a relatively strong legal framework in relation to HIV and AIDS. The biggest challenge that arises is the effective enforcement of the constitutional guarantees and these laws and policies to ensure the optimal respect and fulfilment of human rights in the HIV and AIDS responses. This is evidenced by multiple human rights concerns that still remain in practice such as stigma and discrimination, and rampant violence against women and children, especially sexual violence.

Further research for the *Criminalisation Scan*⁵ found that, the body of laws that make up the protective environment is fraught with deficiencies that detract from the overall effectiveness of the enabling legal framework, especially in the context of women’s rights. Furthermore the legal framework also embodies some laws or legal provisions that are punitive and therefore retrogressive. Some of these legal provisions relate to the issues of: consensual same sex sexual relations; commercial sex work; criminalisation of deliberate HIV transmission; and aspects of the immigration law. Evidence shows that more often than not, such laws, while designed to regulate behaviour and therefore protect people, create barriers to health and interventions and outcomes and therefore become counterproductive. It is therefore imperative that these laws and provisions be revisited in order to create an optimal legal environment for an effective response to HIV and AIDS.

Health rights

In setting out principles of national policy in section 13, the Constitution places a duty on the State to provide *“adequate health care, commensurate with the needs of Malawian society and international standards of health care”*.⁶ The State is further obliged to *“achieve adequate nutrition for all in order to promote good health and self sufficiency”*.⁷ These principles of national policy and all the rights cited above are critical to ensuring the promotion of a rights-based approach in relation to prevention and management of HIV and AIDS.

⁵ Global Criminalisation Scan Malawi Country Assessment 2013, MANET+, 2013

⁶ Section 13 (c) of the Constitution

⁷ Section 13 (b) of the Constitution

Economic and Social rights

The issues of women's property rights and the dispossession of widows also become critical in the context of HIV and AIDS. As aptly noted by the special law commission on the development of the HIV and AIDS law, women are the worst victims with respect to property rights.⁸ Further that, a significant dispossession of property is subjected on women than men, with dispossession occurring in 40% of the cases compared to 20% for men.⁹

The employment sector both private and public has been severely affected by the HIV and AIDS epidemic due to declines in the levels of human resources in whom heavy financial and material investment has been made.¹⁰ The issues of concern under employment include: discrimination against employees living with HIV in the work place; HIV screening for employment; lack of appropriate prevention measures for occupational health and safety, including lack of adequate compensation for employees who are infected in course of employment; and, lack of clarity of employers' obligations in daily work place practices.¹¹

The law that addresses the issues of the rights and duties of employers and employees is contained in the Constitution, the Employment Act (Cap 55:01 of the Laws of Malawi), the Public Service Act, the Labour Relations Act, the Workers Compensation Act and the Occupational Safety, Health and Welfare Act. Sections 20 and 24 of the Constitution address the issue of discrimination, including discrimination in employment. Section 31 (1) of the Constitution provides the right to fair and safe labour practices and to fair remuneration. Furthermore, section 31(3) provides the right to fair wages and equal remuneration for work of equal value without distinction or discrimination of any kind, in particular on the basis of gender, disability or race.

The totality of the above legal provisions entrenches protection of persons from discrimination on the grounds of actual or perceived HIV status in the employment sector. In addition, the Workers' Compensation Act (cap 55:03 of the Laws of Malawi) provides for compensation for injuries suffered or diseases contracted by workers in the course of their employment or for death resulting from such injuries or diseases. The Act provides for a mechanism whereby workers who contract diseases in the course of employment are eligible to claim compensation from the employer. However under the scheduled diseases HIV and AIDS is not included. This might present a problem with respect to claims made by persons that may be exposed to HIV infection in the course of their employment. The Special Law Commission on the Development of an HIV and AIDS Law has recommended that the Workers Compensation Act be amended to include HIV and AIDS in the scheduled diseases.

Women and other key populations

In terms of protection of women's rights, Malawi has a constitution that proscribes gender-based discrimination in sections 20 and 24. Section 24 is more specific on the protection of women from discrimination on the basis of gender or marital status as follows: *"24(1) Women have the right to full and equal protection by the law, and have the right not to be discriminated against on the basis of their gender or marital status"*. Furthermore, gender equality is a principle of national policy as outlined in section 13 of the Constitution and Malawi has a policy on gender, currently undergoing review.

In addition, in March, 2013, Parliament enacted the Gender Equality Act. The new law makes provisions for measures for: the promotion of gender equality and the equal integration of men and women in all functions of society; the prohibition of, and provision of redress for, sex discrimination, harmful cultural practices and sexual harassment, including work place sexual harassment; and, provision for public

⁸ Page 48 of the report.

⁹ *Ibid*

¹⁰ Page 64 of law commission report.

¹¹ *Ibid*

awareness and promotion of gender equality. Most importantly, the Gender Equality Law makes an express provision for the right to access sexual and reproductive health services which is complimented by a right to information about sexual and reproductive health services to enable users of those services to make informed choices. This right, which is conspicuously absent in the Malawi Constitution is critical for women in the context of HIV and AIDS, as it creates a progressive framework for effectively responding to the social and structural factors that increase women's and girl's vulnerability to HIV.

Malawi has ratified the following major international human rights instruments: the United Nations Convention on all forms of Discrimination against Women; the Protocol to the African charter on human and peoples' rights on the rights of women in Africa; and, the SADC Protocol on Gender and Development. All these instruments provide for gender equality and accord women various human rights that are relevant in the context of HIV and AIDS.

However evidence on the ground demonstrates that existing laws and policies are not adequately protecting women from infection and empowering them for effective mitigation of the epidemic. It should also be realised that the effective response to these gender issues does not lie in the law and policy alone. A holistic approach would call for programmes aimed at challenging gender stereotypes in all spheres of life, the economic empowerment of women, and a strict enforcement of the relevant laws and policies.

Violence, including sexual violence, is one of the major problems faced by women and girls in Malawi, both within and outside marriage. Various laws in Malawi address the issue of violence including sexual violence, for example the Penal Code (Cap 7:01 of the Laws of Malawi) and the Prevention of Domestic Violence Act. The Penal Code creates the offences of rape, defilement, incest and sexual assault among others. Recently, the Penal Code has been amended to make the definition of rape cover situations where a female has sex with a male without his consent or where a male has sex with a male without his consent. Previously this was not an offence, and this posed a big challenge considering the increased reports of the sexual abuse of boys by women and men, which predisposes the boys to STIs, including HIV.

However, the major challenge with respect to the laws for the protection of women and girls from violence, including sexual violence arise in terms of the effective enforcement of these legal provisions by the police, and lack of public awareness that leads to underutilisation of these laws, with most of the offences going unreported. Where victims have come forth to report the offences, sometimes they have faced challenges that are inherent in the criminal justice system. For example, the lack of or limited victim-oriented approaches in the criminal processes has sometimes led to the failure by the victims to proffer evidence in courts of law which may lead to successful prosecution of the offenders. Effective enforcement of these laws has also tended to be undermined when the courts have failed to award stiffer penalties to perpetrators of these offences.

Sex workers are at risk of prosecution under Section 192 of the Penal Code that criminalises "any person who unlawfully or negligently does any act which is, and which he knows or has reason to believe to be, likely to spread the infection of any disease dangerous to life, shall be guilty of a misdemeanor". Recently, sex workers in Mwanza Province of Malawi were subjected to compulsory HIV testing and subjected to prosecution under section 192 of the Penal Code.

Human rights

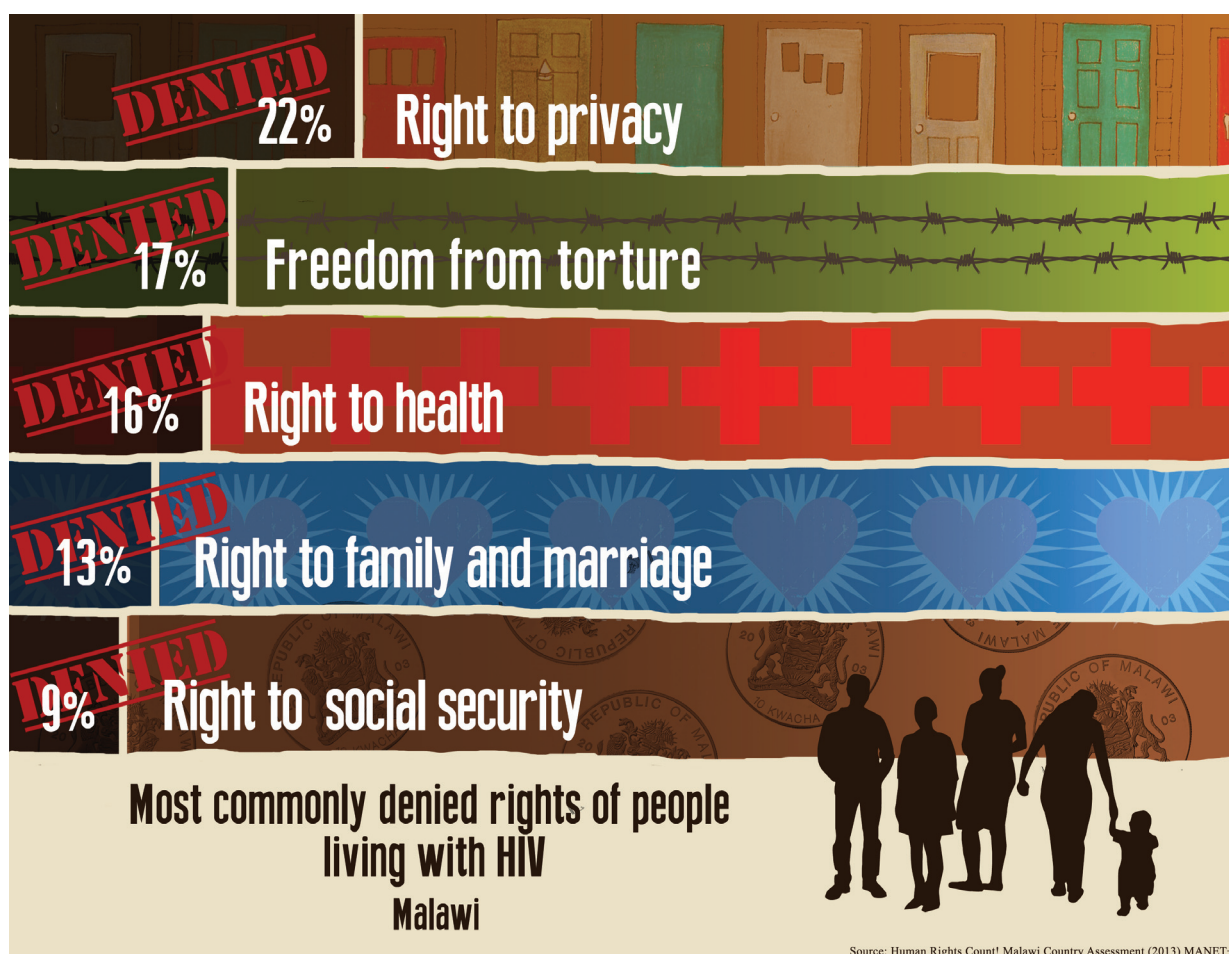
Rights, laws and policies

- Over three quarters of respondents had heard of the Government National HIV and AIDS Policy.¹²
- During the previous 12 months, 20% of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.
- Of the 20% of respondents whose rights had been violated in the previous 12 months, 70% had not tried to get legal redress, of whom 16% cited insufficient financial resources as the reason for this.
- In terms of the most important thing organisations should do to address stigma and discrimination, more than 40% cited advocating for the rights of all people living with HIV.

Source: 2012 PLHIV Stigma Index report

Violations and discrimination

Graphic 1



¹² HNational AIDS Commission (2003) Malawi National HIV AND AIDS policy. Lilongwe. Malawi ; accessible at http://data.unaids.org/Topics/Human-Rights/malawi_national_policy_en.pdf

The *Human Rights Count*¹³ recorded 327 human rights violations from 300 respondents, over three quarters of who were women. The majority of the respondents (78%) indicated that they were subjected to the human rights violation(s) in question on account of their HIV status. **Quite a significant number of respondents (28%) reported to have suffered the human rights violations at the hands of a person(s) who were acting in an official capacity.**

The right to privacy, the right to freedom from torture and other inhumane and degrading treatment, the right to the highest attainable standard of health, and the right to marry and found a family were the most frequently cited as violated rights.

A majority of the respondents reported that the violations of the right to privacy took the form of disclosure of one's status without his/her consent, in a manner that led to their being stigmatised and ostracised by the community. The violation of the right to freedom from torture and other inhumane and degrading treatment commonly manifested in the subjection of PLHIV to degrading treatment, for instance verbal abuse through ridiculing remarks. The right to the highest attainable state of health was reported as being violated in a number of ways including: not being provided with essential drugs in public hospitals, being treated in a degrading manner by medical personnel, and being refused treatment, e.g. to be given alternative drugs in order to avert serious side effects of the first line regimen. Women also reported instances of their ARVs being thrown away by their husbands. The right to marry and found a family was frequently reported by women as taking the form of being subjected to divorce on account of the women's HIV positive status.

While over half of the respondents indicated that they did not report the violations to authorities, quite significant numbers (39%) did. The violations were mostly reported to marriage counsellors, community elders, neighbours, chiefs (more community-based) and, HIV counsellors through support groups. Very few respondents indicated having the cases resolved by head teachers, courts or police (victim support unit). The most common reason for not reporting a violation was because they did not know that they could report it. Over 45% of respondents either did not think the existing laws and policies offered people living with HIV with protection against human rights violations or were not aware of the existence of relevant laws and policies.

Stigma and social exclusion

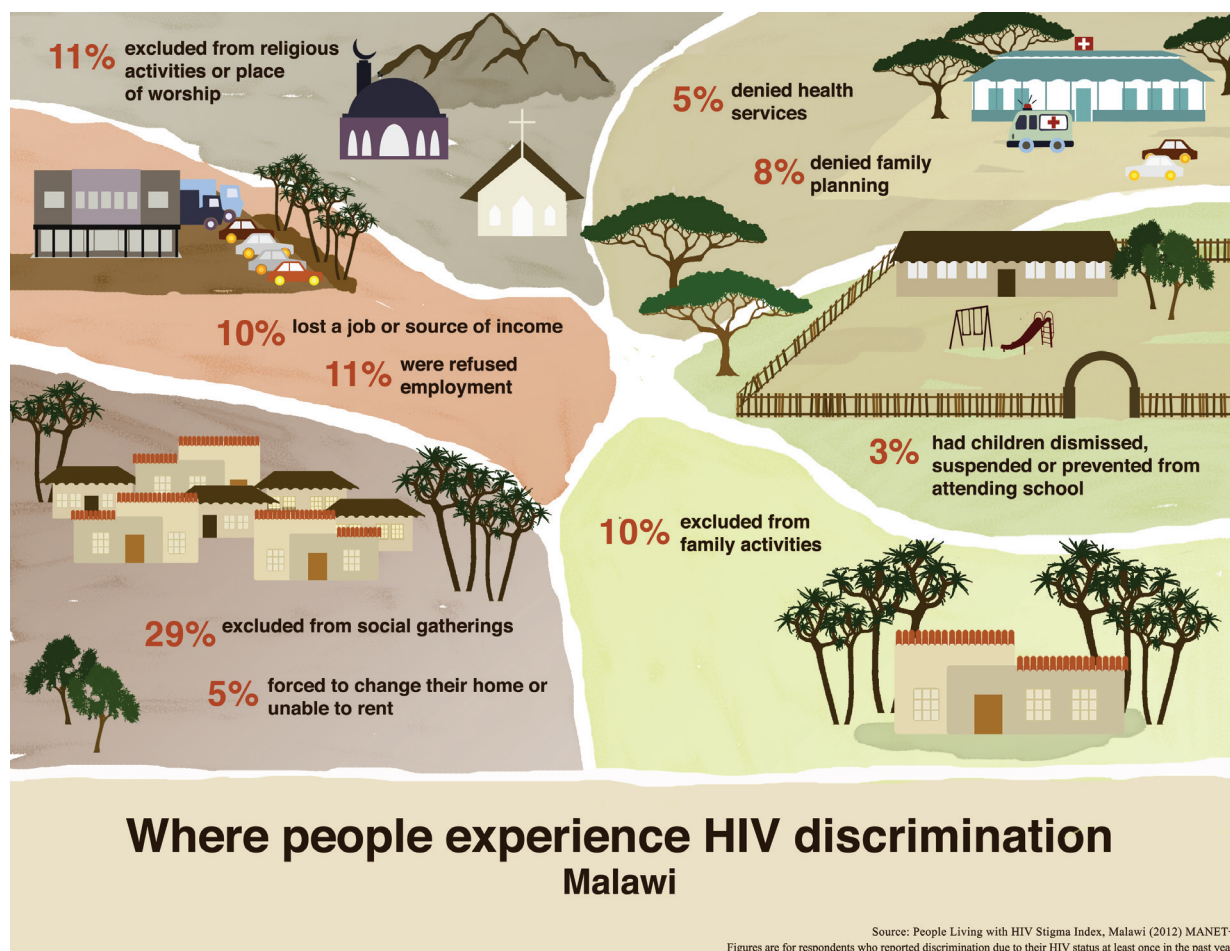
"I understand stigma because I do not talk about somebody; I talk about myself. Because I have gone through some difficult times and I have evidence. Stigma and discrimination exists. I do understand and I am able to see it because there comes times when they put a cross on your plate or your cup. When you ask for water you see that each time they bring you the same cup so that nobody else uses it. Or sometimes when you go to a funeral in the village you will see people eating together in groups of two and so on. You would think it's an honour when they say to you 'aah madam come and have your meal here freely'. You would think it's an honour and respect, not realising they are discriminating against you on the basis of HIV, with the perception that you will pass it on to them when you eat from the same plate"
Respondent in the *PLHIV Stigma Index*¹⁴

In the *PLHIV Stigma Index*¹⁵ study, respondents were asked about their experiences of stigma and discrimination in the previous 12 months and some of the results are depicted in the graphic below.

¹³ Human Rights Count! Malawi: Country Assessment 2013, MANET+, 2013

¹⁴ PLHIV Stigma Index Malawi Country Assessment 2010, MANET+, March 2012

¹⁵ *Ibid*



Other key points include:

- the most prevalent experience of discrimination was being gossiped about with 48% of respondents reporting that they had been gossiped about in the last 12 months, of whom 23% reported being gossiped about often.
- significant percentages of respondents also reported having been verbally insulted/harassed/threatened (35%); physically harassed (16%); and/or physically assaulted (17%) at least once in the last year
- internal stigma - the most frequently cited reactions were not to have children (50%), not to get married (25%), and not to have sex (21%). Internal stigma also affects access to health care: 2% avoided going to a local clinic or hospital when they needed care. In relation to study and employment: 9% withdrew from education or training, 8% decided not to apply for a job or a promotion because of their HIV status and 4% gave up their job.

Women's rights

The stigma research showed that women and men experienced discrimination differently. Overall male and female respondents experienced similar levels of discrimination across all the areas; however, female respondents were significantly more likely to have experienced physical harassment than men in the last 12 months (48% compared to 15%).

During the in-depth interviews, women narrated experiences of discrimination following disclosure to their husband and or his family. Cases abound in which wives were verbally insulted by the husband's family and subjected to psychological pressure where by their HIV status was used against them. By contrast, it was generally found that wives were more tolerant of their husbands' HIV status. Men felt able to live a "normal life" with their family and the community at large. Men depict their wives as understanding and accepting the results.

The *Human Rights Count*¹⁶ recorded that four times as many women reported violations of their human rights (89 women compared to 22 men).

The study also brought out the issue of gender inequality as a factor that compounds the vulnerability of women and girls to the violations of their rights on account of their status. For example, women reported instances of violations of their human rights arising from being blamed for HIV transmission, even in instances where they were infected by their husbands. In other cases, women reported being dispossessed of their inheritance following the death of their husbands. It is therefore important that interventions seeking to address the issue of violations of the human rights of people living with HIV should integrate gender. The study has drawn out several examples including instances of violations of women's human right to freedom from violence including sexual violence, e.g. being forced to have unprotected sex by their HIV positive husbands/partners, thereby exposing them to a risk of infection/re-infection.

Key populations

Research shows that members of key populations feel that the stigmatisation and discrimination that they face relates to their status as, for example, a current or former prisoner, an internally displaced person, a member of an indigenous group or their sexual orientation.

Empowerment of people living with HIV - the GIPA Report Card

What is Greater Involvement of People living with HIV (GIPA)?

The GIPA principle was endorsed by 192 United Nations member states in 2006. The origins of the GIPA principle started in 1983 in Denver (US), when people living with HIV first voiced and demanded that they should be included at every level of decision-making. This became known as the Denver Principles, and it states that:

“PLHIV be involved at every level of decision-making; for example, serve on the boards of directors of provider organizations, and participate in all AIDS-related meetings with as much credibility as other participants, to share their own experiences and knowledge”

The results of the *GIPA Report Card*¹⁷ were varied in terms of knowledge and awareness of the principle and more needs to be done to raise awareness among individuals and institutions. Although there have been meaningful efforts in Malawi to involve PLHIV in initiatives to combat HIV and AIDS, there are still challenges to be addressed. There is a need for more deliberate institutional policies to involve PLHIV in strategic decision-making processes.

The National AIDS Plan

While almost 60% of the respondents indicated that the GIPA principle had been incorporated in the National AIDS Framework (NAF), a quarter of the respondents did not agree that it had. And there was no clear consensus on whether PLHIV were involved in the development of NAF.

National GIPA Plan and Guidelines

Malawi does not have a national GIPA plan or national GIPA guidelines, however only 63% of the respondents knew this. Of those who believed the country had a national GIPA plan almost a quarter believed that it also had a dedicated budget.

¹⁶ Human Rights Count! Malawi: Country Assessment 2013, MANET+, 2013

¹⁷ GIPA Report Card Malawi Country Assessment 2011, MANET+, January 2012

GIPA at District Levels

Around 40% of respondents indicated that GIPA was being adequately implemented at district levels. Although half the respondents agreed that PLHIV were involved in district level structures and policy development, they observed that there was a lack of regional and local support and training for the PLHIV representative at these levels.

Universal Access

Only 8% of the organisations strongly agreed that they were familiar with UNGASS and Malawi's commitments to the HIV response. However, a majority were aware of targets to improve access to antiretroviral treatment. While 40% of the respondents believed that PLHIV were meaningfully involved in the process, many highlighted the need for greater public awareness of national and international targets. Irregular supply and poor quality of drugs as well as inadequate funding for health were identified as some of the major challenges in achievement of the targets.

Policy Development

While over 60% agreed that there is meaningful PLHIV involvement in national policy development a third of respondents disagreed with this. The vast majority of the organisations (86%) indicated that PLHIV are involved in the implementation phase.

Representation of Networks of People Living with HIV

48% of networks of men and women living with HIV stated being involved in the development of national level policy development. However, 29% indicated that they are not involved. Only 21% of the participating organisations indicated that the involvement of these networks in the development of national policy has been effective. Another 25% thought that the networks are not involved, and 54% indicated that they are not sure.

Employment of people living with HIV

The majority of the respondents indicated they do not have an employment policy for PLHIV. Less than half of the respondents were aware that the country had enacted legislation in line with the ILO Code of Practice for HIV and the world of work. Only 25% of the respondents thought PLHIV were meaningfully involved in the development of laws on workplace rights.

Barriers to Greater Involvement of PLHIV

Over half of the respondents indicated that the fear of or actual discrimination is one of the major barriers to involvement of PLHIV. Lack of adequate financial support was another barrier. Only a third of the respondents indicated that PLHIV are adequately paid for their involvement in the HIV response.

Health and Wellbeing

Treatment

Over 80% of respondents in the *PLHIV Stigma Index*¹⁸ study were taking ART at the time of the survey. Some 72% of respondents indicated that they were taking some medication to prevent or to treat opportunistic infections. According to the survey respondents, for those who accessed ART, their main concerns were confidentiality, hospital structures and health worker conduct when dispensing medications. The following quote from case study interviews elaborates one male participant's experience:

"Our hospitals are small structures. There are some people who would not want others to know that they are HIV positive. So, when we talk of confidentiality in our hospitals, it's not there because we use the same structures as those that do not know their status. This, again, facilitates stigma and discrimination"

Other factors mentioned affecting access were the distance that people had to travel to access care, shortage of staff and unreliable equipment – this was especially seen as an issue for people in relation to knowing their CD4 count.

Despite over half of respondents indicating that they discussed HIV treatment options with a health care professional during the last 12 months; 47% had not. Further, 56% reported that they have discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being and drug use with a health care professional during last 12 months; while 44% had not.

Prevention & Care

Testing and Counselling

Roughly a third of those people interviewed for the study said they had undergone HIV testing just to know their status. A further 19% undertook the test following the illness or death of partner/family member, while 15% were referred for HIV testing because they showed symptoms of the illness.

Over 80% of respondents indicated that their HIV test was completely voluntarily. **However a significant percentage (13%) reported that they were forced to take a HIV test and a further 2% indicated they were tested under pressure from others. Another 2% reported that they were tested without their knowledge.**

While over half of respondents received both pre- and post-test counselling; 2% received no counselling at all, a quarter received only post-test counselling, and 16% received only pre-test counselling.

Disclosure and confidentiality

Most respondents reported that they had felt pressured to disclose their HIV status by others. It was reported that is not easy to decide whether to disclose or not given that one is not sure how people would react. Disclosure was reported as requiring a lot of soul searching, and self preparation before taking that 'bold step'.

¹⁸ PLHIV Stigma Index Malawi Country Assessment 2010, MANET+, March 2012

Although 88% of participants agreed that disclosing their HIV status was an “empowering experience”¹⁹, some participants stated that following testing they shared the results with partners/spouses, who often did not support the decision and distanced themselves. Disturbingly, 10% of respondents said that a health care professional told other people about their status without their consent.

Sexual and Reproductive Health

In the *PLHIV Stigma Index*²⁰ study, 2064 respondents indicated that they had children. Of these, nearly one quarter had one or more HIV-positive children.

- Nearly three quarters of respondents indicated that they had received counselling on their reproductive options; while the remainder had not.
- Just under half of respondents had been advised by a health professional not to have children since being diagnosed HIV-positive.
- Over 10% of respondents reported having been coerced by a health professional into being sterilised since their HIV diagnosis.
- 7% of respondents said that their ability to obtain ART was conditional on the use of certain forms of contraception.

Female respondents were also asked about access to services to prevent vertical HIV transmission. 984 women who had been pregnant were asked about access to services to prevent *mother-to-child*²¹ transmission. **Of these, 380 indicated that they had received ART. Over one quarter indicated that they did not know that such treatment existed or that they did not have access to this treatment, while 6 women were refused such treatment.** The remaining women were not HIV-positive while pregnant.

Most of the pregnant women who received ART were also given information about healthy pregnancy and motherhood in order to prevent vertical transmission, however 38% reported that they were not given such information.

Other key populations

Among all respondents who reported a disability in addition to HIV-related ill health, 53% reported limited access to ART, and 46% reported limited access to medications to prevent or to treat opportunistic infections. When access to treatment was disaggregated by key populations, specifically people with disabilities, gay or lesbians, and prisoners:

- All three key populations reported lower percent of respondents taking ART at the time of the survey than the study population (87%) compared with people with disabilities (71%), gay or lesbians (77%), and prisoners (65%)
- All three key populations reported lower percent of respondents taking some medication to prevent or to treat opportunistic infections than the study population (72%) compared with people with disabilities (58%), gay or lesbians (67%), and prisoners (58%)
- All three key populations reported lower percent of respondents have discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months than the study population (56%) compared with people with disabilities (43%), gay or lesbians (50%), and prisoners (41%).

¹⁹ This response is within the context of the person having power over their disclosure- i.e. it was voluntary.

²⁰ PLHIV Stigma Index Malawi Country Assessment 2010, MANET+, March 2012

²¹ We have used the phrase ‘mother-to-child’ here as this is the way the question was phrased. More generally we prefer to use the term vertical transmission.

IN FOCUS: Sexual and reproductive health and rights of sex workers living with HIV in Malawi

In 2013, MANET+ carried out a study to explore the experiences, needs and concerns of female sex workers living with HIV in Malawi²². The study was conducted across four districts: Zomba, Mwanza, Nkhosokota and Mzimba.

Like any other Malawian citizen, sex workers' rights and freedoms are protected under the Malawian constitution. However the specific interpretation and application of the laws that speaks on prostitution are not clear in Malawi. *Section 146 of the Malawi Penal Code makes it an offence for a woman to live on the earnings of prostitution or influencing others to engage in prostitution while Section 147 criminalises the keeping of brothels.* The constitution does not recognise prostitution as an economic activity or a means of earning an income.

There is a great deal of confusion as sex workers are charged with soliciting money through illegal means. Furthermore, when women present themselves in the street at night, they are frequently arrested and charged with rogue and vagabond misconduct and not necessarily sex work. Considering the legal environment in Malawi, female sex workers work in a largely discriminatory setting where they are not protected by any legislation. Their social exclusion and the view that their actions are illegal act as a disincentive for the sex workers to access health and other important services, for HIV prevention and management.

HIV prevalence is very high among sex workers in Malawi. 71% were found to be HIV positive in a survey in 2006²³. Sex workers have been recognised as one of the key populations to the extent that the government, including its partners, have implemented different initiatives aimed at improving their health and wellbeing.

Human rights abuses

During the study, when asked to define human rights in their own understanding, sex workers living with HIV struggled to respond with a clear definition. However, they were able to narrate real life experiences where they felt their rights had been violated. They cited sexual harassment, being beaten by their clients, being forced to have unprotected sex, not being paid after sex, and other instances where their rights were grossly disrespected.

Female sex workers felt that they were perceived negatively in the community, hence, prone to living with abuse, stigma and discrimination. They gave many examples of abuse perpetrated by police, clients/bar patrons, other female sex workers and the community.

Abuse by Police

Some female sex workers report being coerced in to having sex with police officers. In cases where sex workers are arrested for rogue and vagabond misconduct, police officers sometimes take advantage of the situation by demanding sex in exchange for their release. Female sex workers have succumbed to such pressures because they feel terrorised and traumatised when picked up by the police.

²² Advancing Sexual and Reproductive Health and Human Rights Among Sex Workers Living with HIV in Malawi, 2013

²³ National Statistical Office, Behavioural Surveillance Survey. 2006, Zomba, Malawi: National Statistics Office.

“Sometimes when the police arrest us, they tell us to save ourselvesWe either have sex with them or sometimes when you have money, you give them and they release you”
(Sex worker from Mwanza)

“Usually police do not attend to us female sex workers, they say we are murderers....they say we spread diseases. Ironically when they catch you they usually ask to have sex with you for free.”
(Sex worker from Nkhotakota)

It also emerged that female sex workers who are HIV positive are often denied access to medication in police custody. Female sex workers observed that when they are arrested they are not allowed to take their medication despite police officers being aware of their medical needs.

“.....the other day I was arrested by the police, they tore my clothes and did not allow me to get my medication. I stayed there for three days without medication.” (Sex worker from Nkhotakota)

Condom Use

Despite an adequate level of coverage and distribution of condoms in areas where sex workers usually work, female sex workers have little power to negotiate for condoms.

The study found that some men would either tear the condom tip or remove the condom completely in the middle of a sexual act. This unsafe sexual practice not only goes against the will of the sex workers but it puts both the lives of the sex workers and clients at risk.

“We try our best to protect our lives and we always keep condoms but then sometimes temptations just come. For instance, a man would come demanding unprotected sex while you have no money towards a month end and you are yet to pay your house rent and electricity bills. He comes looking for unprotected sex at K6000 and if it were you, what can you do? If all was well, you could easily resist such offer....” (Sex worker from Mzuzu)

Condom use is low with clients with whom sex workers have regular sex and are in a form of “a relationship”.

Accessing health services

Sexual and reproductive health services are mostly accessed from hospitals. However, female sex workers living with HIV face some barriers when accessing these services, including: lack of drugs, negative attitudes, and abuse from health care workers.

Respondents found that female clinicians can appear both unfriendly and unconcerned with the problems of female sex workers. Female sex workers described female health care workers as impatient and unwilling to provide all the necessary attention when they present their problems.

“Female clinicians are hasty in their work. They just write down in your health passport book before you have finished explaining, they are already giving you back the health book. Sometimes they also just shout at us for instance, I was diagnosed with sexually transmitted infection and the female nurse started shouting at me saying ‘such a small child how come you have contracted this, why can’t you be like us.” (Sex worker from Mwanza)

“Some health personnel insult us and accuse us of bothering them as if we are not people. Some people even insult us.” (Sex worker from Nkhotakota)

The clinical experience is also characterised by some levels of mistreatment by male health care workers. In an extreme situation reported in Mwanza, male clinicians made fun of their client’s nudity.

“.....at certain times when we go to the hospital with a sexually transmitted disease, you were being told to lie on the bed, undress and when the doctors come he would start playing with your clitoris and then he would start making fun of it” (Sex worker from Mwanza)

Such experiences discourage female sex workers from accessing reproductive health services.

Economic and Social Rights

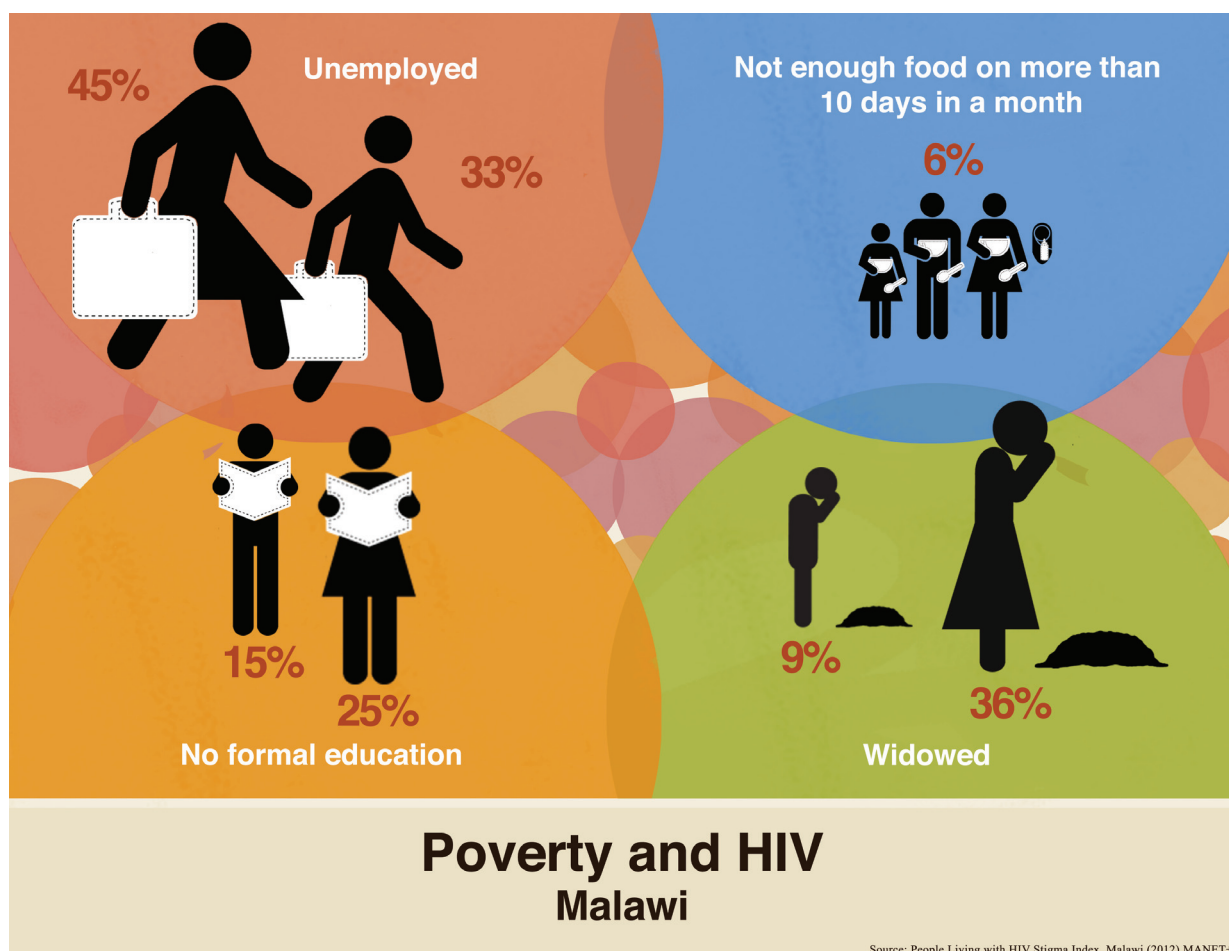
Poverty and unemployment

Poverty reduction strategies in Malawi have been in existence for two decades. The vast majority of respondents in the GIPA Report Card study agreed that such strategies existed. However, less than a third of the respondents indicated that PLHIV had input in the formulation of these policies.

Over 40% of people living with HIV interviewed for the Stigma Index were unemployed with nearly another quarter undertaking casual or part time employment (either self-employed or as an employee); and only just over one third in fulltime employment (either self-employed or as an employee). On average, the reported monthly income was K1416 (\$9) with some participants indicating that they were not receiving any money at all, and the highest monthly income was K185,570 (\$1237).

Over 80% of respondents reported children orphaned due to AIDS living in their household with 72% reporting between 1 and 4 orphaned children.

Graphic 3



Nutrition and food security

Almost three quarters reported that at least one of their family members did not have enough food to eat in the last month. A third reported severe food insecurity with at least one of their family members not having enough food for three or more days in a month.

Education

Over one in five had no formal education. Nearly half only had primary level, while another fifth had a secondary level education and less than 10% had a tertiary education.

Recommendations

Reform of laws/policies

- The Government of Malawi should ensure the comprehensive repeal of punitive laws in order to strengthen the protection of the human rights of people living with HIV or affected by HIV.
- The Government of Malawi should intensify efforts on HIV-related law reform, in particular by expediting the process of enacting the HIV and AIDS (Prevention and Management) Statute, and amending the Workers Compensation Act and the Occupational Health and Safety Act to cover HIV.
- Furthermore, the Government of Malawi should expedite the conclusion of the Constitutional Review process and expand grounds for non-discrimination to include HIV as one of the enumerated grounds for non-discrimination.
- The Government needs to develop deliberate policies to guide the implementation of the GIPA principle and support the active participation of people living with HIV in the development of laws, policies and guidelines; and in providing community-based services and support.

Addressing human rights violations, discrimination and stigma

- Civil society organisations including MANET+ must empower HIV-positive people to know and assert their rights, including by providing information and referrals to organisations and services that can assist them to seek redress in case of rights violations.
- Civil society organisations and donors must build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations and to develop and implement stigma and discrimination reduction programmes.
- The Government must prioritise HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, including support for scaled up implementation of promising programmes. HIV-related stigma and discrimination indicators should be included as part of the national AIDS response M&E systems to monitor and evaluate progress over time.

Prioritising women and other key populations

- Civil society must advocate for the expedited adoption of the revised HIV and AIDS Policy and the Gender Equality Policy.
- The Government must put in place a comprehensive legal framework for post-rape care protocols.
- MANET+ and other support organisations need to include outreach and services for key populations and ensure their meaningful involvement in programmes.
- All stakeholders need to work together to address the stigma and violations faced by female sex workers living with HIV and information on the rights of female sex workers living with HIV should be disseminated to the general public, the police, health care workers, bar patrons and sex workers' clients.

Respecting sexual and reproductive rights

- Given the low level but consistent pattern of denial of SRH rights to people living with HIV, including for young people and people with a disability, the Government must scale up the provision of correct information and appropriate options for the sexual and reproductive health for people living with HIV across all locations. This must include the integration of SRH and HIV services.

Access to comprehensive healthcare

- The Government must lead efforts to revise pre- and in-service training curricula and other protocols to enhance the capacity of health providers to provide non-judgmental and non-discriminatory services to people living with HIV, including key populations and people with disabilities.



Notes



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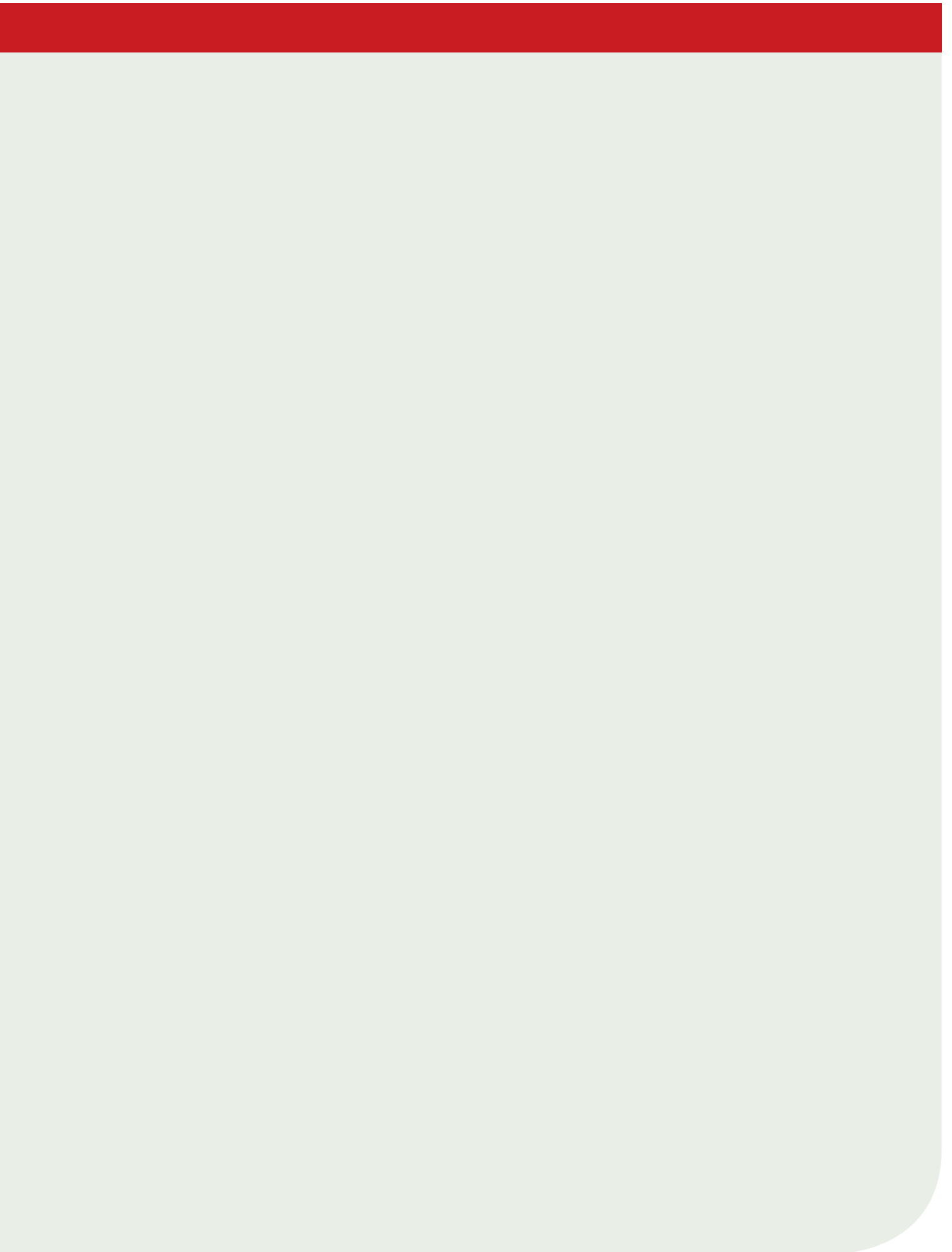
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