My right, my health

Supporting the development of an enabling legal environment for health and well-being in Malawi
The just rule of law is a critical social determinant of people’s health and well-being. The period from 2008 to 2018 saw fundamental shifts in the legal environment in Malawi for people living with, at risk of and affected by HIV. This case study examines the factors leading to change in Malawi, including the critical role played by civil society organizations, the inspiring advocacy of women living with HIV, the strategic dialogues among communities, parliamentarians and government representatives, and the technical assistance and high-level advocacy with the support of the UNAIDS Joint Programme.
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UNAIDS in Focus

The UNAIDS in Focus series features snapshots of the Joint Programme’s work enabling people living with and affected by HIV around the world to realize their human right to health.

UNAIDS advocates for a holistic, multisectoral approach to AIDS, with a long history of working across sectors and building multistakeholder partnerships. As a joint programme, it uniquely leverages the capabilities and comparative advantages of each of its 11 United Nations (UN) cosponsoring organizations (Cosponsors), as well as those of civil society, governments and other partners.

This series of case studies captures compelling stories of how Cosponsors, the UNAIDS Secretariat and a wide range of partners join forces to overcome challenges and build solutions at the country, regional and global levels to address the needs and protect the rights of people living with, affected by and at risk of HIV. The case studies depict a wide array of interventions that make a difference, such as creating a coalition of lawyers to provide pro bono services to defend people living with HIV from discrimination, implementing a partnership in South-East Africa to ensure the continuity of health services for communities suffering from drought, or supporting countries in western and southern Africa to scale up prevention and treatment coverage in countries lagging most behind in their response.

By using evidence-informed and people-centred approaches, UNAIDS acts as an advocate, convener and broker to address obstacles at the global, regional and country levels (including legal environments and social determinants) that are hindering access to essential, quality and sustainable care, treatment, support and prevention services.

The UNAIDS in Focus series shows how the Joint Programme puts its mission into practice, delivering results for people everywhere in order to achieve zero new HIV infections, zero AIDS-related deaths and zero discrimination.
Box 1.
Key milestones towards the elimination of discriminatory provisions in Malawi’s Draft HIV Bill

2008
Malawi’s HIV and AIDS Prevention and Management Draft Bill is introduced, including provisions that reinforce stigma and discrimination against people living with, affected by and most at risk of HIV.

2008
A national reference group on HIV and AIDS is established by the Malawi Department of Nutrition, HIV and AIDS to review the draft bill.

2011
The Assessment of Legal, Regulatory and Policy Environment for HIV and AIDS in Malawi is conducted by the Department of Nutrition, HIV and AIDS and the Department of Justice.

2016
UNAIDS organizes a dialogue entitled “Leaving No One Behind in the National Response to HIV and AIDS,” which leads to a parliamentary leadership decision to introduce a private member’s bill if the revised bill is not presented to Malawi’s Parliament at the next sitting.

March 2017
The President of Malawi announces that the draft bill will be tabled in Parliament with all of its discriminatory provisions.

May 2017
UNAIDS convenes a technical task force in consultation with the government, regional and national civil society organizations, the Southern African Development Community Parliamentary Forum, and the United Nations Independent Regional Think Tank for HIV, Health and Social Justice to review the draft bill and present recommendations to parliamentary leadership.

June 2017
The Minister of Health tables the bill, which retains its punitive and coercive provisions.

June 2017
Civil society organizations develop submissions to Parliament and publish press releases calling for Parliament not to pass the bill in its current form.

June 2017
UNAIDS convenes a meeting in Salima with the HIV/AIDS and Nutrition Parliamentary Committee to allow civil society organizations and community activists to voice their concerns about the bill.

July 2017

July – November 2017
Civil society organizations and activists develop advocacy strategies, work to legally empower affected communities and engage journalists to ensure that the voices of affected individuals and groups are heard.

November 2017
The then Executive Director of UNAIDS, Michel Sidibé, officially writes to the Minister of Health to advocate against the draft bill’s provision on “willful and malicious HIV transmission.”

November 2017
Women living with HIV and activists meet with parliamentarians to advocate against all human rights-infringing provisions in the bill.

November 2017
Parliament votes to remove many discriminatory provisions in line with the report of the HIV/AIDS and Nutrition Committee. It also votes against criminalization of “willful and malicious HIV transmission” in the presence of several women living with HIV.

February 2018
The President of Malawi endorses the revised bill.
HIV was first identified in Malawi in May 1985. Malawi’s HIV prevalence increased significantly in the 1990s, peaking at 15% in 1998 before starting to decline. Since 2010, annual new HIV infections have decreased by 30%, and deaths from AIDS-related illness have decreased by 55%. The number of Malawians accessing antiretroviral treatment has increased from a few thousand people in 2003 to more than 828,329 people by mid-2019, and Malawi is now on course to achieve the UNAIDS 90–90–90 targets by 2020.

Despite this remarkable progress, Malawi had approximately one million adults and children living with HIV in 2018. Lesbian, gay, bisexual, transgender and intersex (LGBTI) individuals, women and female sex workers are currently bearing the highest burden of the epidemic.

Malawi’s 2008 HIV and AIDS Prevention and Management Draft Bill was introduced in the context of prominent discussion about the need for HIV-specific laws. AIDS was—and still is—the leading cause of death in Malawi, and the draft bill addressed issues critical to an adequate response to the epidemic. This included the establishment of the National AIDS Commission (NAC) as an independent institution, as per international guidelines, in order to coordinate and facilitate the national response to HIV and AIDS. Other positive provisions included requiring health-service providers to conduct free pretest and post-test counselling for individuals tested for HIV, and making it illegal to deny a person access to health-care services based on their actual or perceived HIV status.

However, concerns were raised over the human rights implications of certain discriminatory provisions in the bill. For instance, the bill made HIV testing compulsory for both pregnant women and their sexual partners, allowed mandatory pre-employment testing for domestic workers and military personnel, and criminalized “willful and malicious HIV transmission.” The bill also made it permissible under certain circumstances for health workers to disclose the HIV status of patients without their consent.

Civil society organizations and human rights advocates warned of the potentially negative implications and health impacts of these provisions. They feared they would fuel stigma and discrimination, which would in turn reinforce the barriers encountered by vulnerable populations when attempting to access HIV prevention and treatment services.
Laws and policies: key social determinants of health

A country’s social, political, economic and legal environment plays an important role in influencing its capacity to prevent public health challenges and to respond swiftly and effectively to them when they do occur. A supportive legal environment for the AIDS response is one that protects all people, particularly the most vulnerable, from discrimination and stigma and exclusion. A protective and empowering legal framework can ensure access to health services for all and thereby generate positive health outcomes, foster people’s well-being and ultimately help safeguard human rights.

Numerous studies show that discriminatory laws tend to be counterproductive to health promotion. For example, evidence shows that criminalization of HIV transmission is not effective in controlling the epidemic, as it discourages people from seeking counselling, testing and treatment (1, 2). Compulsory HIV testing for pregnant women exacerbates their vulnerability to gender-based violence: because they are usually the first person in a relationship to be tested for HIV, women are often accused of being responsible for transmitting HIV to their partners (3). Mandatory testing in the workplace imperils the rights and dignity of workers, and it is often linked to involuntary disclosure and stigma and discrimination (4).

As discriminatory laws have been increasingly recognized as undermining the AIDS response, progress has been made towards building political commitment to remove legal barriers and create a more equal and just social environment. For instance, the 2016 Political Declaration on Ending AIDS calls for the elimination of all forms of HIV-related stigma and discrimination by 2020. Similarly, the UNAIDS 2016–2021 Strategy commits to working towards the removal of the punitive laws, policies, practices, and stigma and discrimination that block effective responses to HIV. This includes travel restrictions and mandatory testing, and the criminalization of HIV non-disclosure, exposure and transmission, same-sex sexual relations, sex work and drug use (5).
While progress has been made in some places, laws and regulations in many countries still include discriminatory provisions that exacerbate inequalities and marginalize certain groups. According to HIV Justice Worldwide, 72 countries have at some point adopted laws that specifically allow for HIV criminalization. Furthermore, UNAIDS estimates that around 48 countries still impose travel-related restrictions based on HIV status.

To examine the impact of laws, policies and practices on HIV around the world, the United Nations Development Programme (UNDP) convened the Global Commission on HIV and the Law in 2011 on behalf of UNAIDS. The Commission put forward a series of recommendations (see Box 3) that initiated a process of legal review on HIV-related laws and policies at the country level, including in Malawi. A 2018 supplement by the Commission was issued to track the progress of legal reform since the original research was released in 2012; it found that 89 countries have taken action to repeal or reform discriminatory laws. However, the supplement also suggested that much work remains to be done: for instance, HIV prosecutions have been reported in 69 countries as of July 2018, and some countries have reported a shrinking of space for civil society activism.

Some African countries have recently witnessed positive legal changes for people living with, affected by and at risk of HIV. This includes:

2014: Botswana rules that foreign prisoners living with HIV are entitled to receive life-saving antiretroviral treatment.
2015: Mozambique decriminalizes consensual adult same-sex sexual relations.
2016: Seychelles decriminalizes consensual adult same-sex sexual relations.
2017: Ghana establishes a reporting system for key populations to file complaints about human right abuses.
2019: The Botswana High Court declares the criminalization of consensual adult same-sex sexual relations to be unconstitutional.
2019: Kenya becomes the first country in Africa to collect data on intersex people in its national population census.

Box 2.
A trend of positive change

While progress has been made in some places, laws and regulations in many countries still include discriminatory provisions that exacerbate inequalities and marginalize certain groups. According to HIV Justice Worldwide, 72 countries have at some point adopted laws that specifically allow for HIV criminalization. Furthermore, UNAIDS estimates that around 48 countries still impose travel-related restrictions based on HIV status.

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Box 3.
The Global Commission on HIV and the Law: key recommendations

Countries should outlaw all forms of discrimination and violence directed against those who are vulnerable to or living with HIV, or those who are perceived to be HIV-positive. To this end, countries should ensure that existing human rights commitments and constitutional guarantees are enforced.

Countries should repeal punitive laws and enact ones that facilitate and enable effective responses to HIV prevention, care and treatment services for all who need them. No laws that explicitly criminalize HIV transmission, exposure or non-disclosure of HIV status should be enacted, as they are counterproductive.
A national reference group on HIV and AIDS was established in 2008 under the leadership of the Department of Nutrition, HIV and AIDS (within the Ministry of Health and Population) to review the draft bill. The group was composed of representatives from ministries and national institutions, civil society organizations (CSOs), United Nations (UN) agencies and development partners. UNAIDS worked alongside CSOs and other UN agencies to support the work of the group, including by organizing dialogues with a range of stakeholders, such as people living with HIV, religious leaders, women, young people, parliamentarians, government officials, representatives from CSOs, academia and members of the military. This support for the review of the draft bill was intended to be in keeping with public health and human rights standards.

Given the rapid and widespread pushback against the draft bill from human rights activists and other civil society organizations, the bill lay almost dormant from 2008 to 2016, leading many activists to believe that the bill would never actually be enacted. The fact that some provisions—such as the establishment of the National AIDS Council—were supported by some people created divisions among civil society and communities about the urgency to pass the bill. UNAIDS continued to engage with relevant ministers during this period on the contentious provisions in the draft bill (see Figure 1), including the ministers of Health, Gender, Justice, Home Affairs, Defense, Agriculture and Education; it also engaged both the office of the President and the Cabinet. UNAIDS also organized special bilateral sessions for the Women Caucus in Parliament, the Parliamentary Committee on Health, and the Committee on HIV/AIDS and Nutrition.

In 2011, the Assessment of Legal, Regulatory and Policy Environment for HIV and AIDS in Malawi was conducted by the Department of Nutrition, HIV and AIDS (within the Ministry of Health and Population) and the Department of Justice, with support from UNDP Malawi and other UN agencies (including UNAIDS). The subsequent report investigated Malawi’s regulatory and policy environment and pointed to several challenges with regards to HIV, the law and human rights in Malawi:

- Key population groups (e.g., women and children) are at a higher risk of HIV exposure.
- HIV-related stigma and discrimination was found to exacerbate the challenges faced by people living with HIV when it came to accessing appropriate services.
- Access to justice and law enforcement for human rights violations was limited.
- A number of punitive or coercive provisions in law created barriers to the AIDS response.

“...In a country as conservative as ours, where the violations of rights of minorities and other vulnerable groups are often clothed in the dignifying language of culture and religion, it really takes sound principle and leadership to affirm that respect for all rights is non-negotiable.”

Khumbo Bonzoe Soko, Honorary Secretary, Malawi Law Society

From UNAIDS in Malawi: shaping a Fast-Track agenda to end AIDS, biannual report 2014–2015
Resource constraints resulted in incomplete implementation of health policies and services.

There was limited use of international trade agreements (such as the Agreement on Trade-Related Aspects of Intellectual Property Rights [TRIPS]) to promote access to treatment.

The Assessment also called for a number of legal protections for individuals affected by HIV. This included a prohibition on HIV testing without consent, the right to privacy and confidentiality of medical records, and the right to access appropriate HIV prevention, treatment, care and support services.

In November 2016, the UNAIDS country office in Malawi—in collaboration with the UN Independent Regional Think Tank for HIV, Health and Social Justice—held a consultative dialogue entitled “Leaving No One Behind in the National Response to HIV and AIDS.” The week-long dialogue involved round table discussions with a variety of stakeholders, including religious leaders, networks of women and young people, parliamentarians, government officials, international organizations, CSOs (including the Malawi Law Society), academia, the military, key population groups, the National AIDS Commission, and the Malawi Human Rights Commission. The consultations offered the chance to deepen understanding of the critical interventions required to guarantee key and vulnerable population groups the right to social justice and access to essential HIV and health services. It also provided an opportunity to advance policy and legal recommendations for a rights-based AIDS response in Malawi.

Despite the policy recommendations from these consultations and the Assessment report, the President of Malawi announced in March 2017 that the draft HIV bill would be tabled with all the discriminatory provisions initially proposed.

“UNAIDS has helped to widen the space for CSOs in Malawi. Invariably UNAIDS would always be sometimes the only partner who would always include CSOs and even put CSOs first. They would make sure that all key processes happening involve CSOs.”

Abigail Dzimadzi, Executive Director, Malawi AIDS Service Organization

From UNAIDS in Malawi: shaping a Fast-Track agenda to end AIDS, biannual report 2014–2015
Removing discriminatory provisions: civil society advocacy in action

In response to the reintroduction of the bill in March 2017, UNAIDS facilitated a consultative meeting with the National AIDS Commission, the Chairman of the HIV/AIDS and Nutrition Committee and CSOs to agree on a road map towards enacting the revised draft bill into law. UNAIDS and UNDP reviewed the draft bill and created recommendations to ensure that it was consistent with international human rights standards, the Southern African Development Community (SADC) Model Law on HIV and AIDS, and guidance provided by the Global Commission on HIV and the Law.

In May 2017, UNAIDS organized a high-level technical task force that met in Mangochi over two days to consolidate comments and recommendations for parliamentary consideration. Members of the task force included representatives from: the SADC Parliamentary Forum; the UN Independent Regional Think Tank for HIV, Health and Social Justice; the Parliamentary Committee; the Ministry of Justice; the Malawi Human Rights Commission; the National AIDS Commission; the Malawi Law Society; key CSOs (such as the Southern Africa Litigation Centre (SALC); the Centre for Human Rights and Rehabilitation (CHRRRW); The Malawi Network of AIDS Service Organisations (MANASO); Malawi Network of People Living with HIV/AIDS (MANET+)); the Office of the United Nations Commissioner for Human Rights (OHCHR); CEDEP; UNDP and UNAIDS. The two-day meeting was facilitated by three judges: a Supreme Court Judge from Malawi and high court judges from Botswana and Malawi.

On the first day, individuals were asked to form small groups and consolidate their contributions to the bill. On the second day, a session took place to present the consolidated comments and recommendations to parliamentary leadership and the HIV/AIDS and Nutrition Committee. Despite significant interest, this second meeting could only host a limited number of CSO participants. Participants provided a succinct version of the views expressed on the first day.
Concerns were expressed about the presence of key government stakeholders who had been involved in drafting of the bill: the resulting power dynamic might have made it difficult for communities and civil society representatives to express their views fully. Furthermore, funding dynamics may have limited their ability to advocate against the position of the government. Despite this, the meeting was useful in terms of understanding the political landscape and the divided position of some stakeholders. For example, actors involved in service delivery welcomed the positive administrative provisions offered in the bill and seemed less aware of the potential consequences of its discriminatory clauses.

Source: Raw A. My body, my right! The power of women’s advocacy in defeating HIV criminalization in Malawi’s HIV bill. 22nd International AIDS Conference, Amsterdam, the Netherlands, 23 July 2019. Abstract TUPED555.
Despite these collaborative efforts, the Minister of Health tabled the bill in parliament in June 2017 with changes that surprisingly reinforced the punitive and coercive approach of the previous draft. In response, CSOs used their ability to argue against the law in technical terms to convey the human rights issues inherent in the bill through revised written submissions that placed their position directly before the Parliamentary Committee. Furthermore, SALC organized further submissions to Parliament and the Government on behalf of CEDEP, the AIDS and Rights Alliance for Southern Africa (ARASA), Centre for Human Rights Education Advice and Assistance (CHREAA), Youth Watch Society (YOWSO), the MANGO Key Populations Network, International Community of Women Living with HIV (ICW) Global and ICW Malawi; it also coordinated press releases calling on Parliament not to pass the bill in its current form.

UNAIDS convened an additional meeting in Salima with the HIV/AIDS and Nutrition committee to allow CSOs and community representatives to engage directly with parliamentarians. These efforts met with some success: in July 2017, the HIV/AIDS and Nutrition Committee filed a report endorsing most of the concerns of the human rights activists. Despite this, the criminalization of “HIV transmission and exposure” remained.

Following this report, Parliament ended without the bill going to vote in order to allow the Ministry of Justice enough time to consider it.
Accountability: the important role of women living with HIV

Fortunately, the process for redrafting the bill (which took place July to November 2017) gave civil society and communities the time to enhance the legal empowerment of individuals living with HIV. In particular, women living with HIV would have become even more vulnerable under the discriminatory provisions of the bill, especially the criminalization of HIV transmission (9, 10). Despite this, many activists and women affected by HIV supported the bill: dialogues showed that many women had contracted HIV because someone had not disclosed their HIV status to them, leading them to believe that the criminalization of HIV transmission would protect other women from suffering the same fate.

“There is a need to ensure that Malawian women’s voices, particularly the voices of women living with HIV, are incorporated in the law-making process” said Sarai Chisala-Tempelhoff, President of Women Lawyers Association. “Rather than being protective and preventive, the law was paternalistic, positing women as both victims and vectors of HIV. Yet, in reality, women living with HIV rarely describe themselves as ‘victims’ when relaying how they became infected, and the language of vectors is especially harmful for those most marginalized members of society such as female sex workers.”

A multitude of CSOs joined forces, playing a crucial role in informing women living with HIV of how the bill would impact their lives. They met with grass-roots networks of women living with HIV, female sex workers and women lawyers to work through the proposed bill, provision by provision. They considered recent research showing the increasing feminization of HIV criminalization in Africa, discussed how the laws were likely to play out in the lives of Malawian women living with HIV and helped affected individuals articulate their concerns in legal terms. They also invited the press to interview women living with HIV and other members of key populations. All of these activities enabled individuals living with HIV to become legally empowered and publicly voice their concerns.

Women living with HIV became more and more vocal in the conversation, engaging in activism efforts on their own. In November 2017, women living with HIV met with Parliament alongside other activists to protest against the HIV and AIDS Prevention and Management Draft Bill, standing up and singing a protest anthem to denounce its discriminatory provisions. This was a critical moment in the campaign for the removal of the discriminatory provisions in the bill: many law-makers believed the bill would protect women, but after hearing the powerful stories of women living with HIV and how the criminalization provisions would hurt them, they were persuaded to take a
stance against the bill. “The law-makers who listened to women living with HIV were convinced that this bill would harm them, not protect them” said Annabel Raw, health rights lawyer, SALC. “And while pressure against the bill’s coercive aspects through technical submissions was important, the criminalizing provisions would not have been removed had it not been for women living with HIV communicating directly to law-makers how the law would affect them in their real lives.”

The UNAIDS Executive Director, who had been closely following the evolution of the situation in Malawi, became personally involved by writing an official letter to the Malawian Minister of Health that advocated against the criminalization provisions in the bill shortly before it was voted upon. By the end of November 2017, parliament voted to reject most human rights-infringing provisions in the bill, including the criminalization of the deliberate transmission of HIV.
There is still more work to be done to ensure a rights-based response to HIV in Malawi and to prevent discrimination against people living with HIV. Legal education and empowerment efforts for those affected by HIV must continue, and the Women Lawyers Association—in collaboration with the United Nations Entity for Gender Equality and the Empowerment of Women (UN Women)—developed an explainer of the new law. Unless the necessary tools and knowledge reach those who need it most, however, they may not be able to claim protection in instances where it may be denied them.

Key populations, women and girls, and all people living with, affected by and at risk of HIV need to be encouraged to use existing accountability mechanisms against stigma and discrimination. Individuals with the power to enforce the law—both in the official justice system and in the traditional leadership structures within communities—must also be aware of these accountability mechanisms. There also is a continued need for media campaigns that normalize HIV as a health condition; this would help to eradicate lingering stigma and discrimination against individuals living with HIV and prevent the resurgence of HIV criminalization laws in Malawi.

Other countries in southern Africa have been less successful in their campaigns to remove discriminatory HIV laws. For example, HIV transmission remains a criminal offense in Botswana. Similarly, Zambia offers test-and-treat programmes that provide individuals with a quick and free HIV diagnosis, but testing is mandatory for all patients who visit government health facilities. In a joint statement on HIV testing services, the World Health Organization (WHO) and UNAIDS state that HIV testing must always adhere to the “5 Cs”: consent, confidentiality, counselling, correct results and connections to prevention, treatment and care support services (11). However, the practice in Zambia highlights the divisive nature of positive HIV provisions (like test-and-treat programmes) that are coupled with discriminatory practices (like compulsory testing). With shrinking civic space, there is an ever greater risk of individuals choosing not to speak up on controversial issues because they fear retaliation or that activism might be ineffective (12).

“The new Malawi HIV Bill is a victory for the Malawian people whose efforts were supported by strong civil society organizations in the country. It is also a victory for evidence-based law reform and is an example for other African countries that continue to have similar provisions criminalizing HIV transmission.”

Amitrajit Saha, Team Leader, Africa HIV, Health and Development Team, UNDP

From UNAIDS in Malawi: shaping a Fast-Track agenda to end AIDS, biannual report 2014–2015

Encouraging reforms for a healthier society
This case study, however, is an example of why activism matters, and it demonstrates how mobilizing people and fostering an open dialogue with national authorities can make a difference. The overall collaborative efforts of civil society, communities, government, and UN agencies—and the inspiring advocacy of women living with HIV—led to a successful resolution and positive legislative change in Malawi. Furthermore, the work of civil society and other organizations to empower affected individuals legally illustrates the importance of not just involving affected individuals in political discussions, but recognizing and inviting their leadership to enable them to be both empowered and heard.

Respect for human rights is a vital determinant of health and well-being, and it is a key tool for ending AIDS as a public health threat by 2030. To foster legal reform, UNAIDS will continue to provide evidence-informed guidance, support and political space to agents of change: an active and vibrant civil society, strong communities, engaged political leaders and sensitized law-makers—and supportive national and global institutions—all play a critical role in securing social justice and ensuring that no one is left behind.
References


