International HIV/AIDS Alliance

Together to end AIDS

ARASA AIDS & Rights Alliance for Southern Africa

Good Practice Guide

HIV and human rights

About the International HIV/AIDS Alliance

We are an innovative alliance of nationally-based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

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How was this guide developed and who was involved?

This guide was developed by the International HIV/AIDS Alliance (the Alliance) and the AIDS and Rights Alliance for Southern Africa (ARASA) www.arasa.info

The Alliance is committed to a human rights-based approach to HIV programming and advocacy. We recognise that respect for, and the protection and promotion of, human rights is essential to preventing HIV and mitigating its social and economic impact. We are striving towards the fulfillment of the human rights of all people affected by HIV, by addressing not just HIV but wider health and development issues.

ARASA is a regional partnership of more than 70 non-governmental organisations (NGOs) that works collaboratively to promote and build capacity around a rights-based response to HIV and tuberculosis (TB) in 18 countries in southern and east Africa. All ARASA partners are organisations committed to the empowerment of women and men living with, affected by and at higher risk of HIV and TB, so as to achieve their fullest potential rights and health.

This guide draws on the experiences of Alliance programmes globally and those of ARASA and its partners.

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The guide was field-tested in November 2013 in a workshop on the integration of human rights-based programming into the strategy of the Alliance Nationale Contre le Sida (ANCS) in Senegal, with the participation of representatives from wider civil society, including organisations of key populations, United Nations representatives and government officials.

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Designed by: Jane Shepherd

Unless otherwise stated, the appearance of individuals in this publication gives no indication of either sexuality or HIV status.

Cover photos: A youth group in Malnicherra tea plantation in Sylhet, Bangladesh. The group raises awareness of sexual and reproductive health and rights. © Alliance.

Rachel Gawases is a transgender woman with two professions; as a sex worker and the Director of Voices of Hope, a community-based organisation that provides information and support to sex workers. © Alliance.

'George' and 'Michael' are members of the men who have sex with men rights organisation PEMA in Mombasa, Kenya. © Nell Freeman for the Alliance.

Alliance HIV programming principles and standards

The **Alliance accreditation system** promotes evidence-based good practice **principles** and **standards** for:

- **governance and sustainability**
- **organisational management**
- **HIV programming**.

This Good Practice Guide features Alliance HIV programming principles and standards that are relevant to:

- **all HIV programming (for example, human rights, the greater involvement of people living with HIV (GIPA), and the participation of beneficiaries in our programming)**
- **the specific technical area of HIV and human rights.**

This Good Practice Guide contains **information, strategies and resources** to help programmers meet the standards. Implementing these standards is one of the ways that the Alliance, our partners and other organisations define and promote a unified and quality-driven approach to HIV programming.

The Alliance HIV programming standards can be used at any time in the programme cycle to assess good practice, and to help develop proposals and monitoring and evaluation (M&E) frameworks.

Key resource

For further details on the Alliance accreditation system and the full set of principles and standards, please go to: **www.aidsalliance.org/Publicationsdetails.aspx?Id=90660**

Alliance HIV programming

Principle 9: Our programmes are evidence based, promote human rights and prioritise the needs of communities most affected by HIV

Standard 31	Our organisation is committed to a human rights-based approach.
Standard 32	Our organisation is committed to the effective implementation of the greater involvement of people living with HIV (GIPA) principles.
Standard 33	Our organisation promotes the human rights of women, men, other gender identities and those of all sexual orientations by transforming gender relations and reducing inequality.
Standard 34	Our organisation respects and promotes the rights of children and their protection from abuse, exploitation and neglect.
Standard 35	Our organisation's HIV and health programmes are part of a coordinated local/national network of services and programmes, and contribute to the national HIV response.
Standard 36	Our organisation is committed to ensuring the participation of those populations intended to benefit from programmes at all stages of the programme cycle.
Standard 37	Our organisation mobilises communities most affected by HIV in order to ensure an effective HIV response.
Standard 38	Our organisation prioritises communities most affected by HIV and its HIV programmes are tailored to meet their needs.

Alliance HIV programming technical area

A: HIV and human rights

Standard A1	Our programmes are based on a human rights assessment
Standard A2	Our programmes are designed to build the capacity of both rights holders and duty bearers to claim their rights and to promote, protect and respect the rights of others
Standard A3	Our organisation holds both state and non-state actors accountable for the enjoyment of all human rights as a core part of all our programmes
Standard A4	Our organisation promotes and/or provides legal services to ensure redress for HIV-related discrimination experienced by people living with HIV and key populations

Abbreviations and acronyms

CBO	Community-based organisation
CSO	Civil society organisation
LGBTI	Lesbian, gay, bisexual, transgender and intersex
M&E	Monitoring and evaluation
NGO	Non-governmental organisation
PPTCT	Prevention of parent-to-child transmission
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

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What is this guide for?

The *Good Practice Guide: HIV and Human Rights* is an accessible and user-friendly guide to explain:

- what human rights-based HIV programming is
- why it is important
- the different ways that organisations can integrate human rights into their HIV programmes.

It brings together international guidance as well as good practice experience from across the world on HIV and human rights programming.

The guide assists programmers to integrate human rights through all stages of the HIV programming cycle, from design, development and implementation through to M&E. It gives practical guidance on the kinds of human rights programmes recommended by the Alliance and the Joint United Nations Programme on HIV/AIDS (UNAIDS) for protecting and promoting human rights in the context of HIV, and for creating change at individual, community, service provision and law, and policy levels. It provides accessible and practical planning tools, as well as programmatic examples of how to address human rights in a way that includes affected populations, builds capacity, responds to the inequalities underlying HIV and AIDS, and promotes universal access to HIV-related health services. It also includes reference to further information and resources for more in-depth information about human rights, HIV and rights-based programming for HIV.

Who is this guide for?

The guide is for HIV programmers working in community settings. It targets those with skills and experience in community-based HIV programming, but who may have limited experience of integrating human rights into their programmes. Some organisations may even be already including human rights approaches in their HIV programmes, but are unaware that this is the case or are not doing it in a systematic way, as suggested in this guide. The guide aims to build on the existing skills, resources, capacity and networks of programmers to strengthen human rights-based HIV programming.

How is this guide structured?

- The Alliance HIV programming standards for HIV and human rights provide the overall framework for the guide, and tell us **why** and **how** to integrate human rights into HIV programmes, as well as providing **markers of progress**.
- The Ottawa Change Framework helps classify the various human rights-based HIV programmes according to the level of change they create.
- The eight programmatic interventions suggested in this guide (*see* Chapter 3) give us some practical examples of **what** we can do (but is not an exhaustive list). They are based on the UNAIDS seven Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses, plus a key programme to encapsulate core community-led human rights-based responses to HIV.

How should this guide be used?

The Good Practice Guide can be used in its entirety or as individual sections, depending on your needs.

Chapter 1: HIV and human rights is a good starting point for increasing awareness and understanding of what human rights are, why they are important for HIV programming and how they guide your work. This information may also help programmers to advocate within and outside of your organisation for increased commitment to HIV and human rights programming.

Chapter 2: What is a human rights-based response to HIV? outlines key principles of human rights-based HIV programming, such as equality and non-discrimination, full and equal participation and accountability, that should form the basis for all programmes. Programmers can refer to these principles throughout the design, development and implementation of HIV and human rights programmes.

Chapter 3: Human rights and HIV programmes and interventions gives you information and practical examples, together with examples of priority HIV and human rights programmes recommended by the Alliance and UNAIDS, and how these programmes bring about change at different levels.

Chapter 4: The HIV and human rights programme cycle focuses on elements of the project cycle where human rights-based interventions are significantly different from other HIV interventions. There is particular focus on situational analyses, which help you gather and analyse information on HIV, legal and human rights issues for programming and setting human rights-specific goals.

Chapter 5: Monitoring and evaluating HIV and human rights programmes guides you to monitor, evaluate and review all stages of your HIV programmes to see whether they incorporate human rights principles and approaches, respond to emerging human rights issues and achieve human rights goals.

Each chapter contains:

- an introductory page containing an outline of each section, good practice programme standards relevant to that chapter, and key terms used in that chapter
- examples and quotes relevant to the section
- checklists to support your implementation efforts
- links to useful resources for further information.

1 HIV and human rights

In this chapter:

- 1.1 What are human rights?
- 1.2 Where do human rights come from?
- 1.3 What is the link between health, HIV and human rights?
- 1.4 Who are key populations in the context of HIV and AIDS?

STANDARD 31: Our organisation is committed to a human rights-based approach

Key terms

Human rights are basic freedoms and entitlements that all people have simply by being human. They are based on the idea that every person is equal and deserving of dignity.

Key populations are defined by the Alliance as groups that are vulnerable to or affected by HIV and AIDS. Their involvement in HIV programming is vital to an effective and sustainable response to HIV. Key populations vary according to the local context, but are usually marginalised or stigmatised because of their HIV status or social identities. They include people living with HIV, their partners and families, people who sell or buy sex, men who have sex with men, transgender people, people who use drugs, children affected by HIV and AIDS, migrants, displaced people and prisoners.

Domestication is when countries take steps to apply international human rights commitments at the national level (for example, by passing a law).

Signature is when a government signals its political commitment towards making its country bound by an international human rights instrument.

Ratification/accession is when a country signs its agreement to be legally bound by an international human rights instrument.

Chapter 1: HIV and human rights

1.1 What are human rights?

Human rights are basic entitlements that all people have by virtue of being human. They are based on the idea that every person is equal and entitled to be treated with dignity and respect, regardless of their race, sex, gender, age, disability or any other characteristic. They are universal and inalienable, and therefore cannot be transferred or lost.

Table 1: What are the characteristics of human rights?

Human	Human beings are entitled to human rights.
Universal	Human rights apply to all people throughout the world at all times
Fundamental	Human rights are essential to human dignity, survival and development, and should be given special protection by the law
Treat everyone equally	Human rights recognise that all humans are born free and equal in dignity and rights
Protect individuals from the state and non-state political actors such as rebel groups	Human rights protect people from abuse of state or political power. The state must respect, protect, promote and fulfil human rights
Inalienable	Human rights cannot be forfeited, transferred or lost. Some rights, such as the right to life, are absolute and can never be taken away, while others can only be restricted in specified circumstances
Inter-related and inter-dependent	Human rights are linked to and dependent on each other; for example, the improvement of your use and enjoyment of one human right advances the enjoyment of other rights
Recognise the principle of humanity	Human rights treat everyone with respect for their human dignity

1.2 Where do human rights come from?

Today, human rights are ref ected in international treaties, regional documents and the national constitutions of countries across the world. However, human rights is not a modern concept. There are references to human rights in documents from ancient times.

Early references to human rights

The Edicts of Ashoka date back to the reign of Ashoka, king of India between 272 BC and 231 BC, and refer to concepts and principles to protect the freedoms and entitlements of people. In the thirteenth century, the Kourouka Fouga, the constitution of the Mali Empire, also contained references to human rights.

Later examples of human rights documents and campaigns include the French Declaration of the Rights of Man and of the Citizen in 1789 and human rights activism in England to abolish the slave trade in the 1800s.

After the Second World War, human rights and the need to protect them emerged strongly, resulting in the Universal Declaration of Human Rights (UDHR) being adopted in 1948. The UDHR has been translated into over 300 languages. It inspired and underlies later, binding international instruments like the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. Regional instruments, like the African Charter on Human and People's Rights and the American Convention on Human Rights, also draw on the UDHR.

In most cultures and religions there are concepts which describe respect for our common humanity, for example in Botswana there is a concept called Botho or 'humainness'.

Botho basically says that we are all human with the same needs and desires, therefore we should treat everyone else in the same way that we would like them to treat us. Concepts such as Botho are good starting points for discussing human rights.

Can you think of a concept in your own culture or society that relates to human rights?

The Universal Declaration of Human Rights

The UDHR was adopted on 10 December 1948, a date that later became International Human Rights Day. The UDHR is not legally binding, unlike later international and regional human rights instruments. However, it carries great moral weight, and some legal experts have argued that it should be regarded as part of customary international law and therefore as binding on all countries.

The UDHR contains 30 articles that protect:

- civil and political rights, such as the rights to be presumed innocent; not to be subjected to arbitrary arrest, detention and exile; to freedom of movement; and to have a nationality
- social, economic and cultural rights, such as the rights to a standard of living adequate for health and wellbeing; to education; and to participate freely in the cultural life of the community.

Discussion point

Some people argue that human rights are not universal. They say that they are a foreign concept that cannot be forced on countries. They argue that each country is free to determine its own national values, rules, norms and laws without having regard to universal human rights.

Others point out that in many ways human rights simply ref ect our basic ideas of right and wrong, already found in the beliefs, value systems and laws of people the world over. They are not only ref ected at international level, but also in regions and countries across the globe. They have been an important tool to support the liberation struggles of oppressed people, and are now entrenched in the national constitutions of many countries.

Universality of human rights is a cornerstone of international human rights law. This guide is based on the universality of human rights. It applies human rights to all people as a tool to reduce the risk of HIV transmission and the impact of HIV and AIDS.

1.3 What is the link between health, HIV and human rights?

Every person has the right to health. At its most basic level, this means that every person has the right to services to prevent HIV transmission, as well as to treatment, care and support services for HIV and AIDS.

> "The protection of human rights is essential to safeguard human dignity in the context of HIV/AIDS and to ensure an effective, rights-based response. An effective response requires the implementation of all human rights, civil and political, economic, social and cultural, and fundamental freedoms of all people, in accordance with existing international human rights standards. Public health interests do not conf ict with human rights. When human rights are protected, fewer people become infected and those living with HIV/AIDS and their families can better cope with HIV/AIDS."
>
> UNAIDS (1996, 2006). 'International guidelines on HIV/AIDS and human rights'.

We also know that human rights are interconnected and work together to promote the development of people. International law recognises that protecting health and wellbeing means more than simply providing health services. It requires protecting a range of related human rights, such as rights to information and education, and to equality and non-discrimination.

The United Nations General Assembly affirms that the "full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV epidemic".[1] Yet, there are numerous governments with discriminatory laws and practices that effectively criminalise key populations, driving them away from HIV services.[2]

HIV-related stigma and discrimination, and discrimination against key populations, are major barriers to achieving health rights. Human rights violations impact on both the spread of HIV and the impact of HIV on families and communities. Where populations have limited access to health and other human rights, they may be at increased risk of HIV exposure and less able to cope with the impact of HIV on their lives.

The table on page 11 gives some examples of human rights and how they link to health and HIV. This helps us understand how rights are interconnected and indivisible, working together to promote the mental, physical and spiritual wellbeing of people in the context of HIV.

1. United Nations General Assembly Resolution 65/277, 'Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS', 8 July 2011.

2. International HIV/AIDS Alliance and Commonwealth HIV and AIDS Action Group (November 2010), 'Enabling legal environments for effective HIV responses: a leadership challenge for the Commonwealth'.

Understanding the right to health

The right to health is an inclusive right and includes more than medicines and hospitals. Health rights are linked to and dependent on the realisation of other rights. The "underlying determinants of health" (factors that help us lead healthy lives) include things like:

- safe drinking water and food
- adequate housing and sanitation
- health-related education and information
- gender equality.

The right to health contains freedoms, protecting people from actions such as non-consensual medical treatment, including forced sterilisation and mandatory HIV testing.

The right to health contains entitlements, promoting access to goods and services such as:

- a system of health protection providing equality of opportunity for everyone
- prevention, treatment and control of diseases
- essential medicines
- maternal, child and reproductive health
- health-related education and information
- participation in health-related decision-making at all levels.

The right to health is subject to progressive realisation. Some countries may not have the resources to fully implement all aspects of the right to health immediately, so international law requires the "progressive realisation" of the right to health. The Committee on Economic, Social and Cultural Rights says that even poor countries have to take continuous steps to provide and improve access to health for all within the limits of their resources. This should include a minimum of equal access to:

- health facilities, goods and services without discrimination, especially for vulnerable and marginalised populations
- essential food to ensure freedom from hunger
- basic shelter, housing and sanitation, and safe and potable water
- essential drugs recommended by the World Health Organization (WHO).

Health services, goods and facilities must be provided to all without any discrimination.

All services, goods and facilities must be available, accessible, acceptable and of good quality. Public healthcare facilities, goods and services must be **available** in sufficient quantity within a country; they must by **physically** and **financially accessible** to all populations without discrimination (for example, key populations, including children, adolescents and people with disabilities); they must be non-discriminatory, respectful of medical ethics, gender sensitive and culturally appropriate to be **acceptable to all**; and they must be of **good quality**, including the availability of scientifically approved drugs and equipment, trained health professionals, national health standards and protocols, adequate sanitation and safe drinking water.

Ensuring all services, goods and facilities are available, accessible, acceptable and of good quality is the most important thing to remember about the right to health and an easy way of checking whether the right to health is being fully applied.

Source: WHO and OHCHR (2008). 'The right to health: Fact sheet no. 31'.

Table 2: The link between human rights and HIV		
Human right	HIV-related rights violations	Impact on HIV, health and human rights
Every person has the right to equality and non-discrimination	Key populations that are **vulnerable** to and at **higher risk** of exposure to HIV are discriminated against in access to healthcare Laws criminalising key populations (e.g. laws criminalising HIV transmission or sex between men) increase stigma and discrimination against key populations	Discrimination denies key populations access to HIV prevention, treatment, care and support services, placing them at increased risk of HIV Discrimination creates fear and forces key populations to remain 'invisible' in society, limiting their access to important services and negatively impacting on their health
Every person has the right to liberty, security of the person and protection from cruel, inhuman or degrading treatment	People perceived to be at higher risk of HIV exposure (e.g. sex workers) may be subjected to mandatory HIV testing without their voluntary and informed consent	Mandatory HIV testing laws and policies create fear, discouraging pregnant women from accessing healthcare services and increasing their risk of HIV exposure
Every person has the right to privacy	People living with HIV experience breaches of their right to confidentiality about their HIV status	Breaches of confidentiality create fear and discourage people living with HIV from seeking out health services
Every person has the right to marry and found a family	People living with HIV are subjected to marital HIV testing in some countries, are denied access to reproductive healthcare services, pressured not to have children or to have sex, and even forcibly sterilised	Denying people living with HIV equal access to marriage and family rights is unfairly discriminatory
Every person has the right to fair labour practices	People living with HIV are discriminated against and unfairly dismissed in the workplace on the basis of their HIV status	Workplace discrimination denies employees with HIV the ability to earn a living when they may need income most. This increases the impact of HIV on their lives
Everyone has the right to freedom of assembly and association	In some countries people living with HIV and other key populations are denied the right to organise and form support organisations	Where laws or practices prevent key populations from organising, they lose an important source of information and support to promote their health
Every person has the right to freedom of movement	HIV should not be treated differently from other diseases with regard to immigration, long-term residency or short-term visits to any country	Countries that require information about HIV status, that deport people who are living with HIV, and who treat HIV differently from other diseases, can undermine access to healthcare, information and other human rights
Every person has the right to access to information	Laws and policies in some countries prohibit adolescents, children and key populations (e.g. men who have sex with men) from getting appropriate HIV information and education	Affected populations do not receive appropriate HIV information so they are less able to prevent HIV infection or access available services

Key resources

Global Commission on HIV and the Law (2012). 'Risks, rights & health'.

Available at: www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf

Office of the United Nations High Commissioner for Human Rights (2008). 'Fact sheet no. 33: Frequently asked questions on economic, social and cultural rights'.

Available at: www.ohchr.org/Documents/Publications/FactSheet33en.pdf

Open Society Institute (2009). 'Health and human rights: a resource guide'.

Available at: http://equalpartners.info/

Open Society Institute (2009). 'Human rights and HIV/AIDS: now more than ever. 10 reasons why human rights should occupy the center of the global AIDS struggle'.

Available at: www.opensocietyfoundations.org/sites/default/files/nmte_20090923_0.pdf

WHO. 'A human rights-based approach to health'.

Available at: www.who.int/hhr/activities/hrba_to-health_infosheet.pdf

Example

A broad approach to the right to health: Alliance India's Pehchan programme

Pehchan, meaning 'identity' or 'recognition', is a Global Fund supported project running from 2010–15 focusing on the health rights of sexual minorities in India. It works to build the capacity of CBOs of men who have sex with men, transgender people and the *hijra** community to serve as effective HIV prevention partners with India's National AIDS Control Programme. In this way, it aims to improve access to healthcare for over 500,000 community members in 17 states.

The project includes a wide range of interventions, such as organisational development and mentoring of new community leaders; capacity-building on state AIDS control societies; behaviour change communication; condom distribution; referral services for HIV testing and counselling; and care and support for people living with HIV. It also makes other services available to ensure access to comprehensive care and support, such as legal support, psychosocial and mental health counselling; family support peer groups; relationship counselling; life skills; and sexual and reproductive health linkages for married men who have sex with men, and transgender people with female partners. By the end of 2013, over 200,000 members had received direct services.

Over 200 CBOs are empowered to both deliver comprehensive health packages and advocate to local authorities for the right to health for all. The programme has a large research component that builds up knowledge and evidence about the right to health of these key population groups, and informs programme practices accordingly.

With the reinstatement by the Indian Supreme Court in December 2013 of Section 377, effectively re-criminalising the LGBT community, Pehchan reinforced its human rights-based responses. CBOs are providing further legal services for members to challenge the misuse and misinterpretation of the law, reacting to acts of violence in crisis response teams which include community members as well as local authorities, and intensifying advocacy for each state to amend Section 377 internally.

* *Hijras* are people of a biological male gender who identify either as women, or 'not-men', or 'in-between man and woman', or 'neither man nor woman', and who have a significant role in India's social and cultural context.

1.4 Who are key populations in the context of HIV and AIDS?

Key populations are groups that are **vulnerable** to or affected by HIV and AIDS. Their involvement in HIV programming is vital to an effective and sustainable response to HIV.

In every society there are individuals and population groups who are more **vulnerable** than others to harms such as being sick, poor or experiencing social rejection. Often, it is not so much the actual composition of a particular population that makes it more vulnerable, but rather how that population is regarded by others.

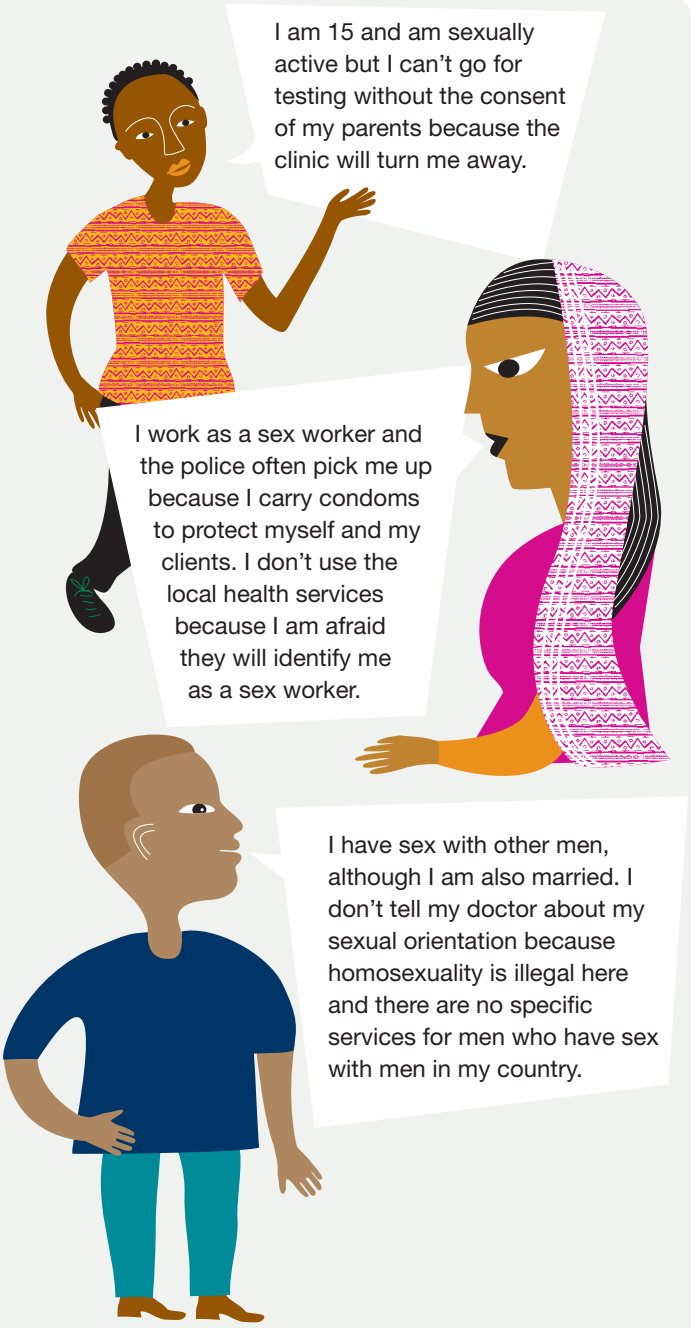
Vulnerability to HIV is a result of a combination of factors, including personal circumstances such as age, social mobility, education and gender identity, as well as circumstances that arise from the environment in which an individual lives, such as poverty, gender discrimination or lack or inadequacy of services. Vulnerable populations include groups that enjoy lesser legal, social or policy protection, which limits their ability to access or use HIV prevention services.

Key populations

In some cultures, girls and women face strong social pressures that make them vulnerable to HIV. For example, harmful social and cultural norms often restrict their access to information about sexual and reproductive health, or limit their decision-making about their sexual life. These norms can undermine girls' and women's autonomy, and may prevent them from insisting on abstinence or condom use by male partners. Social and cultural norms related to masculinity can also mean that in some societies, boys and men are expected by their peers to display dominant, sometimes violent behaviour towards women and girls. Harmful concepts of masculinity can further discourage boys and men from seeking health services, and encourage them to engage in risky behaviour such as substance and drug use or multiple casual sexual relationships.

There are also populations who are at **higher risk of being exposed to HIV** for reasons such as having unprotected sex with a partner whose HIV status is unknown, having multiple sexual partnerships involving unprotected sex, and injecting drugs with contaminated needles and syringes. These populations are usually also vulnerable due to social and institutional rejection and discrimination. Depending on the context, they could include people who use drugs, sex workers, men who have sex with men, transgender people and prisoners.

Source: International HIV/AIDS Alliance (2010). 'Campaign briefing 1: Who are vulnerable and most-at-risk populations?'



The criminalisation of key populations is a major factor that inf uences HIV vulnerability and causes AIDS-related deaths.

Establishing intentionality of HIV transmission is extremely difficult, and the reasons for someone being unable to disclose their HIV status are complex; for example, in the case of women subject to intimate partner violence. Criminalisation of intentional HIV transmission and non-disclosure of HIV status does not protect victims any further than more general legislation. Rather, it singles out HIV and AIDS, contributing to stigma and discrimination against people living with HIV, driving them underground and further away from essential lifesaving services.

Men who have sex with men, transgender people, people who use drugs and sex workers are generally among those with the highest HIV prevalence rates, and are therefore key to the HIV response. Criminalisation makes them much more difficult to reach with HIV programmes, driving them away from these services, undermining their self-esteem and further exposing them to HIV.

Example

Vulnerability and discrimination: forced sterilisation of women with HIV in Namibia

There are many examples of stigma, discrimination and human rights violations of people living with HIV from across the world. HIV-related discrimination increases the burden of HIV and AIDS on the lives of those affected.

In Namibia, the International Community of Women Living with HIV, the Namibia Women's Health Network and the Legal Assistance Centre found a number of cases of women living with HIV who were sterilised without their knowledge or informed consent. In many cases, the women received limited or inaccurate information about sterilisation, why it was important and what their alternatives were – if they received information at all. Some were told it was standard practice for women with HIV. They were not counselled and were rushed to sign documents they did not read or understand, often while they were in labour.

Forced sterilisation violates women's rights to health; their reproductive rights, including the right to make decisions about the number and spacing of children that they want; and their rights to equality and non-discrimination. Forced sterilisation also amounts to cruel, inhuman and degrading treatment. The women told of the pain and hurt they experienced from being forcibly sterilised and never being able to have children again.

For information on how civil society organisations (CSOs) responded to this violation through litigation and related strategies, *see* Legal support services in Chapter 3.

An Alliance common policy position on decriminalisation of key populations

"The Alliance considers that the criminalisation of same-sex activity between consenting adults, drug use, sex work and HIV transmission through specific legislation violates the human rights of and further stigmatises men who have sex with men, people who use drugs, sex workers, transgender people and people living with HIV.

This criminalisation also severely undermines the effectiveness of the HIV response to which the Alliance has pledged to contribute.

The Alliance pledges to advocate for the reform of all legislation criminalising and discriminating these populations and for countries to repeal legislation that specifically criminalises HIV transmission, HIV exposure or failure to disclose HIV status; punishes people who use drugs solely on their grounds of such use; punishes consenting adults involved in sex work; and/or criminalises consenting adults involved in same-sex sexual activity or transgender people for expressing their gender identity."

Adopted at Alliance Directors Meeting, March 2013, Dakar

2 What is a human rights-based response to HIV?

In this chapter:

- 2.1 What is a human rights-based response to HIV?
- 2.2 What human rights norms guide our HIV programming?
- 2.3 Commitments to the HIV response based on human rights
- 2.4 Human rights principles in HIV programming

STANDARD 31: Our organisation is committed to a human rights-based approach

STANDARD 32: Our organisation is committed to the effective implementation of the greater involvement of people living with HIV (GIPA) principles

STANDARD 36: Our organisation is committed to ensuring the participation of those populations intended to benefit from programmes at all stages of the programme cycle

STANDARD A2: Our programmes are designed to build the capacity of both rights holders and duty bearers to claim their rights and to promote, protect and respect the rights of others

STANDARD A3: Our organisation holds both state and non-state actors accountable for the enjoyment of all human rights as a core part of all our programme

Key terms

Duty bearers are those who have an obligation to respect, protect, promote and fulfil rights; for example, a minister of health and a healthcare worker are duty bearers.

Rights holders are those who have rights; they include individuals and communities.

Chapter 2: What is a human rights-based response to HIV?

2.1 What is a human rights-based response to HIV?

A human rights-based response to HIV is an intervention framework which aims to address the impact that HIV and human rights have on one another. A human-rights based response to HIV has three main pillars: the enforcement of **human rights norms**; the implementation of **commitments to HIV response based on human rights**; and the application of **human rights principles** in relation to HIV programming.

> "Human rights are essential to reducing vulnerability to HIV. A human rights approach provides a common framework for translating international and national human rights documentation into practical programming at national level, improving the universal access to health and HIV-specific programmes."
>
> NAF, Mongolia, in International HIV/AIDS Alliance (2010). 'Advancing human rights, responding to HIV: report on the findings of a human rights survey among Alliance partners'.

This chapter examines these three pillars in detail, while the eight key programmes suggested for delivering human rights-based HIV responses are further described in Chapter 3.

Figure 1: Human rights-based response to HIV

2.2 What human rights norms guide our HIV programming?

Legal human rights standards are norms set out in international, regional and national human rights instruments, usually in the form of international and regional treaties, covenants and conventions, and laws at the national level (pillar 1 in Figure 1). They guide your country's human rights-based HIV programming in the following ways.

International human rights instruments

There is a large body of international human rights instruments that become legally binding on countries once they have **signed** and **ratified** or acceded to these instruments. By ratifying an international human rights document, countries legally commit to **domesticating** and enforcing these rights. They are also required to report to the United Nations treaty monitoring bodies on how they are implementing these rights.

These broad international human rights instruments ref ect agreement across the world about civil, political, economic, social and cultural rights. For example, the International Covenant on Civil and Political Rights provides for civil and political rights such as the rights to equality, privacy and dignity. These rights apply to all individuals, including people affected by HIV and AIDS. As discussed earlier, a number of these rights, not only health-specific rights, are important for national responses to HIV and AIDS.

Other international human rights instruments deal with particular issues or the specific rights of certain populations. Many deal with groups who are also key populations in the context of HIV and AIDS. For example, the Convention on the Rights of Persons with Disabilities contains specific guidance on the rights of people with disabilities, and the Convention on the Elimination of All Forms of Discrimination Against Women contains guidance on women's rights and gender equality. They act as an important guideline for human rights-based responses to HIV programming.

Ratification or accession takes place when the head of state signs an international human rights instrument in accordance with its country's laws. This shows that the country agrees to be legally bound by the human rights instrument.

Domestication happens when countries take steps (for example, by passing a law) to make the rights apply at national level. Once an international instrument has been domesticated, a country can be held accountable for failing to implement these laws.

In a dualist country, international instruments do not form part of domestic law until a national law is passed incorporating the provisions into domestic law. In a monist country, treaties and conventions apply directly, and no additional national law is required to domesticate them.

Remember, in dualist countries human rights treaties are implemented only when the government ensures that its laws and policies are consistent with the treaties. In some cases, laws may already respect the rights contained in the treaty. In other cases laws will need to be changed if they violate rights listed in the treaty, and sometimes a country may have to pass completely new laws.

Key resources

The United Nations website contains information that may be useful for human rights advocacy relating to a country's human rights obligations, including:

A list of international instruments that have been ratified by individual countries.

Available at: http://treaties.un.org/pages/Treaties.aspx?id=4

Details of the treaty monitoring bodies and the reporting process.

Available at: http://tb.ohchr.org/default.aspx

The country reports submitted by individual countries and the report assessments by the treaty monitoring bodies.

Available at: http://tb.ohchr.org/default.aspx

The Human Rights Council website contains reports submitted by individual countries, governments and civil society, and recommendations made by the Council to countries.

Available at: www.ohchr.org/EN/HRBodies/HRC/Pages/HRCIndex.aspx

Table 3: Key international human rights legal standards		
Instrument	Purpose	Implications for HIV
International Covenant on Civil and Political Rights (ICCPR)	Describes civil and political rights	People living with HIV are sometimes denied civil and political rights, such as rights to equality, privacy and freedom of movement. Protection of these rights is vital for promoting broader health rights and ensuring universal access to HIV prevention, treatment, care and support.
International Covenant on Economic, Cultural and Social Rights (ICESCR)	Describes economic, cultural and social rights	Protection of socio-economic rights is vital to ensure access to healthcare. It also helps to promote other rights to development (e.g. education, nutrition, property), which in turn reduces vulnerability to HIV and decreases the impact of HIV on people's lives.
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	Describes the rights of all women to be protected from discrimination	Women are a key population. Inequality, poverty and violence place them at higher risk of HIV exposure and exacerbate the impact of HIV on their lives. Protection of their rights promotes universal access to HIV prevention, treatment, care and support for women.
Convention on the Rights of the Child (CRC)	Describes the rights of children	Children are also a key population. Limiting their rights to equality, participation and access to information and services places them at higher risk of HIV exposure. Protection of children's rights promotes universal access to HIV prevention, treatment, care and support.
Convention on the Rights of Persons with Disabilities (CRPD)	Describes the rights of people living with disabilities	Protecting and promoting all the rights of people with disabilities reduces their vulnerability to HIV and promotes universal access to HIV prevention, treatment, care and support.

Regional human rights frameworks

Regional human rights frameworks exist in Europe, Africa, Asia and the Americas. These regional human rights instruments also deal with a range of human rights of priority concern in the region, and in some cases with specific populations. For example, the African Charter on the Rights and Welfare of the Child sets out human rights provisions important for children in Africa.

Like international human rights, regional human rights apply equally to people affected by HIV, and some deal specifically with the rights of key populations. These regional instruments create useful human rights standards for countries within the region, and may be used as a benchmark for national responses to HIV.

National human rights frameworks

National human rights documents, such as a bill of rights within a country's constitution, ref ect national commitments to respect, protect, promote and fulfil human rights. These fundamental human rights, while not HIV-specific, nevertheless apply to people affected by HIV. Many constitutions also create specific protection for the human rights of vulnerable populations such as women, children or people with disabilities.

Many countries have constitutions that include a bill of rights. Countries are required to take steps to make these rights real. Increasingly, countries are also beginning to enact national laws that ref ect their commitment to human rights. Some countries have HIV-specific laws that protect the rights of people infected and affected by HIV to non-discrimination and equality.

National, regional and international human rights commitments provide an important framework for HIV and human rights programmes in the following ways:

- They set out the rights of all people, including people affected by HIV and AIDS. This helps to guide your human rights-based HIV programming to focus on creating a legal and policy framework that protects key rights important for health and HIV.
- They tell us what our states have committed to doing. This gives you an advocacy framework to hold states accountable where they have not developed laws, policies or programmes to meet their human rights commitments.
- They guide the interpretation of laws in the courts and can be used in HIV-related litigation.

See Chapter 3 for practical information on developing human rights and HIV programmes, and more information on actions to monitor, review and reform HIV laws.

2011 United Nations General Assembly Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS

The Political Declaration, adopted by the United Nations General Assembly in 2011, is a pledge by world leaders to "redouble efforts to achieve by 2015, universal access to HIV prevention, treatment, care and support".

It furthermore recognises the importance of removing any barriers that stand in the way of people getting the HIV prevention, treatment, care and support they need. This means reducing stigma and discrimination, including through addressing laws, policies and practices that perpetuate discrimination, inequality and violence against people living with HIV and other key populations. It also means increasing legal and rights literacy, increasing access to justice, and strengthening capacities of law enforcement and health professionals.

2015 targets include:

- Reduce sexual transmission of HIV by 50% by 2015.
- Reduce HIV transmission among people who inject drugs by 50% by 2015.
- Eliminate new HIV infections among children by 2015 and substantially reduce AIDS-related maternal deaths.
- Reach 15 million people living with HIV with treatment by 2015.
- Reduce TB deaths in people living with HIV by 50% by 2015.
- Close the global AIDS resource gap by 2015 and reach annual global investment of US$2–24 billion in low- and middle-income countries.
- Eliminate gender inequalities and gender-based abuse and violence, and increase capacity of women and girls to protect themselves from HIV.
- Eliminate stigma and discrimination against people living with and affected by HIV through promotion of laws and policies that ensure the full realisation of all human rights and fundamental freedoms.
- Eliminate HIV-related restrictions on entry, stay and residence.
- Eliminate parallel systems for HIV-related services to strengthen integration of the AIDS response in global health and development efforts.

For more information on the Political Declaration, *see* the full text at: www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_un_a-res-65-277_en.pdf

Key resources

For more information on responses to HIV that protect and promote rights and remove punitive laws:

ATHENA Network, AIDS Legal Network, ARASA (2009). '10 reasons why criminalization of HIV exposure or transmission harms women'.

Available at: www.athenanetwork.org/advancing-womens-human-rights/10-reasons-why-criminalization-harms-women.html

Global Commission on HIV and the Law (2012). 'Risks, rights & health'.

Available at: www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf

Harvard School of Public Health and ICASO (2004). 'HIV/AIDS and human rights in a nutshell'.

Available at: http://hurilink.org/tools/HIVAIDS_and_HRinNutshell-Webversion1.pdf

Open Society Institute (2008). '10 reasons to oppose the criminalisation of HIV exposure or transmission'.

Available at: www.opensocietyfoundations.org/sites/default/files/10reasons_20081201.pdf

UNAIDS and OHCHR (2006). 'International guidelines on HIV/AIDS and human rights (consolidated version).

Available at: www2.oh chr.org/english/issues/hiv/guidelines.htm

Using the International Guidelines on HIV/AIDS and Human Rights

The UNAIDS International Guidelines on HIV/AIDS and Human Rights were developed in September 1996 and updated in 2006. The guidelines are a helpful tool for determining how key human rights principles can be used for HIV responses. They are built on key international human rights set out in instruments such as the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The guidelines apply these rights to the context of HIV and AIDS, setting out recommendations for what states must do in order to meet their human rights commitments in the context of HIV.

They set out 12 guidelines for state action in order to:

- develop coordinated, participatory and multi-sectoral structures to respond to HIV across all sectors, including through the participation and inclusion of civil society
- develop a legal and regulatory framework that protects and promotes the rights of all people in the context of HIV and AIDS, including key populations
- develop legal support services to increase awareness, access to justice and enforcement of human rights in the context of HIV and AIDS.

For a full copy of the guidelines, *see*: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

2.3 Commitments to the HIV response based on human rights

Along with human rights treaties and other legal standards, there are political declarations signed by governments that are not legally binding but represent a strong political commitment (pillar 2 in Figure 1). In this regard, the United Nations General Assembly Political Declaration on HIV/AIDS contains essential commitments by all governments on HIV and human rights (*see* box on page 19).

There are also resolutions by relevant human rights bodies, such as the Human Rights Council, and international human rights guidelines that deal specifically with health and HIV. For example, the UNAIDS International Guidelines on HIV/AIDS and Human Rights provide detailed guidance on human rights-based responses to HIV. Both have been used extensively to lobby governments for policy change and law reform.

2.4 Human rights principles in HIV programming

Key resource

For further details on the Alliance accreditation system and the full set of principles and standards, please go to: www.aidsalliance.org/Pagedetails.aspx?id=546

The Alliance HIV and human rights programme standards recommend that human rights form the basis of all HIV programming.

These aspirational standards define and ref ect the Alliance's values and experiences of evidence-informed good practice in the field of HIV and human rights. The standards recognise the need to put human rights at the centre of HIV programming through all stages of the programme cycle, from design through to implementation, monitoring and evaluation.

2.4.1 Equality and non-discrimination

HIV programmes should respect, protect, promote and fulfil the right to equality and to non-discrimination:

- They should be available, acceptable and accessible to all people, without discrimination.
- They should seek to promote the equal rights of women, men and other gender identities.
- They should be adapted to meet the needs of all key populations to ensure they receive equal access to services.
- They should integrate specific strategies to actively promote the right to equality of all people, including women, men, other gender identities and key populations, and to prohibit unfair discrimination.

2.4.2 Equal and full participation of all stakeholders

All relevant stakeholders should be involved in HIV programmes as full and equal partners. This promotes the right to participation. It also gives stakeholders the power to bring about change in their own lives. Equal and full participation ensures that HIV programmes are designed, developed and implemented by stakeholders and respond to their specific needs. This helps to create available, acceptable and accessible HIV programmes that respond across all sectors of society.

In order to maximise equal and full participation, organisations should:

- involve a diverse range of people living with HIV and other key populations within the organisational structures and processes
- involve all stakeholders, including CBOs of key populations and other affected communities, CSOs and faith-based organisations working for and with these communities, government and parastatal institutions, traditional leaders, the private sector, donors and international organisations, in all stages of the HIV programming process
- ensure that structures and processes are designed to promote the equal and full participation of all stakeholders
- identify capacity-building needs to promote the equal and full participation of stakeholders who lack experience and skills
- identify and address other barriers to equal and full participation for specific populations.

Example

Using human rights to strengthen HIV law in Mauritius: review and reform of criminal laws

In 2006 Mauritius introduced a draft HIV law to respond to their HIV epidemic. At the time, there was limited protection from the discrimination people affected by HIV experienced in their daily lives. A local human rights-based CSO, PILS, advocated for an HIV law that protected and promoted national, regional and international human rights commitments.

While developing the HIV law, PILS held meetings with the attorney general and a range of government and other CSOs, as well as the minister of health, to sensitise stakeholders to HIV and human rights. Their main concern was that the HIV law should protect rights and remove criminal laws that blocked effective responses to HIV. In particular:

- Mauritian criminal laws criminalised the possession or distribution of equipment related to drug use, like needles or syringes. This limited the ability of harm reduction programmes to respond to the growing HIV incidence among people who use drugs. The HIV law needed to include internationally recognised harm reduction measures to protect human rights.
- Draft versions of the HIV law proposed criminalising the wilful transmission of HIV. There is no evidence that criminalising HIV transmission reduces the spread of HIV. Instead, it contributes to further stigma and discrimination against people living with HIV or at higher risk of HIV exposure.

As a result of advocacy, the Mauritius HIV and AIDS Act 2006 became a protective human rights-based law that protects the rights of people and does not contain coercive responses to HIV, in line with human rights commitments and international recommendations.

Key message

The greater involvement of people living with HIV (GIPA)

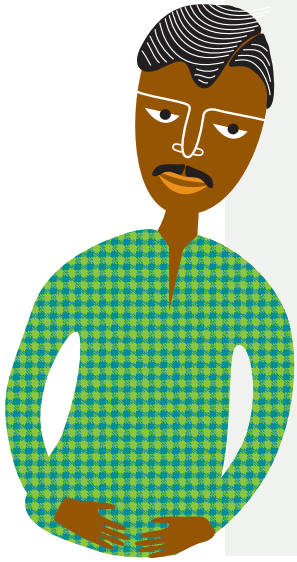
The call for active and meaningful involvement of people living with HIV was formally recognised in 1994 when 42 countries signed the Paris Declaration. This declaration formalised and declared, "The Greater Involvement of People Living with, or affected by HIV/AIDS is critical to ethical and effective national responses to the epidemic", and they agreed to "support a greater involvement of people living with HIV at all … levels … and to … stimulate the creation of supportive political, legal and social environments."

2.4.3 Community at the centre of all programmes

Communities and the organisations that represent them (CBOs) must be at the centre of all HIV programmes. Placing communities at the centre of responses to HIV ensures a rights-based response to HIV. It respects the right of communities to participate in bringing about change in their own lives. When communities are involved in identifying needs and designing and developing services, this encourages community ownership of the programmes. It also creates a demand for, and increases access to, appropriate, effective and sustainable services that fulfil the needs of all, including the most vulnerable populations.

What is a community?

A community is a group of people who feel that they have something in common. For example, a community might be people who live in the same village or area; people who work together; or a group of people who share interests or circumstances. This means that formal and informal organisations may feel that they too are part of a community (rather than separate from it) if they share the same interests and circumstances. People can also belong to more than one community at the same time. For example, a healthcare worker may identify herself as part of the local community where she lives and part of the wider 'health community' in the region.



New communities form when people find themselves in new circumstances. For example, people living with HIV might begin to see themselves as a community as they identify shared problems, needs and challenges. Understanding communities involves understanding how people identify themselves rather than relying on the views or definitions of others.

Source: International HIV/AIDS Alliance (2006). 'All together now! Community mobilisation for HIV/AIDS'.

HIV programmes mobilise communities, placing them at the centre in the following ways:

- Communities participate as full partners in all aspects of HIV programming, including planning, research and M&E.
- Communities are involved in the initial phase, to identify important stakeholders and key populations vulnerable to and at higher risk of HIV exposure.
- Communities participate in the human rights assessment to identify inequalities and imbalances, key issues, priorities and concerns.
- Communities are involved in the planning, design and development of HIV programmes that protect and promote their health rights.
- Communities participate in and support the implementation of HIV programmes.
- Communities are integrally involved in monitoring and evaluating HIV programmes.

Example

Viviendo en Positivo in Peru puts community at the centre

Vivendo en Positivo, an Alliance partner organisation made up of key populations in Lambayeque, northern Peru, has demonstrated the benefits of putting communities at the centre of HIV programmes. The project was set up by Via Libre in 2008 to support key populations and key population CBOs to tackle stigma and discrimination in the Andean region. Through the project, people living with HIV, gay men and other men who have sex with men, sex workers and transgender people began to prioritise their health needs by participating in health- and HIV-related decision-making at local and regional levels.

Initially, Via Libre supported communities outside of the capital to mobilise, organise and identify their capacity-building needs for targeted training and skills-building. These communities then developed an advocacy agenda and underwent advocacy training based on adapted Alliance advocacy materials. A working group, the Advocacy Regional Space centre (ARS), was set up to represent the various key population organisations in the region. ARS aimed to mobilise, mediate and advocate for policy change; to position representatives of key populations within decision-making structures; and to engage with the media and the general public. Communities also undertook education, awareness-raising, and stigma and discrimination reduction campaigns (initially with Via Libre, and later on their own) with healthcare workers, educators and journalists, as well as the general public.

The project has helped increase the empowerment, visibility and inf uence of key populations, including transgender people, who now represent their communities at local, national and regional levels. This has helped to place issues of sexual diversity, gender identity and sex work on the public agenda. It has supported increased access to decentralised HIV and TB care, and a strengthened legal and regulatory framework for HIV. The increased visibility of key populations and the awareness-raising work has also sensitised stakeholders and helped to decrease stigma and discrimination.

A key lesson learnt during the project was the value of time spent on community mobilisation and empowerment at the outset. This created strong, involved and independent community organisations, with the skills to lead the project into the future. The project also highlighted how decentralised, community-led agendas allowed for an approach that responded to the differing needs and prioritise of each local area.

Key resources

For more information on the Alliance's work with communities, including people living with HIV:

Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance and Open Society Institute (2008). '"Nothing about us without us": Greater, meaningful involvement of people who use illegal drugs'.

Available at: http://issuu.com/aids_alliance/docs/nothing_about_us_report_english?

International HIV/AIDS Alliance (2010). 'Good Practice Guide: Greater involvement of people living with HIV (GIPA)'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=464

International HIV/AIDS Alliance (2007). 'Keep the best, change the rest: participatory tools for working with communities on gender and sexuality'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=257

International HIV/AIDS Alliance (2006). 'All together now! Community mobilisation for HIV/AIDS'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=228

Duty bearers are those who have an obligation to respect, protect, promote and fulfil rights. Important categories of duty bearers in relation to health include policymakers at the health ministry, hospital managers, health professionals, inspectors and parliamentarians.

Rights holders are individuals and communities who have rights, including marginalised populations. In order to effectively claim their rights, they must be able to access information, organise and participate, advocate for policy change and obtain redress.

Source: WHO (2009). 'Policy brief: A human rights based approach to health'.

2.4.4 Capacity-building of rights holders and duty bearers

Capacity-building helps to ensure that HIV programmes become available and accessible. It supports duty bearers to implement programmes and rights holders to access programmes. Capacity-building also helps to promote accountability. It educates duty bearers about their obligations, and tells rights holders about their rights so that they can take action when these are violated or unfulfilled.

Organisations can assess and take steps to integrate capacity-building needs in various ways:

- Build the capacity of your own organisations to undertake human rights-based HIV work. Your organisation can start by identifying the skills and capacity you need to develop human rights-based HIV programmes. This should be integrated into your organisation's capacity-building plans.
- Your HIV programmes can integrate activities to build the capacity of rights holders to claim their rights. The communities you work with need awareness, knowledge and skills to understand what HIV services are available, what are their rights to access them, how to access them, and what they can do when their rights are denied.
- Your HIV work can also help to build the capacity of duty bearers to respect, protect, promote and fulfil the rights of all citizens. Service providers also need awareness, knowledge and skills to understand how to design and deliver services that respect and protect the rights of affected communities.

See Chapter 3 for more information on useful programmes to build the capacity of rights holders and duty bearers to protect health rights.

Example

Building the capacity of communities in Zimbabwe to protect human rights

The work of ARASA and its partners in Zimbabwe shows how capacity-building can be integrated into existing HIV programmes to support rights holders to claim health rights and duty bearers to uphold their obligations.

Two ARASA partners, Zimbabwe Lawyers for Human Rights (ZLHR) and the Zimbabwe National Network for People Living with HIV (ZNNP+), adapted ARASA's human rights, HIV, TB and treatment literacy manual for local communities in the Masvingo province. They started by training local participants to document human rights examples from their districts, communities and healthcare facilities. This community-driven approach helped to identify key problems and solutions from within communities. The examples were integrated into a booklet that included information on available legal services, community-based models of dispute resolution and rights-based responses within treatment literacy.

The booklet has empowered 300 community stakeholders on the human rights challenges within Zimbabwe's healthcare system, where access to health goods and services is limited. The trained cadres then sensitised communities, patients, healthcare workers, village chiefs and community leaders on the importance of rights-based approaches to community health issues.

The project has increased knowledge and understanding of human rights. It has empowered communities, and increased engagement and advocacy for health and human rights. Communities themselves are able to identify problems and solutions to increase universal access to HIV-related healthcare. Advocacy district team clusters now report to the Provincial Health and Rights Advocacy Forum to ensure ongoing monitoring of access to medicines, stock-outs and other human rights violations in access to healthcare.

2.4.5 Accountability

Accountability is an important principle in human rights discourse. States are duty bearers. They have a duty to uphold human rights in line with international human rights laws and standards, as well as regional commitments and national laws. When states fail to fulfil their duties – for example, by withholding treatment from key populations, making HIV testing mandatory, limiting access to harm reduction, or excluding people living with HIV and members of key populations from participating in the national response – they should be held accountable. Rights holders, who include individuals, communities and civil society, are entitled to take action to get redress when governments violate human rights.

States are not the only duty bearers. In some circumstances, non-state actors such as individuals and companies also have human rights responsibilities, and can also be held accountable when they do not comply with these.

Your HIV programmes can integrate the principle of accountability by including activities that do some or all of the following:

- Ensure the equal and full participation of, and respond to the prioritised needs of, all key stakeholders and communities.
- Mobilise communities to demand their rights; for example, by training communities on their rights and building their capacity to document human rights violations and advocate for change.
- Provide legal support services; for example, to help people to get legal advice, legal representation and support for enforcing rights through courts and other mechanisms.
- Strengthen mechanisms for developing and enforcing HIV-related human rights; for example, through training lawyers, parliamentarians and human rights institutions.
- Support the inclusion of human rights-related issues and of representatives of key populations in the advocacy and campaigning work of the HIV and broader health coalitions your organisation belongs to.
- Support advocacy for changes to laws and policies; for example, through advocacy capacity-building of affected individuals and communities, and training on key accountability mechanisms, such as parliaments and national human rights institutions, to help them inf uence law and policy review and reform.
- Support engagement with human rights mechanisms; for example, by reporting human rights violations and challenges to the United Nations treaty monitoring committees set up to oversee country compliance with the various international human rights treaties.

Example

Uniting to demand action and accountability in Senegal

Senegal has been praised for its success in fighting HIV and AIDS. Yet as the government tried to scale up its HIV response, a number of problems emerged:

- There was no clear strategy or vision for scaling up the HIV response.
- Key populations were not being targeted with interventions.
- Respect for the rights and dignity of people living with HIV was lacking.
- Access to HIV testing and treatment remained limited.

In general, civil society felt that it had been pushed aside and had no real impact on government decision-making or on holding government accountable. So a group of five NGOs came together to highlight these problems, propose constructive solutions, and participate in making necessary changes. They formed an informal network, the Observatoire de la Réponse au VIH/SIDA au Sénégal (Watchdog of the response to HIV and AIDS in Senegal), which:

- drafted a position paper highlighting the group's collective ref ections and recommendations on how to improve Senegal's response to HIV
- met with national HIV and AIDS authorities and international organisations to present their analysis and seek feedback
- held a press conference to release a position paper and demand action
- became actively involved in the processes and mechanisms established to deal with the identified problems.

Today, civil society is more meaningfully involved in key aspects of Senegal's response to HIV and AIDS, and many of the problems highlighted by the Observatoire are being addressed. The project has shown that strong civil society engagement with government can improve the response to HIV and AIDS. It has also shown that civil society organisations are most effective when they build coalitions and work together, propose practical solutions based on sound analysis, and remain independent and critical of government while engaging with government officials.

Source: Open Society Institute (2009). 'Health and human rights: a resource guide'. Available at: www.equalpartners.info/Chapter2/ch2_4Examples.html#ch2_4anch6

Example

Advocacy campaign to end forced sterilisation in Namibia: my body, my womb, my rights

In 2008, a coalition of civil society organisations in Namibia, led by groups working on women's rights and HIV, formed an advocacy campaign to respond to the forced sterilisation of pregnant women with HIV. The campaign, called Non-negotiable: my body, my womb, my rights, aimed to generate public debate on stigma and discrimination against women with HIV, and to increase public pressure on the government to protect women with HIV from forced sterilisation.

A court case was brought against the government for violating the women's rights by allowing them or forcing them to be sterilised without their informed consent. Alongside the court case, communities were mobilised to attend a public march at the start of the trial. There were sit-ins by women living openly with HIV in the courtroom and at public health facilities, and a petition was circulated that was handed to the minister of health. Thanks to the broad coalition of organisations involved, the campaign received regional and international support, with hundreds of individuals and organisations signing the petition.

The media was an important part of the campaign. The campaign generated significant media support from both national media houses and the regional and international press. All press releases, interviews and public statements emphasised the fact that forced sterilisation was a blatant act of discrimination against women living with HIV. Media coverage and radio interviews were undertaken in vernacular languages with women living with HIV. The campaign website included ongoing updates of campaign actions and outcomes.

In 2012, the court handed down judgement in the case. They found that the women had been sterilised without giving proper, informed consent and should be compensated for their loss.

For more information on the campaign go to www.endforcedsterilisation.wordpress.com and on the outcome of the case www.southernafricalitigationcentre.org

3 Human rights-based HIV programmes and interventions

In this chapter:

- Recommended HIV and human rights programmes and interventions
- 3.1 Stigma and discrimination reduction programmes
- 3.2 Legal support services
- 3.3 Monitoring and reforming laws, regulations and policies
- 3.4 Legal literacy
- 3.5 Training healthcare workers
- 3.6 Training lawmakers and law enforcement officials
- 3.7 Reducing gender inequality, harmful gender norms and gender-based violence
- 3.8 Core community-led interventions

STANDARD 33: Our organisation promotes the human rights of women, men, other gender identities and those of all sexual orientations by transforming gender relations and reducing inequality.

STANDARD 37: Our organisation mobilises communities most affected by HIV in order to ensure an effective HIV response.

STANDARD A2: Our programmes are designed to build the capacity of both rights holders and duty bearers to claim their rights and to promote, protect and respect the rights of others.

STANDARD A3: Our organisation holds both state and non-state actors accountable for the enjoyment of all human rights as a core part of all our programmes.

STANDARD A4: Our organisation promotes and/or provides legal services to ensure redress for HIV-related discrimination experienced by people living with HIV and key populations.

Key terms

Programme levels of intervention are individual, community, health services and structural.

Structural level includes changing laws and policies to better respect, protect and promote human rights.

Chapter 3: Human rights-based HIV programmes and interventions

Recommended HIV and human rights programmes and interventions

Human rights-based HIV programmes specifically aim to promote the right to health, as well as a range of other civil, political, economic, social and cultural rights linked to health and wellbeing in the context of HIV. Programmes are firmly based within their surrounding social, political, economic and cultural contexts. They **recognise** and **respond** to underlying inequalities, prejudices and power relationships that increase vulnerability and risk of exposure to HIV.

> "Many people suffering from AIDS are not killed by the disease itself but are killed by the stigma surrounding everybody who has HIV/AIDS. That is why leaders must do everything in their power to fight and to win the struggle against this stigma."
>
> Nelson Mandela, 14th International AIDS Conference, Barcelona, 2002

In this chapter we describe key evidence-based HIV and human rights interventions largely guided by:

- the Alliance's good practice HIV programming principles and standards
- UNAIDS Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses.

In keeping with the Alliance programme standards, these programmes aim to bring about change at various levels, by:

- building capacity among rights holders to claim their rights
- building capacity among duty bearers to promote and protect rights
- increasing accountability for human rights and HIV
- providing support services for claiming and enforcing rights in the context of HIV.

Bringing about change at different levels

In order to promote universal access to HIV prevention, treatment, care and support without discrimination, human rights-based HIV programmes, as with all HIV programming, should lead to change at four levels: individual, community, services and structural.

The Change Framework and the Ottawa Charter both acknowledge that individuals, households and communities cannot always realise their right to health without support. A variety of factors impact on a person's ability to realise their rights, and some of these, especially structural factors, may be beyond their control. By understanding the challenges at various levels, human rights-based HIV programmes can develop a mix of interventions at all these levels to bring about change.

Key resources

Alliance accreditation principles and standards.

Available at: www.aidsalliance.org/Pagedetails.aspx?id=546

International HIV/AIDS Alliance (2014). 'EMPowerment for Advocacy: the EMPAD Policy Framework for national advocacy by and with key populations'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=90667

UNAIDS (2012). 'Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses'.

Available at: www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_May2012.pdf

Lists seven key programmes for HIV and human rights, with an explanation of the purpose of, and examples of, each programme.

The Ottawa Change Framework

The Ottawa Change Framework encourages the development of human rights-based HIV programmes to bring about change at different levels in order to promote universal access to HIV prevention, treatment, care and support.

1. Change at the level of **individuals**, peers, relationships and households.
2. Change in **community**, social and cultural values and norms.
3. Change in health and support **services**.
4. Changes in laws, policies and other **structural** factors.

Changes at the structural level are particularly important for promoting human rights.

Key resource

For more information on the Ottawa Charter:

WHO (1986). 'The Ottawa Charter for Health Promotion'.

Available at: www.who.int/healthpromotion/conferences/previous/ottawa/en/

Suggested human rights-based HIV programmes and intervention level

The programmes suggested below are based on UNAIDS's recommended practical programmes to reduce stigma and discrimination, and strengthen access to justice in national responses to HIV and AIDS. The Alliance has added one critical programme underpinning core human rights-related interventions led by CBOs and CSOs. Each programme operates at one or several of the levels described by the Ottawa Framework.

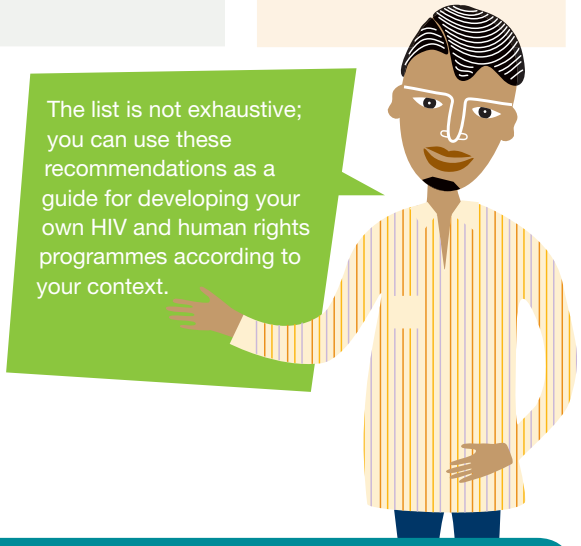


Figure 2: Key human rights-based programmes and primary intervention levels

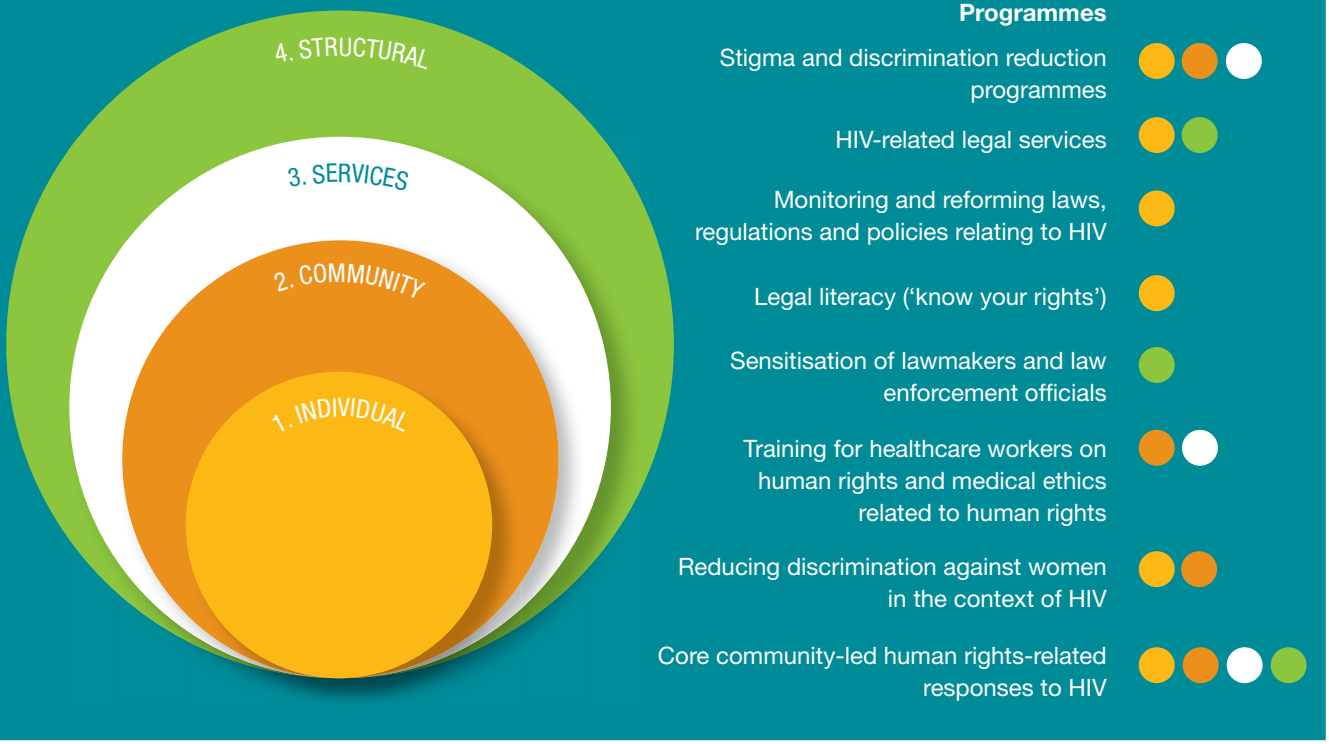


Table 4: Key human rights-based programmes for the HIV response	
The programmes	**How can you use them?**
Stigma and discrimination reduction programmes	These programmes help to address actionable causes of stigma and discrimination, and to empower people affected by HIV and AIDS.
HIV-related legal services	These programmes facilitate access to justice and redress in cases of HIV-related human rights violations.
Monitoring and reforming laws, regulations and policies relating to HIV	Programmes to monitor, review and reform laws help to create laws and policies that support rather than block, access to HIV and health services.
Legal literacy ('know your rights')	Legal literacy programmes teach those living with HIV and key populations at higher risk of HIV exposure about laws, their rights and how to enforce them.
Sensitisation of lawmakers and law enforcement officials	These programmes sensitise lawmakers and law enforcers about how the law impacts on HIV and about the rights of key populations, in order to support protection of rights and access to services.
Training for healthcare workers on human rights and medical ethics related to human rights	Training programmes improve healthcare workers' understanding of their own and their patients' rights, and help to reduce stigma and discrimination in the health sector.
Reducing discrimination against women in the context of HIV	These programmes address gender inequality and gender-based violence as both causes and consequences of HIV infection.
Core community-led human rights-related responses to HIV	These programmes are core CSO and CBO interventions, including crisis response (reacting to emergencies regarding security and protection from exposure of individuals and their organisations); effective human rights-related advocacy; and the production of evidence to inform human rights programming and advocacy.

The United Nations confirms that more than 20 years into the epidemic, stigma and discrimination remain highly prevalent. The Political Declarations on HIV and AIDS of 2001, 2006 and 2011 all commit to reducing stigma and discrimination against people living with HIV and other key populations.

3.1 Stigma and discrimination reduction programmes

3.1.1 What are stigma and discrimination?

People living with HIV often experience stigma and discrimination. HIV-related discrimination is grounded in stigma that attaches not only to people living with HIV and their families, but to other, often already stigmatised populations, such as women, sex workers, men who have sex with men, transgender people, people who use drugs, refugees and displaced people, and people with disabilities.

Stigma refers to negative beliefs, feelings and attitudes towards people living with, or seen to be linked to, HIV. It is expressed in stigmatising language and behaviour, such as shunning and avoiding everyday contact, verbal harassment, blaming and gossiping, as well as physical violence. Stigma often lies at the root of discriminatory actions. Stigma may also be internalised by stigmatised individuals in the form of feelings of shame, self-blame and worthlessness.

Discrimination refers to the unfair and unjust treatment of an individual because of HIV.

3.1.2 Why is it important to address stigma and discrimination in HIV programming?

Stigma and discrimination are major barriers to universal access to prevention, treatment, care and support. They also undermine the effectiveness of national responses to HIV. Stigma and discrimination harm individuals, violate their human rights and undermine public health.

- **Discrimination causes harm to individuals**. Stigma can lead to a wide range of human rights violations against people living with HIV, including violence and abuse. This has negative consequences for the physical and mental wellbeing of individuals.
- **Discrimination is a human rights violation**. HIV-related discrimination undermines the right to non-discrimination and equality that are the cornerstone of human rights. It also leads to violations of other human rights, such as the right to live free from violence and cruelty, and the rights to education and health. For example, children living with HIV have been expelled from schools, which infringes on their right to education. Healthcare workers have disclosed the HIV status of patients without their consent, undermining their right to privacy. Sex workers experience daily violence and abuse, violating their rights to physical integrity and to live lives free from violence.
- **Discrimination undermines public health.** HIV-related stigma and discrimination push people away from important services and sources of care and support. They cannot access information to help them reduce their risk. They may be afraid to have an HIV test or to disclose their HIV status to their sexual partners, families and friends. Stigma and discrimination can also undermine treatment where people hide or don't take their medicine in case it exposes their HIV status. Women may be afraid to disclose their HIV status to husbands or sexual partners, and may have to hide their medication. This can interrupt treatment and undermine their right to health.

3.1.3 Key programmes to reduce stigma and discrimination

UNAIDS recommends that all national responses to HIV include programmes specifically aimed at reducing stigma and discrimination. All of the recommended HIV and human rights programmes set out in this chapter ultimately work together to reduce stigma and discrimination. However, in this section we look at programmes specifically designed to address stigma and discrimination at the individual and community levels. These programmes work to address the causes of stigma and discrimination, and to empower people living with HIV and other key populations. They can be integrated within existing HIV prevention, treatment, care and support programmes. Examples include:

- Support groups of people living with HIV can invite community members to attend their meetings (where appropriate) or attend other community meetings. This provides an opportunity to share information and discuss fears and experiences with the broader community. It can also help to diminish stigma against people living with HIV.
- Popular TV and radio shows can integrate non-stigmatising messages into their programming.
- Community, religious and traditional leaders, and celebrities can be mobilised to speak out against stigma and discrimination and to publicly disclose their HIV status.
- People living openly with HIV and representatives of key populations can participate in organisations, structures and processes to provide the perspectives of affected populations.

People are disclosing their status to their families, which helps with reducing transmission. There is a general improvement in relationships between couples as there is no need of hiding the drugs in the chickens' houses as some couples used to. This results in an improvement in adherence as families can remind one another what time to take medication.

Key resources

For more information on how to develop good stigma and discrimination reduction programmes:

UNAIDS (2007). 'Reducing HIV stigma and discrimination: a critical part of national AIDS programmes. A resource for national stakeholders in the HIV response'.

Available at: www.unaids.org/en/media/unaids/contentassets/dataimport/pub/report/2008/jc1521_stigmatisation_en.pdf

UNAIDS (2005). 'HIV-related stigma, discrimination and human rights violations: case studies of successful programmes'.

Available at: www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub06/jc999-humrightsviol_en.pdf

- HIV-related stigma can be documented and monitored through the Stigma Index survey (see key resources), which helps us to understand HIV-related stigma and improve programmes to address it.
- Messages on stigma and discrimination can be included in HIV programmes in key institutions like hospitals and clinics, schools and other government institutions.

Table 5: Stigma and discrimination reduction programmes

What?	Why?	How?	What change?
Programmes addressing causes of stigma and discrimination, and to empower people living with HIV and other key populations.	■ HIV-related stigma and discrimination push people away from important services and sources of care and support. ■ Key populations may be afraid to have an HIV test or to disclose their HIV status to their sexual partners, families and friends.	■ People living with HIV support groups invite community members to attend their meetings. ■ TV and radio shows integrate non-stigmatising messages into their programming. ■ Mobilisation of community, religious and traditional leaders to speak out against stigma and discrimination. ■ Representatives of key populations participate in State institutions. ■ HIV-related stigma can be documented and monitored through the Stigma Index survey ■ Messages on stigma and discrimination in HIV programmes in key institutions.	■ **Change at individual level:** people living with HIV and other key populations feel empowered to attend health services and claim their rights. ■ **Change at community level:** Communities are inclusive of diversity and understand the needs and rights of people living with HIV and other key populations.

Example

Stigma trainers' programmes in Zambia

Alliance Zambia's Regional Stigma Training Programme integrates stigma and discrimination reduction within existing HIV programmes with different stakeholders. To do this, the programme team provides training, action planning and technical support for stigma reduction interventions across Africa as part of the Alliance's Africa Regional Programme. Working across the region allows for sharing and learning from a range of backgrounds and sectors.

Training addresses three main factors driving stigma and discrimination: a lack of awareness and understanding of stigma and discrimination; misguided fears of becoming infected with HIV; and values and attitudes that link HIV with 'immoral' behaviour. Participatory exercises help trainees to identify, understand and change manifestations of stigma against people living with HIV and other key populations, such as men who have sex with men.

For example, a teacher in Zambia used his training to sensitise children at his school about HIV-related stigma and discrimination. The children responded by encouraging a former learner who had been ostracised from school to return to an accepting school community.

The programme has highlighted the usefulness of integrating stigma and discrimination reduction activities into existing programmes in order to increase their reach and impact. In Zambia, treatment support workers in the Antiretroviral Community Education and Referral project were trained as stigma reduction agents to integrate stigma reduction in their work. Stigma reduction activities were also integrated into the Copperbelt programme for orphans and vulnerable children to address their support needs within the community. The integration of the stigma reduction training with staff from these and other projects, such as STAMPP and ZAMBART, increased the success of the programme.

Example

Responding to stigma and discrimination in El Salvador

People living with HIV and other key populations in El Salvador report stigma, discrimination and even violence in accessing basic health services, education and employment. The police and healthcare workers are said to be particular offenders. Discrimination is linked to high levels of violence against lesbian, gay, bisexual, transgender and intersex (LGBTI) communities.

Starting in 2009, Atlacatl (an organisation of people living with HIV representing HIV and human rights issues for key populations in El Salvador) adapted the Vida Digna project to reduce HIV-related stigma and discrimination. First, ViiV Healthcare's Positive Action and the Alliance supported a learning exchange between Atlacatl and Colectivo Sol in Mexico. This was followed by workshops with partner organisations representing sex workers, transgender women, women living with HIV, gay men and men who have sex with men. The workshops used the Vida Digna Participatory Community Assessment (PCA) tool to identify the nature and extent of stigma and discrimination; to discover which service providers discriminated; and to find out what key populations wanted to do about it.

Based on this, Atlacatl and the Salvadoran partner organisations have used the PCA tool since 2011 to run stigma and discrimination workshops with key populations, service providers, law enforcers and the broader community. They aim to reduce stigma and discrimination in service delivery, and to build the capacity of key populations to participate in decision-making and advocate for change. Initial feedback is that the project has already improved relationships between key populations and service providers, which will help to improve services.

The initial time spent on learning exchange and capacity-building also meant that partner organisations gained the experience, visibility and confidence to participate in policymaking bodies and advocate for the rights of key populations. Several partner organisations now participate in the Country Co-ordinating Mechanism, which is working with government to pilot specialised health units for meeting the needs of the LGBTI community in El Salvador. Key populations are being brought out of the margins and into the decision-making spheres of society, helping to reduce stigma and discrimination in law, policy and practice.

What is Vida Digna?

Vida Digna, first established in Mexico in 2005, is an innovative programme to reduce HIV-related stigma and discrimination. The programme, supported by its donor ViiV Healthcare's Positive Action and implementing partner Colectivo Sol, helps key populations to organise, analyse and take action to reduce stigma and discrimination in their communities by sensitising service providers, the general public and government.

3.2 Legal support services

3.2.1 What are legal support services?

Legal support services help people to access justice when their rights have been abused. They are an important mechanism for holding governments accountable to protect and promote the rights of people living with HIV and other key populations. Legal support services aim to make rights real by giving people the tools to claim their rights in various ways, including by:

- providing legal advice and assistance when rights have been violated
- holding officials accountable when they fail to implement and enforce legal rights for people living with HIV and other key populations
- helping people living with HIV and other key populations to use redress mechanisms like the courts or an alternative dispute forum to enforce their rights.

Example

Access to justice for widows in Kenya: using alternative dispute resolution to protect property rights

Many women in rural Kenya have lost partners to AIDS. According to customary traditions of some tribes, a female widow is 'inherited' by a male relative of the deceased – a brother, uncle or cousin. Originally, this tradition aimed to provide for and protect widows. However, it has been misinterpreted over time to oblige a widow to have sex with a male relative. Those who refuse to be 'inherited' are often evicted them from their land and lose their property; they become 'disinherited' and homeless.

In response, KELIN, an ARASA partner organisation supporting health and human rights in Kenya, developed a cultural structures project to support justice for women who have been disinherited. The project focuses on alternative forms of dispute resolution to promote access to justice. KELIN engages respected elders of the Luo tribe, training them on human rights and supporting them to work with families to resolve disputes. Meetings with elders are held twice a month to support their work. Widows and orphans are thereby supported to return to their original villages and homes, or to resettle elsewhere. In 36 months, KELIN supported elders to resolve 88 cases successfully.

See http://kelinkenya.org/wp-content/uploads/2010/10/Working-with-Cultural-Structures-A4FINAL.pdf for a publication on how to work with traditional leaders.

3.2.2 Why are legal support services important?

Legal support services are essential to creating an enabling legal and regulatory environment for HIV, and to enforce existing laws. Protective laws, regulations and policies are only effective if people living with HIV and other key populations know their legal rights and are able to claim them. Legal support services help by giving advice, referring people to complaints mechanisms and helping people use these systems and processes, which can be complicated and difficult to navigate.

Examples of legal support services:

- Information to sex workers about their health rights and how to report violations helps them to challenge and report health workers who discriminate against them.
- Legal support services to assist widows to reclaim their family property when it has been taken away after the death of their husbands, giving them economic stability to care for themselves and their children.
- Litigation to challenge unprotective or discriminatory laws relating to healthcare. This helps to enforce or change law, policy and practice to protect HIV-related health rights. Strategic litigation is often a faster way of starting law reform.

In all these ways, legal support services help to build effective and supportive national responses to HIV.

Key resources

IDLO and UNAIDS (2009). 'Toolkit: scaling up HIV-related legal services'.

Available at: http://data.unaids.org/pub/Manual/2010/20100308revisedhivrelatedlegalservicetoolkitwebversion_en.pdf

Open Society Foundations (2010). 'Community-based paralegals: a practitioner's guide'.

Available at: www.opensocietyfoundations.org/sites/default/files/paralegal-guide-20101208.pdf

Southern Africa Litigation Centre (2011). 'Equal rights for all: litigating cases of HIV-related discrimination'.

Available at: www.southernafricalitigationcentre.org/1/wp-content/uploads/2012/10/HIV-and-Discrimination-Manual-pdf.pdf

UNAIDS (2006). 'Courting rights: case studies in litigating the human rights of people living with HIV'

Available at: www.unaids.org/en/media/unaids/contentassets/dataimport/pub/report/2006/jc1189-courtingrights_en.pdf

Example

The Treatment Action Campaign case: litigation to advance access to HIV treatment in South Africa

In 2001, the Treatment Action Campaign (TAC) and the AIDS Law Project took legal action against the South African minister of health for failing to provide national prevention of parent-to-child transmission (PPTCT) programmes. At the time, estimates showed that approximately 70,000 children were at risk of mother-to-child transmission of HIV. Although antiretroviral treatment was shown to significantly reduce mother-to-child transmission, the government had only provided PPTCT programmes in two pilot sites in each province.

After various advocacy strategies had still not brought about change, TAC brought legal action against the national and provincial ministers of health. They argued that the government's actions were a breach of the constitutional right to have access to healthcare services, since only those women near the pilot sites could access PPTCT services. In December 2001, the high court ruled in favour of TAC and ordered the minister of health to make nevirapine available in all public hospitals and clinics where testing and counselling facilities existed.

The victory showed that litigation can be an effective tool to advance access to treatment, especially in countries with constitutionally protected rights to health. However, litigation was only one of many strategies that contributed to the successful campaign. Other important strategies included a broad social movement mobilising community support, committed leadership from people living with HIV, and alliances with treatment activists around the world.

For more information *see*: Open Society Institute (2009). 'Health and human rights: a resource guide'. Available at: www.equalpartners.info

Table 6: Legal support service interventions and impact on change

What?	Why?	How?	What change?
■ Provide legal information, advice and referrals ■ Provide legal support and representation	■ To inform affected populations about their legal rights ■ To improve access to justice for HIV-related human rights violations ■ To improve universal access to HIV-related prevention, treatment, care and support	■ Train paralegals, law clinics and human rights organisations to provide HIV-related human rights services ■ Train networks of people living with HIV and other key populations to provide legal advice ■ Encourage private lawyers to provide *pro bono* (free) services ■ Support national human rights commissions, alternative dispute resolution mechanisms, and traditional and religious leaders to respond to HIV-related human rights violations	■ **Change at individual level:** increased awareness, knowledge and empowerment in ability to access justice. ■ **Change at service level:** increased knowledge, awareness and skills to provide legal support services; increased accountability from services (e.g. health services) if violations are challenged ■ **Change at community and structural levels** may occur where successful challenges bring about changes in law, policy, values and practices

"I couldn't use public services because the name on the documents, the name my parents gave me, wasn't me, and a person who doesn't have their identity doesn't have rights."

Marcela Romero, regional coordinator of REDLACTRANS (Latin American and Caribbean Network of Transgender People) and president of ATTA (Asociación de Travestis, Transexuales y Transgéneros de Argentina)

3.3 Monitoring and reforming laws, regulations and policies

3.3.1 What are monitoring and law reform programmes?

These programmes examine laws, regulations and policies that affect people living with HIV and other key populations vulnerable to or at higher risk of HIV exposure. They aim to monitor and review the legal environment to see how it impacts on the HIV response. The overall aim of these programmes is to create strong, supportive laws, regulations and policies, and a legal environment that is conducive to universal access. They help to:

- collect information on the legal and regulatory framework
- identify protective as well as discriminatory laws, policies and practices
- assess how these impact on HIV and on key populations
- advocate for law review and reform to hold governments accountable for creating an enabling legal environment.

3.3.2 Why are they important?

HIV-related laws, regulations and policies can impact positively or negatively on the lives and rights of affected populations and on the national HIV epidemic. Protective anti-discrimination laws and policies can help to eliminate stigma and discrimination and promote universal access. Discriminatory laws and policies can increase stigma and undermine access to healthcare, education, employment and social services for key populations. It is vital that organisations providing HIV prevention, treatment, care and support also work with partners to monitor, review and reform HIV-related laws and policies.

Table 7: How punitive laws and policies impact on national responses to HIV

Law, regulation or policy	Impact on key population	Impact on response to HIV
Mandatory HIV testing and forced disclosure policy for pregnant women	Pregnant women, especially marginalised women such as those who use drugs and sex workers, avoid antenatal healthcare services for fear of being forced to have a test. They fear blame and violence from a partner when they test positive for HIV, or abandonment by a partner, family and friends	Pregnant women remain unaware of their HIV status. They do not receive HIV-related treatment. They may also unknowingly transmit HIV to partners and unborn children. HIV prevention, treatment, care and support efforts are not supported
Law or policy permitting pre-employment HIV testing for job applicants	Job applicants are forced to test for HIV. They may be discriminated against and denied employment where they test positive. Their negative experiences may discourage them from accessing other services for fear of further discrimination	People living with HIV are unable to earn a living. This increases the negative economic impact of HIV on themselves and their families. Discrimination also exacerbates the emotional impact of HIV and AIDS. HIV care and support services are undermined
Law criminalising sex between men	Men who have sex with men experience stigma and discrimination. They are harassed by law enforcement officials, and they fear arrest and prosecution in countries where same-sex sexual conduct is illegal. They choose to remain 'invisible' in society	Men who have sex with men may avoid using HIV prevention, treatment, care and support services. Services may also not be tailored to their needs. This undermines HIV prevention, treatment, care and support for a population at high risk of HIV exposure
Law permitting children to access sexual health services only with the consent of a parent or guardian	Adolescents cannot access HIV health services without a parent's or guardian's permission. So they may avoid accessing HIV information, education and testing services	Adolescents remain unaware of their HIV status, do not get treatment and may continue to unknowingly transmit HIV to sexual partners

Table 7 (Cont.)

Law, regulation or policy	Impact on key population	Impact on response to HIV
Law prohibiting provision of safe injection equipment to people who inject drugs	Organisations cannot offer harm reduction programmes. People who inject drugs may struggle to access clean needles	People who inject drugs remain at higher risk of HIV exposure through unsafe injection equipment. HIV continues to spread among this population

Example

Law reform in Argentina: advocating for the Gender Identity Law in Argentina

In Argentina and other countries, transgender people experience high levels of stigma and discrimination. They are often the targets of hate crimes; they struggle to complete school and find employment; and they do not receive appropriate care at health facilities, increasing their risk of exposure to HIV. In many countries, transgender people do not have the right to a gender identity. They are not viewed as a person in the eyes of the law, exacerbating stigma, discrimination and marginalisation.

Although sex reassignment surgery was banned in Argentina, from the 1980s onwards progressive provincial court rulings have recognised the rights of people who had undergone surgery outside of the country to change their name and gender. Building on these successes, ATTTA, formed in 1993 to promote the rights of transgender people, have brought successive court challenges to repeal police edicts that sanctioned violence, repression and detention of transgender people.

In 2007, ATTTA took the campaign to the national level, bringing together leaders from across the country to develop a national advocacy campaign that included:

- capacity-building of members to undertake awareness-raising and advocacy
- a communication strategy to increase awareness of the importance of a gender identity law
- lobbying of decision-makers from across sectors, including academia and parliament
- judicial action for *amparo* (a constitutional court remedy) to protect rights
- participation of transgender organisations in law review and reform processes
- working with other networks and organisations such as LGBTI networks.

In 2012, the Gender Identity Law was passed by the Senate by a majority of 55–0, confirming transgender people as full citizens in the eyes of the law. The law includes the right to gender identity, and allows a person to reassign their name and gender without having to seek approval from doctors or judges, or undergo surgery first. It also guarantees access to comprehensive healthcare, including sex-change surgery or hormone therapy, as part of public or private healthcare plans. Marcela Romero states, "*With this law we are claiming our right to identity. We will no more be forgotten by democracy. With this law we are here to make history.*"

ATTTA attributes the success of the law reform initiative to strong leadership; commitment and increasing visibility of transgender people and organisations; collaboration across organisations; and the support gained from a wide spectrum of political, social and cultural organisations. With a strong, protective law in place, transgender people in Argentina can continue to work to challenge stigma, discrimination and mistaken public perceptions.

Source: adapted from REDLACTRANS, UNAIDS, International HIV/AIDS Alliance, ATTTA. 'Making rights a reality: the experiences of organizations of transgender people'. Available at: www.unaids.org/en/resources/presscentre/featurestories/2012/may/20120517atransla/

Table 8: Monitoring, review and reform interventions and impact on change

What?	Why?	How?	What change?
■ Audit legal and regulatory environment, including laws, regulations and policies; access to justice and law enforcement to determine their impact on national HIV response, including: > relevant laws and policies (e.g. human rights obligations, equality laws, health laws, laws affecting key populations, employment laws, customary and religious laws) > access to justice, such as knowledge of rights, availability of legal support services, sensitised lawyers and judiciary > law enforcement (including rights protection for key populations), enforcement of protective laws, sensitised law enforcement officials. ■ To identify whether a country has protective or discriminatory/ punitive HIV-related laws and policies	■ To identify whether a country has protective or discriminatory/ punitive HIV-related laws and policies ■ To determine whether key populations know their rights and are able to access justice for violations of their rights ■ To determine whether laws are enforced in a manner that protects (or punishes) key populations ■ To identify strengths, gaps and challenges in the legal and regulatory framework; to make recommendations for strengthening the legal framework to promote health rights	■ Desk review of laws, regulations, policies and relevant research reports ■ Informant interviews with key stakeholders, including CSOs and organisations of key populations ■ Focus group discussions with key affected populations ■ Analysis of impact of laws, regulations and policies; access to justice and law enforcement on HIV and AIDS and on key populations ■ Identification of protective laws and of punitive/ discriminatory laws; identification of gaps and challenges for review and reform	■ **Change at service level:** increased knowledge and understanding of legal and regulatory framework and its impact on HIV and AIDS among those carrying out the audit ■ **Changes at individual and community levels:** may occur where the process increases awareness, understanding and knowledge of laws, regulations and policies among participants ■ **Changes at structural level,** when the recommendations are taken up to advocate for reform

Key resources

For more information on appropriate laws and policies to protect rights and promote universal access to HIV prevention, treatment, care and support:

Canadian HIV/AIDS Legal Network (2009). 'Respect, protect and fulfil: legislating for women's rights in the context of HIV/AIDS'.

Available at: www.aidslaw.ca/publications/publicationsdocEN.php?ref=976

Canadian HIV/AIDS Legal Network (2006). 'Legislating for health and human rights: model law on drug use and HIV/AIDS'.

Available at: www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1052

ICASO (1999). 'An advocate's guide to the International Guidelines on HIV/AIDS and Human Rights'.

Available at: www.tbhiv-create.org/sites/default/files/res_AdvocatesGuide-IGHR-English.pdf

Open Society Institute (2009). 'Health and human rights: a resource guide'.

Available at: www.equalpartners.info

Open Society Institute (2009). 'Human rights documentation and advocacy: a guide for organisations of people who inject drugs'.

Available at: http://inpud.files.wordpress.com/2010/11/hrdaa_doc.pdf

UNAIDS (2006). 'International Guidelines on HIV/AIDS and Human Rights'.

Available at: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

World Bank (2007). 'Legal aspects of HIV/AIDS: a guide for policy and law reform'.

Available at: https://openknowledge.worldbank.org/bitstream/handle/10986/6754/409260PAPER0Le101OFFICIAL0USE0ONLY1.pdf?sequence=1

3.4 Legal literacy

3.4.1 What is legal literacy?

Legal literacy enables people to take action in response to problems involving the law. Legal literacy programmes provide information, education and training to people living with HIV and other key populations. Know Your Rights programmes focus on human rights and national laws (including statutory and common law, as well as customary and religious law) that relate to HIV. They aim to empower people living with HIV and other key populations to know their legal rights and to take action when their rights are violated.

Key resource

For more information on various HIV-related legal services, including legal literacy:

IDLO and UNAIDS (2009). 'Toolkit: scaling up HIV-related legal services'.

Available at: http://data.unaids.org/pub/Manual/2010/20100308revisedhivrelatedlegalservicetoolkitwebversion_en.pdf

3.4.2 Why is legal literacy important?

Information, awareness and education about human rights and the law help to reduce stigma and discrimination, and facilitate access to universal HIV prevention, treatment, care and support. When people know their rights it helps them to prevent HIV transmission and get treatment, care and support. For example, they may be better able to avoid violence, negotiate safer sex, have an HIV test, disclose their HIV status safely, or get access to and adhere to treatment.

Legal literacy programmes can be included in other HIV-related programmes. For example, Know Your Rights programmes can be provided at hospitals and clinics while people are waiting to have an HIV test or get their medicines. They can be provided by peer groups or HIV support groups as part of their empowerment programmes for members. Legal literacy can also be a stand-alone programme, and can include activities such as awareness raising campaigns that provide information about rights and laws related to HIV through the media (for example, television, radio, print, social media), community mobilisation and education, peer outreach and telephone hotlines

Table 9: Legal literacy interventions and their impact on change

What?	Why?	How?	What change?
Build the capacity of people living with HIV, people affected by HIV and other key populations to know their legal and human rights, and take action when these are violated	■ To increase awareness and understanding of what rights are and when they have been infringed ■ To increase knowledge of available legal services and avenues for redress ■ To support people being able to enforce their rights when they are infringed ■ To encourage universal access to HIV prevention, treatment, care and support	■ Awareness campaigns on human rights and law through television, radio, print media and social media ■ Community mobilisation and education workshops and trainings ■ 'Edutainment' shows ■ Training and awareness-raising through peer outreach ■ Telephone hotlines and drop-in centres	■ **Change at individual level:** increased awareness, knowledge, skills, empowerment, participation. Affected populations know their rights and how to enforce them ■ **Change at community level:** communities are increasingly mobilised around law and human rights issues ■ **Change at service level** may come about when people are increasingly encouraged to access services without fear of discrimination

3.5 Training lawmakers and law enforcement agents

3.5.1 What are programmes to train lawmakers and law enforcement agents?

There is increasing evidence and acceptance of the role of the law in national responses to HIV.[3] This includes law 'on the books' (written law) as well as law 'on the streets' (the way that law is enforced). However, lawmakers and law enforcement agents often fail to develop laws that respect rights or to implement laws in ways that protect rights.

Training and capacity-building for lawmakers and those who are required to implement and enforce laws, helps to ensure that:

- Parliamentarians understand the role of the law in the national response to HIV and what laws are needed to protect the rights of affected populations.
- Ministers and ministry officials understand the importance of overseeing the implementation of protective laws.
- Judges and prosecutors are sensitised to HIV-related human rights concerns and better able to enforce rights in the courts.
- Law enforcement officials, such as the police and prosecutors, know their legal obligations, are sensitised to the rights and needs of key populations, and have the skills to enforce protective laws. Sensitisation can also increase their understanding of the impact of stigmatising attitudes, discriminatory behaviours and the failure to enforce laws.

Example

Sensitizing law enforcement officials and others about harm reduction practices in Sichuan province, China

In China, people who use drugs are largely seen as a 'public order problem' best dealt with by the Public Security Bureau (PSB) or the police. They are forced into detoxification centres and labour camps, with limited services and support for rehabilitation or harm reduction. This results in a cycle of arrest, detention and release that increases the risk of HIV exposure. Support for harm reduction programmes, like methadone maintenance treatment (MMT) and needle and syringe exchange, comes mostly from the public health sector.

In 2008, Alliance China initiated a pilot project to improve communication between the health sector and the police; reduce harassment, discrimination and detention; and increase access to harm reduction for people who use drugs. The project aimed to get healthcare workers, law enforcement officials, communities and families working together.

People who use drugs were trained to give peer support within communities and clinics to other drug users and their families in Emei and Fushun. Communities were mobilised through various peer-led interventions. Family committees were set up to support those in treatment. Healthcare staff, lawmakers and law enforcement authorities were sensitised on the rights of people who use drugs and the importance of harm reduction.

To improve communication, neighbourhood committees and the PSB were regularly invited to visit the centres to observe and better understand the work. Structures such as the Stakeholder Platform in Emei and Fushun, bring together members of the PSB and the health department to ensure regular dialogue on the programme and on human rights violations against people who use drugs. This has improved collaboration between the PSB and local health bodies, and also increased funding support for harm reduction programmes.

The police and local authorities now have an increased understanding of harm reduction practices, leading to changes in attitudes and behaviours. In 2010, service providers noted that arrests of people who use drugs have reduced, many more people are on MMT without disruptions, and there is an almost total adherence rate. In Fushun, the PSB director reported a 20% decrease in crime since the beginning of the project. The Fushun Civil Affair Bureau is now funding MMT and providing assistance to those on the programme to secure employment in the cleaning and service industries.

3. Stephens, D. and Urbano, M. (2010). 'HIV and legal empowerment', Legal Empowerment Working Papers 12, IDLO. Available at: www.idlo.int/publications/LEWP/LEWP_StephensUrbano.pdf

Training of lawmakers and law enforcers helps to increase protection and to prevent violence against and abuse of people living with HIV and other key populations, by increasing access to justice and improving law enforcement.

3.5.2 Why is training for lawmakers and law enforcement agents important?

Many countries have either limited protection in law or discriminatory laws against people living with HIV and other key populations. Even where protective laws exist, police may fail to enforce them or they may use a range of laws inappropriately to target key populations; for example, vagrancy laws may be used to arrest people who use drugs and sex workers. If lawmakers and law enforcement officials are sensitised to HIV and human rights issues, and the impact of punitive laws and practices on affected populations, they are better able to respond. Lawmakers may improve protection by developing new laws, and law enforcers may use laws to protect rather than punish populations.

> "In many countries, the law (either on the books or on the streets) dehumanises many of those at highest risk for HIV: sex workers, transgender people, men who have sex with men (MSM), people who use drugs, prisoners and migrants. Rather than providing protection, the law renders these 'key populations' all the more vulnerable to HIV. The criminalisation of sex work, drug use and harm reduction measures create climates in which civilian and police violence is rife and legal redress for victims impossible. Fear of arrest drives key populations underground, away from HIV and harm reduction programmes."
>
> Global Commission on HIV and the Law (2012). 'HIV and the law: risks, rights and health'.

Training should explore the attitudes of participants to people living with HIV and members of key populations. It should also ensure that participants understand the science of HIV, including how it is transmitted, available treatment and disease progression, and the meaning of a rights-based approach to HIV.

Key resources

For more information on working with lawmakers and law enforcers to protect HIV-related human rights:

Stephens, D. and Urbano, M. (2010). 'HIV and legal empowerment', Legal Empowerment Working Papers 12, IDLO.

Available at: www.idlo.int/publications/LEWP/LEWP_StephensUrbano.pdf

IDLO and UNAIDS (2009). 'Toolkit: scaling up HIV-related legal services'.

Available at: http://data.unaids.org/pub/Manual/2010/20100308revisedhivrelatedlegalservicetoolkitwebversion_en.pdf

UNAIDS and IPU (1999). 'Handbook for legislators on HIV/AIDS, law and human rights'.

Available at: www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub01/jc259-ipu_en.pdf

Example

Workshop for lawyers in Madagascar

In 2010, ARASA and the International Development Law Organisation (IDLO) brought together human rights lawyers from 15 Southern African Development Community countries to develop a regional toolkit on HIV-related legal services. The toolkit targets policymakers, lawyers, magistrates, judges and parliamentarians on ways to scale up HIV-related legal support services within their countries.

In 2011, the toolkit and other ARASA materials were used to train coalitions of people living with HIV and other key populations, legal and healthcare service providers, parliamentarians, justice ministers, state counsels, attorneys general and magistrates working in Indian Ocean island countries. The training encouraged participants to identify gaps in their legal frameworks and to develop action plans to strengthen legal environments for key populations in the context of HIV. Examples from the region highlighted strategies such as developing protective laws and removing punitive laws (for example, laws criminalising HIV transmission, same-sex activity and sex work), and improving access to justice through alternative dispute resolution methods. Many participants identified the need to repeal laws criminalising HIV transmission.

The workshop assisted the legal fraternity in the Indian Ocean islands to integrate human rights into their national laws, regulations, policies and programmes for HIV. The toolkit allowed sharing of experiences from the region in strengthening HIV law, policy and services.

Example

Harm Reduction Law in Ukraine: working with parliamentarians to create an enabling framework for harm reduction

Every citizen of the Ukraine has the right to health protection and medical care, in terms of section 49 of the constitution. However, until recently, substitution maintenance therapy (SMT) was unavailable for people who use drugs in the Ukraine, violating their rights to treatment and healthcare. SMT prescribes a non-injectable substitute drug for people with chronic opiate dependency. It has been shown to be highly effective for treating their dependency and also for preventing the spread of HIV.

In 2003, at a parliamentary hearing on the Ukraine government's response to HIV and illegal drug use, Alliance Ukraine's executive director emphasised the need for SMT programme implementation. Following this, ongoing advocacy, including through partnerships with international organisations, led to increased political commitment to SMT implementation. From 2004 onwards, government took steps to strengthen an enabling legal and regulatory framework for implementating an SMT programme in Ukraine. This culminated in an amendment to the drug law in 2008 to identify drug-related harm reduction as a key strategy of government drug policy, and to support NGOs in implementing SMT programmes in Ukraine.

While there remain some legal barriers to SMT implementation in Ukraine, evaluations of the current SMT programme show an enormous impact. Illegal opiate use among clients has reduced substantially and risk behaviours have reduced fourfold. Over a quarter of clients are receiving antiretroviral treatment and nearly 20% are on TB treatment or follow-up. Importantly too, the attitudes of many patients have changed from distrust to willingness and active participation. Working with lawmakers and those who implement the laws was critical to the success of the programme.

Source: HIV/AIDS Alliance in Ukraine (2008). 'Substitution maintenance therapy in Ukraine: can the community respond effectively to the challenges of HIV/AIDS?' Available at: www.aidsalliance.org.ua/ru/library/our/pbzt/pdf/pb_en.pdf

Table 10: Lawmakers and law enforcement agents training interventions and impact on change

What?	Why?	How?	What change?
Sensitise lawmakers on the link between HIV and human rights, and the rights of people in the context of HIV and AIDS	■ To raise awareness about the link between HIV and human rights ■ To encourage lawmakers to develop human rights-based laws, regulations and policies ■ To encourage universal access to HIV prevention, treatment, care and support	■ Education and sensitisation workshops for parliamentarians, ministers of justice, judges, prosecutors and lawyers	■ **Change at structural level:** improved protection where laws, policies and judgements on HIV and AIDS increase protection for people living with HIV and other key populations ■ **Change at service level:** improved access to justice for HIV-related human rights violations
Sensitise police officers to improve law enforcement in relation to HIV, law and human rights	■ To raise awareness and understanding, and build the capacity, of police to respond to HIV and human rights issues ■ To reduce stigma, discrimination and human rights violations by police ■ To encourage access to justice	■ Education and training workshops ■ Facilitated dialogue between affected populations, service providers and law enforcement officials ■ Involvement of people living with HIV and other key populations	■ **Change at service level:** increased awareness and understanding among law enforcers; improved access to justice for HIV-related complaints ■ This **may lead to changes at individual and community levels**, with reduced stigma and human rights violations of key populations, and increased access to justice

Table 10 (Cont.)

What?	Why?	How?	What change?
Train prison personnel to manage HIV, law and human rights issues	■ To raise awareness about the health and human rights of prisoners in the context of HIV	■ Education, training and media campaigns, including involving people living with HIV and other key populations ■ Support for developing prison HIV policies and programmes	■ **Change at multiple levels, including individual, community, service and structural**, as above.

3.6 Training healthcare workers

3.6.1 What are programmes to train healthcare workers?

Healthcare workers play an important role in helping affected populations to use HIV prevention, treatment, care and support services.

Human rights training aims to train healthcare workers about basic human rights in relation to HIV. It aims to ensure that they know about their own human rights to health and to non-discrimination in the context of HIV. It also helps to reduce stigmatising attitudes by giving healthcare workers information, tools and skills to protect patients' rights. These programmes aim to create informed, sensitised and knowledgeable service providers.

3.6.2 Why are they important?

All people have the right to health and to universal access to HIV prevention, treatment, care and support services. However, people living with HIV and other key populations commonly report human rights violations in health settings, such as:

- being tested for HIV without providing voluntary and informed consent
- breaches of confidentiality of HIV status
- being denied access to healthcare services
- in the case of pregnant women with HIV, being forced or coerced into being sterilised
- in the case of sex workers, men who have sex with men and transgender people, being humiliated by healthcare workers.

Stigma Index studies and other international studies show that stigma and discrimination are major obstacles to an effective national response to HIV, and discourage affected populations from accessing and using potentially life-saving services.[4] Human rights training for healthcare workers reduces stigma and discrimination. It helps to create supportive health services, where healthcare workers with HIV can continue to work, and where key populations feel encouraged to access their health rights.

Similar training may also be useful for other service providers, such as social welfare workers and educators. For example, where children affected by HIV and AIDS are able to access education without discrimination, this has positive benefits for their mental, physical, emotional and spiritual wellbeing. Schooling also provides children with access to HIV-related information to further protect them from HIV infection.

"Of the estimated 15 million people living with HIV/AIDS who will likely need treatment in 2011, many face considerable stigma associated with HIV/AIDS, threats to their human rights, structural barriers to accessing medicine and health care services and personal and social challenges in making and following through on HIV treatment decisions."

Barr, D., Amon, J., Clayton, M. (2011). 'Articulating a rights-based approach to HIV treatment and prevention interventions', *Current HIV Research* 9(6): 396–404.

4. *See* www.stigmaindex.org/335/feature-articles/new-report-late-testing-late-treatment-hivrelated-stigma.html

Table 11: Healthcare worker training interventions and impact on change			
What?	**Why?**	**How?**	**What change?**
Train healthcare workers on HIV and human rights	■ To educate healthcare workers on workplace HIV rights ■ To educate healthcare workers on patients' rights and the impact of discrimination ■ To reduce stigma and discrimination, and promote access to HIV-related healthcare	■ Awareness, education and training workshops, courses and campaigns ■ Media on patients' and employees' rights ■ Involvement of people living with HIV and other key populations in activities	■ **Change at service level:** increased awareness, knowledge and acceptance of human rights; improved services and increased access to prevention, treatment, care and support ■ This leads to **change at individual level** for affected populations
Train healthcare administrators on the rights of healthcare workers with HIV	■ To raise awareness of rights of employees with HIV ■ To provide a safe working environment that reduces the risk of HIV transmission and supports affected workers ■ To reduce stigma and workplace-related discrimination against employees with HIV	■ Education and training sessions for healthcare administrators ■ Media on the rights of healthcare workers with HIV ■ Support for developing and implementing workplace HIV policies and programmes	■ **Change at service and structural levels**: increased protection for employee rights of healthcare workers; improved ability to delivery HIV-related healthcare

3.7 Reducing gender inequality, harmful gender norms and gender-based violence

3.7.1 Women, gender identity, sexual orientation and HIV and human rights

All over the world, people face inequality, discrimination and violations of their human rights, including high levels of gender-based violence because of their sex, gender identity and sexual orientation.

> "Gender equality must become part of our DNA – at the core of all of our actions. This will require a social revolution. Addressing gender inequality as a human right and development imperative constitutes a main plank of this social revolution. This is not only necessary for social justice but also for achieving universal access to HIV prevention, treatment, care and support."
>
> Michel Sidibe, UNAIDS executive director, International Women's Day 2009

For example, women experience domestic and sexual violence at the hands of their partners, including same-sex partners. Transgender men and women may experience high levels of discrimination and violence, including sexual violence, from sexual partners, law enforcement officials and community members.

In many places, governments have failed to address these abuses or hold perpetrators accountable. These violations may place people at higher risk of HIV exposure, reduce their ability to prevent HIV infection, and create barriers to their access to treatment, care and support services. In many countries, large numbers of women and girls face particular challenges in accessing sexual and reproductive health services in order to protect themselves.

Key terms

Gender refers to the rules, norms, customs and practices through which the biological differences between males and females are transformed into social differences between men and women, girls and boys. Women and girls and men and boys are therefore valued differently, resulting in unequal opportunities and life chances.

Sexual orientation refers to each person's capacity for profound emotional, affectional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender, the same gender or more than one gender.*

Gender identity refers to each person's deeply felt internal and individual experience of gender that may or may not correspond to the sex assigned at birth, including their personal sense of the body (that may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, such as dress, speech and mannerisms.*

* Yogyakartha Principles: The application of international human rights law in relation to sexual orientation and gender identity

3.7.2 Violence against women and HIV

Many groups of people are vulnerable to gender-based violence. Women face disproportionately high levels of gender-based violence. Violence against women occurs in all societies. This not only violates women's rights, it also constrains their choices and limits their ability to exercise other rights, such as the rights to the highest attainable state of health, including reproductive health, and education.

> "Violence against women is perhaps the most shameful human rights violation. And, it is perhaps the most pervasive. It knows no boundaries of geography, culture or wealth. As long as it continues, we cannot claim to be making real progress towards equality, development and peace."
>
> Kofi Annan, 8 March 1999

Violence against women takes many forms:

- domestic violence, which can include rape and sexual violence, economic abuse, emotional abuse, eviction and stalking
- sexual violence, including in conf ict situations
- harmful traditional practices such as female genital mutilation and early marriage
- femicide
- human trafficking for sex or labour
- sexual harassment.

Femicide is commonly understood as meaning the killing of women because they are women. It is sometimes also referred to as misogynist murder.

UNAIDS (2012). 'Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses'.

Key message

UNAIDS recommends that programmes that seek to address women's and girls' rights in the context of HIV must address the intersections between gender inequality, gender-based violence and vulnerability to HIV infection and impact.

Key resource

For more information on violence against women:

United Nations General Assembly (2006). 'In-depth study on all forms of violence against women: report of the Secretary-General'.

Available at: http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N06/419/74/PDF/N0641974.pdf?OpenElement

Violence against women and girls places them at higher risk of poor health, including as a result of HIV. There are clear links between HIV and gender-based violence. HIV status is a cause of violence against women, and various forms of violence against women increase their risk of, and vulnerability to, HIV. In addition, violence and the threat of violence prevent women and girls from accessing and using HIV-related information, having an HIV test, accessing PPTCT services, and receiving counselling and treatment.

Key message

"Studies show the increasing links between violence against women and HIV and demonstrate that HIV-infected women are more likely to have experienced violence, and that women who have experienced violence are at higher risk for HIV."

United Nations General Assembly (2006). 'In-depth study on all forms of violence against women: report of the Secretary-General'.

Key resources

For more information on responding to gender inequality, gender-based violence and harmful gender norms in your HIV programmes:

amfAR AIDS Research (the MSM Initiative) (2010). 'Integrating rights and health for MSM and other LGBT people: the role of HIV/AIDS implementers and PEPFAR'.

Available at: www.amfar.org/uploadedFiles/Articles/Articles/Around_The_World/MSM/amfAR_Integrating%20Rights%20%20%20and%20Health%20for%20%20%20MSM%20and%20Other%20%20%20LGBT%20People.pdf?n=239

ATHENA Network and HEARD (2010). 'Framework for women, girls and gender equality in national strategic plans on HIV and AIDS in southern and eastern Africa'.

Available at: www.heard.org.za/gender/nsp

International HIV/AIDS Alliance (2007). 'Sex work, violence and HIV: a guide for programmes with sex workers'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=308

International Planned Parenthood Federation (2009). 'The truth about men, boys and sex: gender transformative policies and programmes'.

Available at: http://ippf.org/resources/publications/Truth-About-Men-Boys-and-Sex-gender-transformative-guide

Promundo, MenEngage, UNFPA (2010). 'Engaging men and boys in gender equality and health'.

Available at: www.promundo.org.br/en/sem-categoria/engaging-men-and-boys-in-gender-equality-and-health-download/

UNAIDS (2010). 'Agenda for accelerated country action for women, girls, gender equality and HIV Operational plan for the UNAIDS action framework: addressing women, girls, gender equality and HIV'.

Available at: www.unicef.org/aids/files/20100226_jc1794_agenda_for_accelerated_country_action_en.pdf

Table 12: Gender equality interventions and impact on change

What?	Why?	How?	What change?
Programmes to reduce gender inequality to raise awareness about different gender identities, and to reduce gender-based violence among young people	■ To raise awareness among young people of gender equality, different gender identities, gender-based violence, and the link between this violence and HIV ■ To reduce gender-based violence and discrimination among young people in and out of school	■ Training for educators, including peer educators, about gender equality, gender identities and gender-based violence in the context of HIV ■ Training for all gender identities in schools on rights to gender equality, different gender identities, and gender-based violence	■ **Change at service level:** increased awareness, knowledge and understanding among educators; increased access to non-discriminatory and appropriate information and education ■ Leads to **change at individual and community levels:** increased awareness, knowledge and acceptance; increased access to non-discriminatory information and education; improved gender equality, reduced harmful gender norms and gender-based violence; increased safety, decreased risk of exposure to HIV.

Table 12 (Cont.)

What?	Why?	How?	What change?
Monitoring, reviewing and reforming legal and regulatory frameworks to promote gender equality and to eliminate gender- based discrimination and violence	■ To raise awareness about the links between gender-based discrimination and violence, and HIV ■ To protect the human rights of all gender identities from gender inequality and gender-based violence ■ To promote universal access to HIV prevention, treatment, care and support	■ Audits to identify gaps in protection or where laws and policies create barriers to HIV prevention, treatment, care and support ■ Advocacy for inclusion of programmes to support gender equality and reduce gender-based violence in national strategic plans ■ Advocacy for law and policy reform to remove laws that discriminate against women, girls and other gender identities, or that fail to protect from gender-based violence	■ **Change at structural level:** improved understanding of legal and regulatory environment, and law and policy review and reform; improved implementation of laws, policies and plans ■ **Change at individual and community levels:** empowerment and improved gender equality; increased protection from gender-based discrimination and violence
Legal literacy relating to gender rights and HIV	■ To ensure that women, girls and other key populations know their legal rights, along with avenues for redress ■ To ensure that women and other key populations are able to access acceptable and appropriate legal support services	■ Public awareness campaigns ■ Training and capacity-building for women, girls and other gender identities ■ Training for legal sector workers to increase capacity to provide legal advice and representation to women, girls and other gender identities	■ **Change at service level:** increased awareness, knowledge and skills among legal support service providers; increased access to justice ■ **Change at individual level:** increased awareness, knowledge and skills; increased access to justice

Table 12 (Cont.)

What?	Why?	How?	What change?
Addressing harmful gender norms and cultural practices that put women, girls and other gender identities at risk of HIV	■ To raise awareness of the links between harmful practices and HIV ■ To reduce the risks of HIV transmission as a result of harmful practices	■ Training for religious leaders, traditional leaders and community members about the links between harmful practices and HIV transmission ■ Programmes to increase economic empowerment of women and to increase access to education and training resources ■ Awareness-raising with communities about the links between harmful practices and HIV transmission	■ **Change at community level:** increased awareness, understanding and acceptance; increased gender equality; decreased risk of HIV exposure ■ **Change at individual level:** increased awareness, understanding and empowerment; increased gender equality; decreased risk of HIV exposure
Engagement with decision-makers on gender equality principles in both human rights and HIV policies	■ To ensure that the needs of women, girls and other gender identities are adequately ref ected in national strategic plans ■ To ensure that the human rights of women, girls and other gender identities are recognised and protected in the national response to HIV ■ To ensure universal access to HIV prevention, treatment and support for women, girls and other gender identities	■ Conduct advocacy with relevant national ministries and institutions to ensure that national strategic plans mainstream gendered human rights	■ **Change in law and policy:** increased awareness and knowledge; increased political commitment and mobilisation for change; improved national strategic plans on HIV, gender equality and gender-based violence

3.8 Core community-led interventions

3.8.1 What are core community-led interventions?

As previously described programmes have shown, the role of CSOs and CBOs in providing human rights responses to HIV is crucial. It is also a key principle of human rights-based programming that communities and those organisations representing them be at the centre of all responses. CBOs of people living with HIV and populations at higher risk, and other CSOs, should have a leading role in designing and implementing each of the human rights programmes suggested in this guide.

The specific community-led interventions described here relate to the core work of CSOs and CBOs in generating evidence to better respond to the human rights-related needs of beneficiaries; to advocate for human rights-based responses to HIV; and to participate in decision-making processes that affect the communities they represent.

Core community-led human rights-related interventions can be classified in three main spheres:

1. Responding to human rights-related crises affecting beneficiaries/clients and members This entails responding to emergencies regarding security and protection from exposure of individuals and their organisations to violence and other human rights abuses.

Examples of interventions in this area include:

- **Risk assessment.** Guidelines, training and implementation of assessment analysis of potential risks to CSOs and CBOs and their members, and protocols to react.
- **Safety and security training.** For individuals working for and in contact with CSOs and CBOs and their inner circle of family and friends, and CSO and CBO premises and materials.
- **Small grants schemes.** For CSOs and CBOs to be able to provide at least elementary, emergency, short-term support to members who are victims of violence or other human rights abuses, including food, shelter and covering hospital or medicine costs.
- **Identity/data protection systems and training**
- **Coordination of national, regional and international responses** to individual crises and emergencies. Devising communication platforms and rapid reaction tools among national-level actors, as well as regional and international players, to ensure strategic collaborative responses to crises, such as passing of punitive legislation, arrests of activists, media campaigns against CSOs and CBOs or their members, and attacks on CSOs and CBOs or their members.

2. Community-led human rights-related advocacy and coordination efforts with wider civil society to effect changes in policy to increase the human rights protection of key populations, and for effective public HIV policies based on human rights.

Examples of community-led advocacy interventions can be found in the Alliance's EMPowerment for ADvocacy framework (EMPAD) (*see* the key resources box on page 53). EMPAD proposes a pathway for strategic collaboration on advocacy between mainstream HIV and other key population CSOs and CBOs. It is built around five key high-level strategies:

1. **Strengthen alliances and advocate in support of key populations and a shift in social perceptions** through interventions such as stakeholder analysis, training on human rights-based programming and advocacy for CSOs, and involving key population CBOs in wider civil society coalitions.

2. **Increase the organisational capacity of CBOs of key populations to carry out advocacy** through activities like organisational advocacy assessment and organisational development training of CBOs, and training for CBOs on advocacy and human rights-based responses.
3. **Engage in national policy processes** through interventions such as national-level technical workshops on rights-based responses to HIV, establishing national multi-sector human rights monitoring committees, and joint advocacy between HIV and wider key population CSOs and CBOs.
4. **Link grassroots, national, regional and global policy** by reporting human rights-related barriers to HIV, and rights to inf uence donors, grassroots mobilisation of advocacy and campaigns, and multi-level campaigning (local, national, regional, international).
5. **Promote knowledge-sharing among advocacy programmes and decision-makers** through high-level regional workshops on rights-based responses to HIV for government officials and key population CSOs and CBOs, regional consensus and good practice forums, and regional horizontal advocacy skills and strategies exchange.

3. Community-based data collection systems among beneficiaries to inform evidence-based human rights programming and advocacy

The establishment of such systems should include as a minimum:

- **Training on human rights-related individual case research**. Personnel in CSOs and CBOs who are in charge of data collection must be trained in human rights research principles and techniques, and on the selection of human rights-based HIV programmes available to respond to the needs of individual cases.
- **Community consultation and ethical research protocol guiding and training**. To ensure that data collection responds to the needs of beneficiaries, and is sensitive to the specific contexts and vulnerabilities of individuals and communities.
- **Provision of data management materials, and training on data management, data protection and M&E**. CSOs and CBOs must have the right data collection platforms for their capacity to sustain data collection.

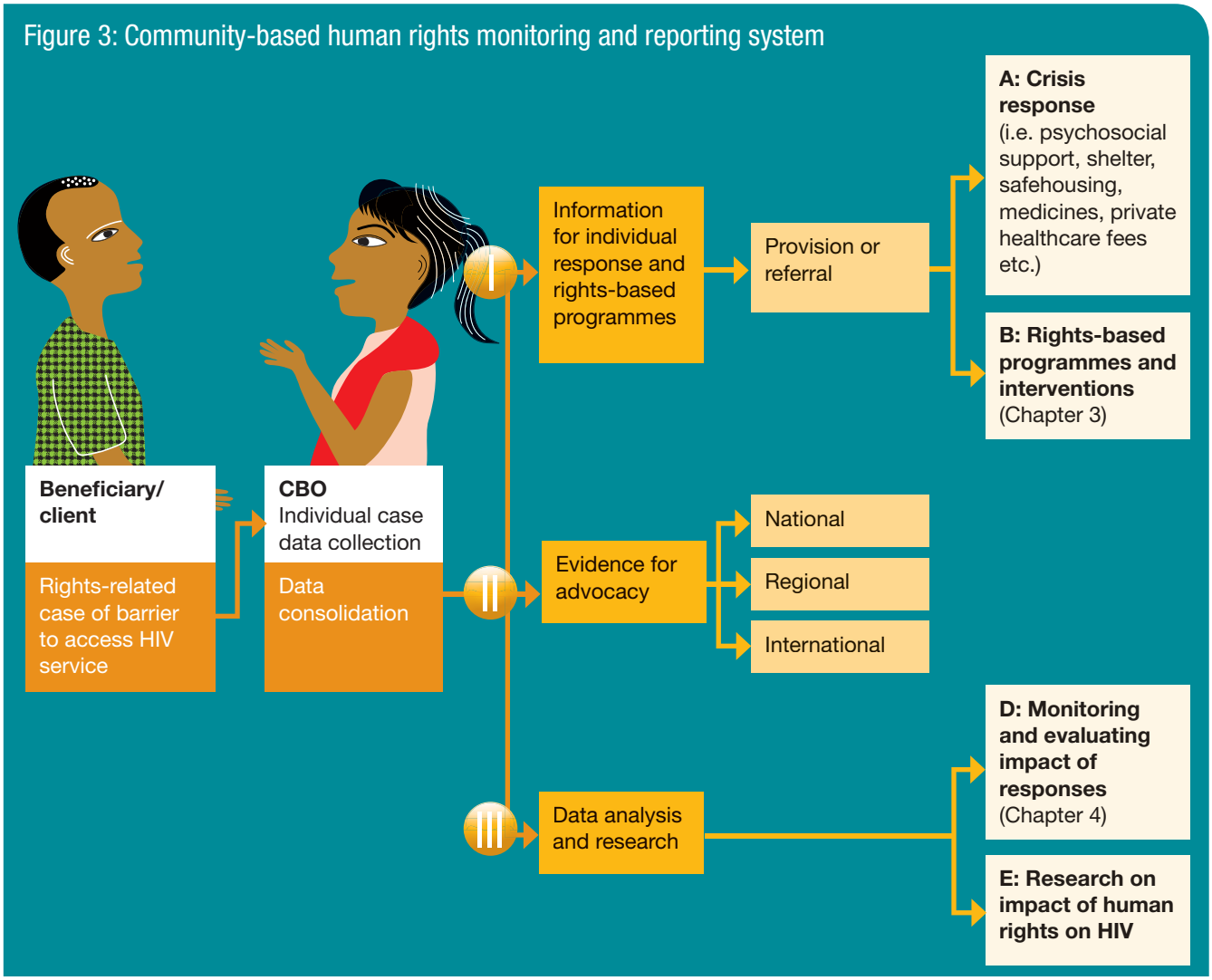
Figure 3 on page 53 describes how these three sets of interventions interact in the Alliance-proposed model of a community-based human rights monitoring and reporting system. In such a system, a CBO collects the necessary human rights-related information from each member or individual who agrees to it. Analysis of this information allows the CBO to:

1. Identify if there is an urgent response required for the individual (for example, to provide safe shelter, food or psychological counselling).
2. Identify which of the other seven human rights-based programmes could best respond to the specific situation of the individual, and enrol or refer them to the relevant programmes.
3. Build up evidence of human rights-related barriers to HIV services to be used in advocacy, and to monitor and evaluate the CBO's human rights-based programming.

3.8.2 Why are core community-led interventions important?

Key population CSOs and CBOs are essential to providing effective responses to HIV; a principle that is at the core of the Global Fund's Community Systems' Strengthening (CSS) Framework. This centres on promoting the development of CBOs and structures as a key mechanism through which health outcomes can be improved.

Figure 3: Community-based human rights monitoring and reporting system



The CSS Framework's principles are closely related to the principles of human rights-based programming. They state that CBOs, key affected populations and communities should have a significant and equitable role in all aspects of programme planning, design, implementation and monitoring; that programming should be developed based on human rights, including the right to health and non-discrimination; and that CBOs contribute to a system of multiple accountability (of them to their members, of government to their citizens, and of donors to the communities they aim to serve).

"I first came to this organisation because I was worried about HIV. I couldn't tell anybody that I was gay. My family still doesn't know. But here I also learned that I am ok, that I have my rights. I am much happier with myself. We care for each other and I feel safer. When I go back home … nobody knows what I do, even when I have been on TV while marching for LGBT rights. But I am an activist now, and I feel I belong here."

Allan, member of CBO of MSM, Uganda

The role of CBOs in responding to HIV and AIDS is particularly critical for members of key populations in contexts of high vulnerability to human rights violations, violence, and stigma and discrimination. These circumstances dissuade or prevent key populations from reaching HIV and human rights services. In such cases, CBOs are the only agencies able to reach these populations and respond to their

immediate HIV and human rights-related needs with the maximum possible level of protection for members, beneficiaries and the organisations themselves.

The involvement of CSOs and CBOs in providing human rights-based responses to HIV cannot be limited to consultation and implementation as partners. These communities must have the capacity to provide human rights-based programmes themselves, and take strategic and sustainable decisions about the human rights context where their members and beneficiaries evolve.

Table 13: Core community-led interventions

What?	Why?	How?	What change?
CSOs and CBOs react to crises among beneficiaries/ clients and members	■ To improve the services CSOs and CBOs provide to key populations ■ To contribute to key populations accessing HIV services, and members/beneficiaries carrying out their HIV and human rights activism safely	■ Risk assessment, safety and security training, small grants schemes, data protection systems and training, coordination of national, regional and international responses to individual crises and emergencies	■ **Change at individual level:** members and beneficiaries/clients feel safer to approach services and mobilise within their community
CSOs and CBOs coordinate effective human rights-related advocacy	■ To ensure that key populations have full participation and inf uence in decision-making processes on HIV and human rights that affect them	■ Coordinating advocacy efforts and strategies between CSOs and CBOs to carry out effective human rights-related advocacy	■ **Change at individual level:** members of CBOs feel empowered to demand their rights ■ **Change at community level:** communities around key populations interact with CBO members on health and rights
CSOs and CBOs collect relevant information among members to inform evidence-based human rights programming and advocacy	■ To ensure that data from members and beneficiaries/clients is relevant, in order to be able to provide (or refer to) the most adequate human rights-based responses to individual needs, and focus their advocacy on the most pressing human rights-related issues affecting the community they represent	■ Establishing a CBO-based evidence collection system from members to inform human rights programming and advocacy, including training on human rights-related individual case research, community participation and ethical research, together with training on data management, data protection and M&E	■ **Change at service level:** members of CBOs/beneficiaries feel empowered to share experience to access adequate services, and receive human rights- as well as HIV-related services. ■ **Change at structural level:** sound evidence and civil society support leads to a more enabling environment with changes in law and practice

Example

Transgender organisations in Latin America and the Caribbean monitor and respond to human rights violations

Stigma, discrimination and violence drive many transgender people to the margins of society and prevent them from realising their right to health and other human rights. In response, REDLACTRANS, the Latin American and Caribbean network of transgender people, was formed in 2005. The aim was to challenge the social exclusion and lack of representation of the transgender community in a region where there are alarming levels of transphobia and human rights violations against transgender people with impunity. Since then, REDLACTRANS has gained an increasingly strong voice in national and regional policy arenas *(see* example on page 37), and currently has national CBOs affiliated to the network in over 14 countries.

REDLACTRANS wanted to generate evidence of violence and human rights violations against its organisations' members in order to inform advocacy and support. So the network launched an innovative human rights monitoring mechanism: a secure online portal that is being used to document human rights-related issues affecting individual members. REDLACTRANS consulted with transgender communities across the region before developing questionnaires (in terms of community-sensitive language and issues covered), data collection methodology, and system specification in order to ensure that they would be adequate and useful. The system is now exclusively run by trained personnel within the CBOs affiliated to REDLACTRANS, and provides valuable quantitative and qualitative evidence for the network and its members.

In 2012, REDLACTRANS published *The night is another country*. This ground-breaking report documented shockingly high rates of violence against transgender human rights defenders in Latin America, fuelled by widespread violations of transgender people's rights by law enforcement officers with almost total impunity. All the testimonies collected and presented in the report were based on information provided by the data collection system and individual interviews with members.

The night is another country was launched at a series of high-profile policy seminars in Brussels, Geneva, London and Washington DC in early 2013. These events were the first step in an advocacy campaign (Just Like You, *Igual a ti*) with national, regional and global partners, calling for national gender identity laws, like Argentina's *Ley de Identidad de Género*, across Latin America. By the end of 2013, a number of Latin American countries were at various stages of passing gender identity legislation along the lines of Argentina's.

Key resources

On community-based crisis responses:

Avahan India AIDS Initiative (2013). 'Community led crisis response systems: a handbook based on the experience of the Avahan India AIDS Initiative'.

Available at: http://futuresgroup.com/resources/publications/community_led_crisis_response_systems_a_handbook_based_on_the_experience_of

International HIV/AIDS Alliance India (2010). 'Crisis response teams in core advocacy groups'.

Available at: www.aidsalliance.org/includes/document/IndiaCS.pdf

On community-based advocacy:

International HIV/AIDS Alliance (2014). 'Empowerment for Advocacy, the EMPAD policy framework by and with key populations'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=90667

International HIV/AIDS Alliance (2002). 'Advocacy in action, a toolkit to support NGOs and CBOs responding to HIV/AIDS'.

Available at: www.aidsalliance.org/Publicationsdetails.aspx?Id=142

On community-based monitoring and reporting systems:

Benetech. Martus: open source technology for data gathering for human rights defenders: http://benetech.org/our-programs/human-rights/

GNP+, ICW, IPF, UNAIDS. The People Living with HIV Stigma Index: www.stigmaindex.org

GNP+, Human Rights Count! www.humanrightscount.gnpplus.net

KANCO. Digital mapping of HIV, TB and human rights-related services in Kenya: www.kanco.ushahidi.com/main

On Community Systems Strengthening Framework:

Global Fund (February 2014). 'Community Systems Strengthening Framework'.

Available at: www.theglobalfund.org/en/civilsociety/reports/

UNAIDS (2011). 'Supporting community-based responses to AIDS, tuberculosis and malaria: a guidance tool for including community systems strengthening in proposals for the Global Fund to Fight AIDS, Tuberculosis, and Malaria'.

Available at: www.unaids.org/en/media/unaids/contentassets/documents/programmes/programmeeffectivenessandcountrysupportdepartment/gfresourcekit/20110920_JC2170_community_systems_strengthening_en.pdf

4 The HIV and human rights programme cycle

In this chapter:

- 4.1 Introduction
- 4.2 Step 1: Doing a situational assessment
- 4.3 Step 2: Analysing the problems and priorities
- 4.4 Step 3: Setting goals, objectives and indicators
- 4.5 Step 4: Implementing the programme
- 4.6 Step 5: Monitoring, evaluating and learning

STANDARD A1: Our programmes are based on a human rights assessment.

STANDARD 31: Our organisation is committed to a human rights-based approach.

STANDARD 26: Our organisation has a monitoring and evaluation plan with clearly defined indicators linked to objectives, and the plan is adequately budgeted for.

STANDARD 36: Our organisation is committed to ensuring the participation of those populations intended to benefit from programmes at all stages of the programme cycle.

Key terms

Goal states what you ultimately want to contribute to.

Objectives state key areas of change you focus on to achieve your goal.

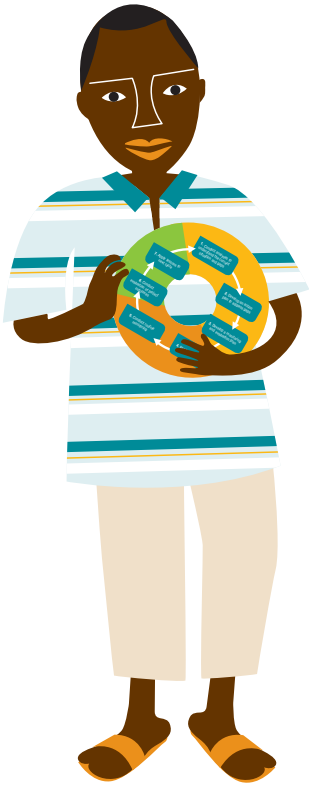
Activities state actions you will take to achieve your objectives.

Chapter 4: The HIV and human rights programme cycle

4.1 Introduction

Good planning is vital for successful and effective programming. In this chapter, we look at the basic steps involved in planning a human rights programme. The information relates to the diagram below that gives an example of a programme cycle. However, it can be adapted to whichever cycle or planning approach your organisation prefers to use.

Figure 4: The project planning cycle



Chapter 2 takes a detailed look at the **principles** of human rights programming. In this chapter, attention is given to the principles that are especially important during planning. These include:

- the greater involvement of people living with HIV (GIPA) and key populations
- equality and non-discrimination
- protection and promotion of the basic human rights of all.

Key message

The greater involvement of people living with HIV (GIPA) and planning a human rights programme

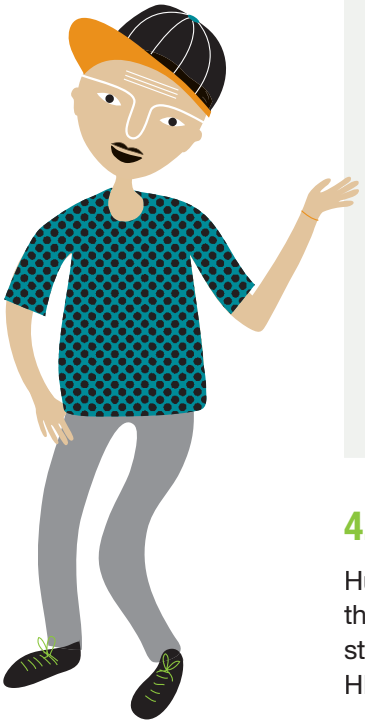
The Alliance is committed to the involvement of people living with HIV and key populations at all stages of the programme cycle (Good practice programming standard 3). In practice, however, human rights violations can prevent communities' participation, as well as their access to HIV prevention, treatment, care and support.

Examples of barriers include:

- stigma and discrimination
- fear of criminal sanctions (especially with sex workers and people who inject drugs)
- social and cultural inequality
- poverty
- illiteracy
- language
- distance from urban areas.

To address these challenges, human rights programmes can take steps such as:

- Actively involve people living with HIV and other key populations, ensuring that they are not just **represented** in discussions, but can **participate** meaningfully.
- Ensure that policies and practices provide for confidentiality, privacy and 'safe spaces' in all aspects of the work.
- Support networks and build links with organisations that represent people living with HIV and other key populations.
- Address practical issues, such as by working in local languages.



Key resource

For guidance about how to carry out each of these assessments, go to the Alliance human rights toolbox at: www.aidsalliance.org/publicationsdetails.aspx?Id=90668

4.2 Step 1: Doing a situational assessment

Human rights programmes need to begin with an assessment of the context in which they are based. Assessments are vital to ensure that programmes respond to the real strengths and weaknesses of the human rights situation faced by people living with HIV and other key populations, and make the best use of available resources.

An assessment should aim to identify how these different factors impact on the lives of people living with HIV and other key populations. Its results will guide the planning of programmes that, by having a clear focus and target, can contribute to promoting the rights and reducing the vulnerability of such groups. They can also contribute to increasing universal access to HIV prevention, treatment, care and support.

There are many different ways to carry out a situational assessment. However, with human rights, it is particularly important to include attention to:

- law, access and enforcement analysis
- stakeholder analysis
- gender analysis
- internal analysis.

How to design a situational assessment

A situational assessment for human rights programming needs to answer four key questions:

1. What do you need to know? For example, what do you need to know about the legal and policy environment; how human rights affect the lives of people living with HIV and other key populations; other organisations involved in human rights; and your own organisation's resources for addressing human rights? What do you need to know about particular areas, such as how gender affects human rights? It is also important to define the scope of the assessment. This includes the geographic scope (such as a community, region or country) and population scope (such as all communities or specific ones, such as sex workers).

2. Which types and sources of information will tell you what you need to know? Examples of types of information include:

- official national documents, such as laws and policies relevant to HIV, people living with HIV and other key populations
- quantitative data, such as mapping exercises or figures on the number of cases of human rights violations
- qualitative data, such as interviews with the targets of human rights violations
- 'grey literature', such as reports and examples by groups of people living with HIV or key populations.

3. Who do you need to involve to get that information? Examples of stakeholders and organisations include:

- people living with HIV and other key populations
- NGOs and other organisations supporting those communities
- human rights organisations and experts
- government policymakers
- the judiciary and law enforcement agencies such as the police
- gender organisations.

4. How will you involve those stakeholders? Depending on the participants and the time and resources available, examples of assessment methods include:

- interviews with key stakeholders
- surveys and questionnaires
- meetings
- focus group discussions
- literature review of participants' resources.

When selecting the methods that you will use, it is important to consider ethical issues (such as confidentiality and safety for the participants) and practical issues (such as what locations to hold meetings).

Example

Informing a human rights programme through a situational assessment

In Burkina Faso, a pilot project by the International Development Law Organisation (IDLO) identified that the failure to protect people living with HIV and other key populations (especially sex workers and men who have sex with men) was hampering HIV programmes. Challenges included the low level of collaboration among stakeholders; lack of affordable and accessible legal services; and the socio-cultural context, with people not wanting or knowing how to bring their cases to court. In response, the Initiative privée et communautaire de lutte contre le VIH/SIDA (IPC) (Private and community initiative to fight HIV/AIDS) developed a project in collaboration with other organisations, including Association des Femmes Juristes (Association of female jurists) and groups working with people living with HIV and other key populations, such as Réseau pour une grande implication des personnes infectées par le VIH (GIPA network) and Association African solidarité.

The project started with a situational assessment. This aimed to map the existing situation and identify gaps. The process involved identifying key populations and the organisations that work with them; training people living with HIV and other key populations to conduct the assessment in order to better reach and engage communities; and analysing existing legal services and laws that could be used to protect these populations.

The assessment aimed to answer questions such as:

- What problems do sex workers, men who have sex with men, and people living with HIV face because of their occupation, sexual orientation or HIV status?
- What available legal services can be strengthened to become more sensitive to these communities?
- What organisations are already working with these groups, know the problems that they face, but lack financial or technical capacity to address their problems?

The participants included key population groups, religious organisations and representatives of the high court, ministry of social affairs and police. The assessment provided a detailed understanding of the problems faced by those living with and affected by HIV, and the gaps in legal services for them. The results were shared with all civil society organisations and national institutions working on HIV.

The assessment showed a need to take action on multiple areas, such as to:

- implement policies to reduce stigma and discrimination against key populations
- raise awareness and acceptance of legal protections for key populations
- create human rights guidelines or professional codes of conduct among key stakeholder groups
- educate people living with HIV and other key populations about their legal and human rights
- educate lawyers, paralegals, judiciary, NGOs, prosecutors and police about HIV, human rights and the law, as well as the effective provision of HIV-related legal services
- educate healthcare workers about HIV, human rights and the law
- disseminate the existing law (No. 030-2008/AN) that aims to promote protection of people living with and affected by HIV
- research trends of HIV-related legal cases, including the monitoring of human rights violations
- advocate for policy and law reform, changes to practices and increased resources.

The assessment was used to design a programme that focuses on protecting the rights of people living with HIV, men who have sex with men, and sex workers. The activities included disseminating knowledge through educational sessions; creating professional networks; building institutional capacity among the government, civil society and the private sector; and providing legal aid and services.

The results of the project have been shared with all stakeholders, including the target populations. The project has demonstrated gaps in the system; sensitised civil society and local authorities on the scale of problems these populations face; improved access to legal services; and promoted and defended the rights of people living with HIV and other key populations to groups that had not been concerned previously. Although the project has now ended, people living with HIV and other key populations are still accessing legal services through the continuing collaboration of many organisations, including Association des Femmes Juristes.

4.3 Step 2: Analysing the problems and priorities

Once the situational assessment is complete, you need to look at what you have learnt and what it tells you about what needs to be done. This includes answering the questions:

1. What needs to change? This involves using the findings of the situational analysis to:

- **Identify the key challenges** in relation to the human rights of people living with HIV and other key populations. For example, are the key challenges that laws are discriminatory? Non-discrimination laws are not applied? People lack information about their human rights? People cannot take action, such as through the courts, to defend their rights? Some specific groups, such as young sex workers, are especially vulnerable to human rights violations but are not being addressed by policies?
- **Prioritise those challenges**; for example, which challenges present the largest barrier to people living with HIV and other key populations fulfilling their rights? Which prevent them from accessing HIV services? Which would – if addressed – bring the most significant benefit to communities and the response to HIV?

2. What are others doing? This involves using the findings of the situational analysis, especially the stakeholder analysis, to assess the scale and quality of human rights programming by others (such as NGOs, networks of people living with HIV and government bodies), and identify the strengths, weaknesses and gaps.

3. What is our organisation best placed to do? This involves using the findings of the situational assessment, especially the internal analysis, to draw a realistic conclusion about the role your organisation might take in relation to the priorities you have identified. This will involve ref ecting on what resources (such as funding, commitment, expertise and reach) you have available and the stage that your organisation is at, such as in terms of its mission and strategic directions.

4.4 Step 3: Setting goals, objectives and indicators

Once the situational assessment is complete and the problems and priorities have been identified, planners should have a clear sense of the priority issues they wish to address; what change is needed; who is affected; and who are potential partners and allies.

Taking into account the relevant strengths of their organisation and its existing programmes, and the response of others, you can then identify and set a strategic framework to take the work forward. This might involve integrating attention to human rights into existing HIV programmes; integrating attention to HIV-related human rights into other types of programmes, such as those focused on gender; and/or setting up specific, new human rights programmes.

A strategic framework includes identifying the:

- **Goal** – what you ultimately want to contribute to through your human rights programme.
- **Objectives** – the key areas of change that you will focus on to achieve your goal.
- **Key activities** – the key actions you will take to achieve your objectives, focusing on one or a combination of the human rights-based programmes suggested in this guide (*see* Chapter 3).
- **Indicators** – the targets or 'measures' against which the programme can be assessed to see if you are meeting your goal and objectives, and achieving results through your activities.

Including human rights programmes in the national strategic plans cycle

Between 2012 and 2014, UNAIDS and the Alliance provided training on incorporating human rights-based programmes into national strategic plans.

Five regional workshops were held for East and Southern Africa, the Middle East and North Africa, Asia/Pacific, Latin America and the Caribbean regions. Participants from over 50 countries attended, including national AIDS programme managers; officials from ministries of health, gender and justice; civil society representatives; members of affected communities; and United Nations staff.

The workshops provided practical training on the introduction of human rights programmes into the national strategic plan project cycle, including costing and M&E tools.

Source: 'Integrating human rights into national strategic plans on HIV training guide for national workshops'.

'Making it work: lessons learned from three regional workshops to integrate human rights into national HIV strategic plans'.

Available at: www.aidsalliance.org/NewsDetails.aspx?Id=291439

4.5 Step 4: Implementing the programme

When implementing a programme, it is essential to ensure that it actively involves those it aims to support – people living with HIV and other key populations – not simply as beneficiaries but as partners and decision-makers. Participation is a key principle of human rights programming as described in Chapter 2.

The **other planning steps** can inform the implementation of your human rights programme. For example, the results of the situational analysis can serve as an ongoing checklist to ensure that you are continuing to respond to the evidence you gathered of the needs of people living with HIV and other key populations.

4.6 Step 5: Monitoring, evaluating and learning

When you have established your strategic framework and started implementing your human rights programme, it is vital to **monitor, evaluate and learn** from your human rights programming. This will help your organisation to ensure that is achieving results and can constantly improve its work. This section is further expanded in chapter 5, where monitoring, evaluating and learning are also addressed in more detail.

5 Monitoring and evaluating HIV and human rights programmes

In this chapter:

- 5.1 Why do we do it?
- 5.2 Evaluating the outcome
- 5.3 Key indicators

STANDARD 26: Our organisation has a monitoring and evaluation plan with clearly defined indicators linked to objectives, and the plan is adequately budgeted for.

Key terms

Monitoring is the systematic collection and analysis of information as a project progresses.

Evaluation is the comparison of actual project impacts against the agreed strategic plans.

Chapter 5: Monitoring and evaluating HIV and human rights programmes

5.1 Why do we do it?

The Alliance places high emphasis on M&E in all its programmes, including human rights programming. Monitoring and evaluating human rights-based HIV programmes helps programme officers to assess whether the programmes are meeting their strategic goals, identify and correct problems, and create better accountability mechanisms for our responses.

Monitoring is the systematic collection and analysis of information as a project progresses. It aims to improve the efficiency and effectiveness of a project or organisation. It is based on targets set and activities planned during the planning phases of work. It helps to keep the work on track, and can let management know when things are going wrong. If done properly, it is an invaluable tool for good management, and it provides a useful base for evaluation. It enables you to determine whether the resources you have available are sufficient and are being well used, whether the capacity you have is sufficient and appropriate, and whether you are doing what you planned to do.

Evaluation is the comparison of actual project impacts against the agreed strategic plans. It looks at what you set out to do, at what you have accomplished, and how you accomplished it. It can be formative (taking place during the life of a project or organisation, with the intention of improving the strategy or way of functioning of the project or organisation). It can also be summative (drawing learnings from a completed project or an organisation that is no longer functioning).

Source: CIVICUS. 'Monitoring and evaluation toolkit'. Available at: www.civicus.org/new/media/Monitoring%20and%20Evaluation.pdf

Monitoring and evaluating HIV and human rights-based programmes is, in many respects, similar to the M&E conducted for other programmes, and you can use and adapt existing M&E skills, experience and resources from these programmes. The Alliance has created various tools, guidelines and resources to ensure consistency across the organisation.

However, we often fail or neglect to do M&E exercises for human rights programming, or to invest enough resources, both financial and personnel, in conducting these exercises. This failure has weakened programmes, and has also contributed to a lack of good practice examples and knowledge base about successful human rights programming.

The following key points are important to note when designing M&E programmes:

- It is important to evaluate both the *process* and *outcomes* of human rights-based HIV programmes, to determine:
  - > whether the process for designing, developing and implementing the programme is based on human rights principles, including the involvement of people living with HIV and other key populations at all stages of the process
  - > whether the outcomes do in fact protect, respect, promote and fulfil their human rights-based and public health objectives.

- Measuring human rights goals can be difficult. Developing appropriate indicators and data collection methods is key to evaluating HIV and human rights-based programmes.
- M&E should incorporate human rights principles in its methodology. It should involve programme beneficiaries, such as people living with HIV and other key populations at higher risk of HIV exposure; ensure confidentiality; and reduce opportunities for stigma and discrimination.

Checklist for evaluating the process

- ✔ Was the programme based on the findings of a human rights analysis?
- ✔ Were the beneficiaries involved in the design and development of the programme?
- ✔ Are the beneficiaries involved in the implementation of the programme?
- ✔ Does the programme aim to protect, respect, promote and fulfil rights?
- ✔ Does the programme's implementation respect basic rights to privacy, confidentiality and informed consent?
- ✔ Is the programme available, accessible and acceptable to all without discrimination?
- ✔ Does the programme prioritise the needs of the most vulnerable or most affected populations?

5.2 Evaluating the outcome

In order to evaluate the outcomes of HIV and human rights-based programmes, we need to know what the situation was before the programme started (often called the 'baseline data') and collect important data on both human rights and health outcomes and impact. Human rights data needs to be **linked** to public health impact data in order to help us to understand how protecting rights promotes health.

The evaluation should aim to determine:

- whether the programme fulfils international and regional commitments on human rights
- whether the programme promotes the human rights of key populations
- whether the programme promotes public health in the context of HIV and AIDS
- what difference the programme has made to people living with HIV and other key populations, and what value it has added to the overall response.

Human rights-based programmes in Global Fund applications

Under the Global Fund's new funding model, countries are strongly urged to identify human rights barriers to accessing health services in their concept notes requesting funding, and to explain how they will address them.

Applicants are requested to 1. Define the epidemic; 2. Define what activities are needed to address the epidemic among the specific key affected populations; 3. Define the financial gap to implement these activities.

For 2013–14, the Global Fund prioritised four human rights interventions: **1. Legal and policy reform** (equivalent to the suggested programme in Section 3.3 in this guide); **2. Human rights training and capacity-building** (equivalent to the suggested programmes in Sections 3.5 and 3.6 in this guide); **3. Access to justice programmes** (equivalent to the suggested programmes in Sections 3.2 and 3.4 in this guide); **4. Human rights monitoring** (included in Section 3.8 on community-led interventions in this guide).

For more information, *see*: www.theglobalfund.org/en/about/humanrights

Key resource

For resources on monitoring and evaluating human rights-based programming approaches:

HRBA Portal: http://hrbaportal.org/?tools%5B%5D=monitoring-and-evaluation

Checklist for evaluating the outcome

- ✔ Does the programme protect, respect, promote and fulfil human rights commitments?
- ✔ Does it promote equality and non-discrimination?
- ✔ Does it reject discriminatory, punitive or coercive measures to respond to HIV?
- ✔ Does it advance the health-related rights of key populations?
- ✔ Does it support key populations to claim their rights?
- ✔ Does it hold key stakeholders accountable for protecting rights?
- ✔ Are affected populations:
  - > experiencing less stigma, discrimination and human rights violations?
  - > aware of their rights?
  - > able to access legal support services?
  - > able to enforce their rights?
  - > at lower risk of HIV exposure?
  - > able to prevent HIV transmission?
  - > able to receive treatment?
  - > able to access care and support to cope with the impact of HIV and AIDS on themselves and their families?

5.3 Key indicators

Human rights indicators can be difficult to choose, and there is currently no generally accepted set of indicators that can easily be adapted to different contexts. However, there are resources that may help to develop useful indicators for HIV and human rights programmes. We have also suggested some examples below. However, these indicators may all have limitations, which should be considered when they are used:

- The indicator may not tell the whole story about whether the human rights of people living with HIV or other key populations are protected. For example, a protective HIV law may be put in place that could be seen as an indication that progress is being made to protect human rights. But if the law is not properly implemented, it will not protect human rights. Despite the passing of the law, reports of HIV-related discrimination and other abuses may occur.
- However, the act may be adequately implemented and reports of HIV-related discrimination may still continue to arise. This is not necessarily an indication that the act has failed and that human rights violations have increased. It may mean that more people know their rights and know how to access and use legal support services. We need to link various forms of data collection to get the whole picture of the outcome.
- The indicator may not provide detailed, disaggregated information. We know that people are affected differently by human rights. Often, it is those populations who are already most marginalised who experience the worst human rights violations. Data on HIV and human rights should try to give us more information about the people and their characteristics, so that we can be sure we are reaching those most vulnerable.

Table 13 provides examples of indicators for different human rights programmes. As an example of human rights-related indicators in wider organisational strategies, the Alliance has human rights-related indicators as a part of the core indicators of the Alliance partnership strategy. These indicators are therefore top level, but they are designed to measure impact on the human rights context of the people the Alliance reaches. Here are some examples:

Disaggregating data by sex and age

UNAIDS recommends that data collected to evaluate programmes is disaggregated by sex and age. This means that when you are designing an indicator, it is important to make sure that you include information about the sex and age of beneficiaries, and when you report about a programme, you are able to provide this information. This data is very helpful to identify who benefits from programmes, but also who is being excluded.

- Percentage of locations with programmes where violence and discrimination against people most affected by HIV is recognised by the state and addressed by CBO-led individual case response systems. Number of members/partners monitoring and reporting rights-related barriers to access to HIV and healthcare services.
- Proportion of incidents of violence and harassment addressed within 24 hours.
- Number of locations where support has been provided to key populations' advocacy for rights through specific programmes.

Example

Uganda and Kenya

It may help to develop indicators in the community or institution where the human rights programme is planned. In Uganda and Kenya, stigma trainers asked communities how they would know that stigma was reduced in the community. Many community members gave answers relating to the way children living with HIV, or children whose parents had died of AIDS, were treated. Communities suggested that indicators could relate to an increase in the number of these children attending school or being cared for by families.

Source: IHAA (2011). 'Integrating stigma reduction into HIV programming'.

Example

Stigma Index

The Global Network of People living with HIV (GNP+) and the International Planned Parenthood Federation (IPPF) have developed the People Living with HIV Stigma Index. It is used to monitor the nature and extent of HIV-related stigma and discrimination in countries, and is carried out by people living with HIV themselves. It is also a strong form of advocacy about stigma and discrimination and how it impacts on access to HIV prevention, treatment, care and support. It may also be a very useful source of baseline information for you to help with evaluating the impact of your human rights-based HIV programmes.

The Malawi Network of People Living with HIV and AIDS (MANET+) conducted research with over 2,000 people living with HIV in Malawi to determine the nature and extent of HIV-related stigma and discrimination in the country. The findings of the Stigma Index survey have not only provided vital information for understanding, documenting and advocating for HIV, law and human rights issues in the country; they have also informed a recent legal audit in Malawi.

Table 14: Indicators for health and human rights programmes		
Programme	Human rights indicators (outcome indicators in bold)	Health indicators
Stigma and discrimination reduction programmes	■ Number of community mobilisation campaigns ■ Number of stigma reduction media campaigns ■ Number of health facilities training providers on stigma and discrimination reduction ■ **Reduction in number of people living with HIV or members of key populations excluded from social gatherings** ■ **Reduction in number of people living with HIV or members of key populations who have lost their employment** ■ **Reduction in number of people living with HIV or members of key populations who have been abandoned by partners and/or families**	■ Willingness and ability to use healthcare services ■ Increased access to and uptake of HIV testing ■ Increased access to and uptake of prevention services ■ Adoption of safer behaviours ■ Increased access to treatment ■ HIV incidence ■ HIV prevalence ■ Morbidity ■ Mortality
HIV-related legal services	■ Number of legal support/advice services for people living with HIV and affected populations provided ■ Number of cases taken to judicial process ■ Number of people using legal support services ■ **Number of cases satisfactorily resolved**	
Monitoring and reforming laws, regulations and policies	■ Number of discrimination cases documented ■ Number of discriminatory laws/policies reviewed and repealed ■ Progress in a particular policy change: baseline of policies undertaken; engagement with decision-makers taken place; policies developed; endorsement by government; policy implemented ■ **Number of protective laws adopted**	
Legal literacy	■ Number of campaigns that include key populations ■ Number of Know Your Rights media campaigns ■ Number of education and training sessions for service providers	
Sensitising law makers and law enforcers	■ Number of education and training sessions for lawmakers and law enforcers ■ Number of internal disciplinary investigations related to human rights undertaken ■ Number of police demonstrating increased understanding of rights ■ **Number of instances of discrimination/human rights violations by law enforcers reduced** ■ **Number of discriminatory policies reviewed and repealed**	
Training healthcare workers	■ Number of education and training sessions for healthcare workers ■ Number of healthcare workers aware of rights ■ Number of internal disciplinary investigations related to human rights undertaken ■ Number of healthcare workers aware of patients who have been discriminated against because they were known or suspected of having HIV ■ Number of facilities that have a stigma policy in place ■ **Number of instances of discrimination/human rights violations in healthcare settings reduced**	

Table 14 (Cont.)

Programme	Human rights indicators (outcome indicators in bold)	Health indicators
Reducing gender inequality, harmful gender norms and violence against women	■ Number of men participating in PPTCT programmes ■ Number of incidences of intimate partner violence ■ Number of women who know their rights ■ **Number of discriminatory laws reviewed and repealed**	
Core community-led human rights-related interventions	■ Number of individual cases documented ■ Number of advocacy campaigns undertaking by CSOs and CBOs targeting policy change ■ Progress in a particular policy change: engagement of CBOs with wider CSO coalitions; human rights issues appropriated by coalitions; engagement of decision-makers with issue; direct engagement with decision-makers ■ Number of CSO and CBO members trained in human rights-based programming ■ **Number of individual cases satisfactorily responded to with crisis response and/or human rights programmes**	

Key resources

ICRW (2006). 'Can we measure HIV-related stigma and discrimination?'

Available at: www.icrw.org/files/publications/Can-We-Measure-HIV-Stigma-and-Discrimination.pdf

GNP+, ICW, IPPF, UNAIDS (2008). The People Living With HIV Stigma Index:

www.stigmaindex.org

Office of the High Commissioner on Human Rights (2012). 'Human rights indicators: a guide to measurement and implementation'.

Available at: www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf

UNAIDS (2011). 'Global AIDS response progress reporting 2012. Guidelines: construction of core indicators for monitoring the 2011 Political Declaration on HIV/AIDS'.

Available at: www.unaids.org/en/media/unaids/contentassets/documents/document/2011/JC2215_Global_AIDS_Response_Progress_Reporting_en.pdf

Chapter 6: Last thoughts

The Good Practice Guide gives you and your organisation guidance on human rights HIV programmes to help you to understand

- **Why** it is important to include human rights in your HIV programmes
- **How** you can identify some of the most important HIV and human rights issues in your community
- **What** kinds of activities you can undertake to promote human rights in your HIV programmes.

The Good Practice Guide cannot provide detailed step-by-step information on how to develop and implement each and every type of human rights-based HIV programme. However, we hope that you will use the examples of other successful programmes, as well as the resources on different kinds of HIV and human rights programmes, to supplement your learning on human rights HIV programmes.

The checklist below gives you some final tips for developing your own human rights HIV programmes that suit the needs of your community and the objectives and capacity of your organisation.

Table 15: Checklist for developing human rights HIV programmes for your organisation

Situational analysis	✔ Have you conducted a situational analysis of the key HIV and human rights issues, gaps and challenges in your community? ✔ Has a Stigma Index study been done that identifies key stigma and discrimination issues? ✔ Is there other information available on HIV and human rights issues? ✔ Have the voices and concerns of marginalised populations been included?	It is important to ensure you develop human rights-based HIV programmes that respond to the needs of your community, including the most marginalised populations.
Priority issues	✔ What are the priority issues identified by the situational analysis? ✔ Which human rights programme/s will best address the HIV and human rights issues in your community?	The particular programme you develop should best respond to the identified need. For example, if police action is one of the most significant issues being faced by a population, working with law enforcement officers is vital.
Existing organisational work	✔ Which human rights programme fits well with your existing aims, objectives and programmes? ✔ Which programme/s can be integrated within one of your existing programmes?	The most successful programmes are often those that can easily be integrated into your existing work; for example, integrating Know Your Rights campaigns into your treatment literacy projects.
Organisational capacity and skills	✔ What existing capacity do you have for implementing the programme? ✔ What additional capacity and skills would you need to implement the programme?	It is important to plan for programmes that can use your existing skills, and to plan for capacity-building where new skills and information are needed.
Partnerships	✔ Which organisations can you partner with to better develop, implement, monitor and evaluate the programme? ✔ What are the capacity and skills that you and your partners can each bring to the process? ✔ Who is best placed to undertake the various elements of the programme?	Your organisation may find it easier to implement human rights-based HIV programmes in collaboration with other organisations. For example, a support network of people living with HIV can work with a legal aid organisation to monitor stigma and discrimination. This way, each organisation can work to their specific strengths.

Good Practice Guide series

This guide is one in a series of good practice guides produced by the International HIV/AIDS Alliance in collaboration with partner organisations. This series brings together expertise from our global community-level HIV programming to define and guide good practice in a range of technical areas, including:

- Greater involvement of people living with HIV (GIPA)
- Community guide to HIV treatment as prevention
- Integration of HIV and sexual and reproductive health and rights
- Community-based TB and HIV integration
- Family-centred HIV programming for children
- HIV and drug use

Alliance Good Practice Guides:

- are user-friendly 'how to' guides
- target HIV programmers working in community settings in developing and transitional countries
- help to define what is good practice for community-level HIV programmes.

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