



DISCRIMINATION

A PRACTICAL GUIDE

**IMPLEMENTING  
AND SCALING UP  
PROGRAMMES  
TO REMOVE  
HUMAN RIGHTS-  
RELATED BARRIERS  
TO HIV SERVICES**

## ABOUT FRONTLINE AIDS

Frontline AIDS wants a future free from AIDS for everyone, everywhere. Around the world, millions of people are denied HIV prevention, testing, treatment and care simply because of who they are and where they live.

As a result, 1.7 million people were infected with HIV in 2018 and 770,000 died of AIDS-related illness.

Together with partners on the frontline, we work to break down the social, political and legal barriers that marginalised people face, and innovate to create a future free from AIDS.

## ACKNOWLEDGEMENTS

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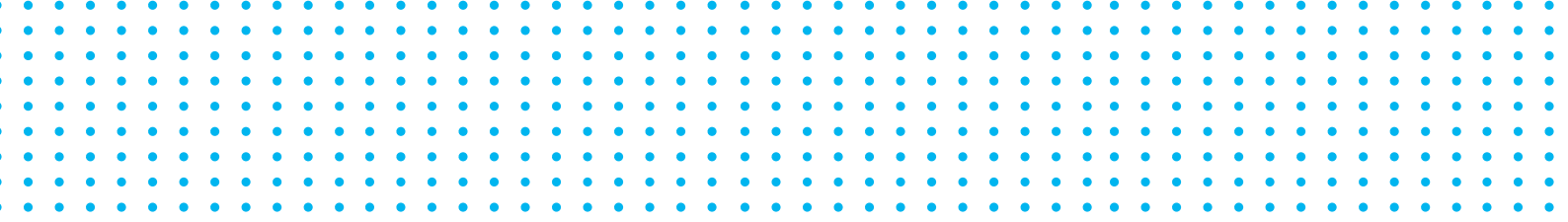
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## ACRONYMS AND ABBREVIATIONS

AFSA	AIDS Foundation of South Africa
AIDS	Acquired immune deficiency syndrome
ALN	AIDS Legal Network
ARASA	AIDS and Rights Alliance for Southern Africa
ART	Antiretroviral therapy
BMZ	German Federal Ministry of Economic Cooperation and Development
BONELA	Botswana Network on Ethics, Law and HIV/AIDS
CBO	Community-based organisation
COE	Challenging operating environment
CRG	Community, Rights and Gender
CSO	Civil society organisation
DHIS	District Health Information Software
GAM	Global AIDS Monitoring
GBV	Gender-based violence
GIZ	Deutsche Gesellschaft für Internationale Zusammenarbeit GmbH
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
GNP+	Global Network of People Living with HIV
HIV	Human immunodeficiency virus
IBBS	Integrated Biological and Behavioural Surveillance
KELIN	Kenya Legal and Ethical Issues Network on HIV & AIDS
LEA	Legal environment assessment
LGBT	Lesbian, gay, bisexual and transgender
M&E	Monitoring and evaluation
MEL	Monitoring, evaluation and learning
MoU	Memorandum of understanding
NACOSA	Networking HIV and AIDS Community of Southern Africa
NCPI	National Composite Policy Index
NGO	Non-governmental organisations
NSP	National Strategic Plan
OHCHR	Office of the United Nations High Commissioner for Human Rights
OSF	Open Society Foundations
REAct	Rights – Evidence – Action
SALC	Southern Africa Litigation Centre
SANAC	South African National AIDS Council
SDGs	Sustainable Development Goals
TB	Tuberculosis
ToC	Theory of change
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
WHO	World Health Organization

## FOREWORDS

On behalf of **Frontline AIDS**, it gives me great pleasure to share this publication with you. It builds on existing global technical guidance in human rights responses, and with it we seek to further advance efforts to support implementers to design and deliver high quality human rights programmes that are well integrated, sustainable, and at scale. In so doing, we aim to advance the health and rights of those who are most marginalised in the HIV response.

Over the last two decades, civil society organisations have led the way, innovating and delivering human rights programmes that have made it possible for the most marginalised to access HIV-related health services that they not only need, but are entitled to. Despite the gains made, rights-related barriers continue to impede access to HIV-related health services and undermine efforts to end AIDS. Marginalised communities continue to be disproportionately affected by HIV. The fact remains – we are simply not reaching everyone, everywhere.

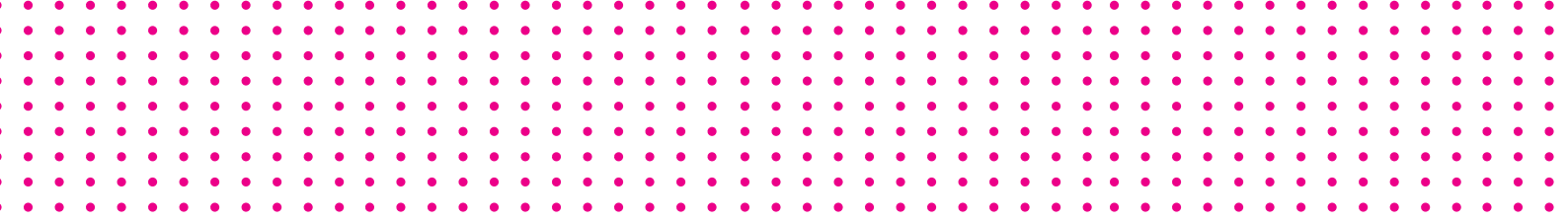
If we are to end AIDS, we must invest in comprehensive human rights programmes at the right level of investment, directed to the right populations and with the right combination of programmes. To do so, we must overcome three central issues. The first is political will. It is the responsibility of states to guarantee the human rights of all and to address HIV-related discrimination and stigma against any person, regardless of their status or identity. Only a few governments have lived up to this responsibility with real conviction. The second is money – investment has been far below the mark. This has constrained the reach and impact

of these programmes, and made it incredibly difficult to substantiate the critical role human rights play in ending AIDS, which would provide incentives for governments to scale up investment. Even the most sympathetic governments will require evidence of impact if they are to fund human rights programmes. The third challenge is that although we know that there a critical need, comprehensive human rights programming has simply not been attempted before. This guidance seeks to explore this new frontier alongside implementers, to grapple with questions about how to choose and integrate programmes and interventions, scale them up and sustain them.

No single person or organisation can end AIDS and we are incredibly thankful to BACKUP Health of the Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH and the Human Rights Department of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) for taking this journey with us. I would also like to thank the many other technical contributors, including dozens of country-based implementers. We are encouraged by the positive feedback that this guidance is timely and much needed. We know it won't answer every question, but we hope it will take you all a step further in finding the answers.



**Christine Stegling**  
Executive Director  
Frontline AIDS



This publication is the result of a joint cooperation between the Global Fund, Frontline AIDS and GIZ BACKUP Health on behalf of the German **Federal Ministry of Economic Cooperation and Development (BMZ)**.

Our aim is to provide human rights experts with practical guidance on how to implement and scale up comprehensive programmes to reduce human rights-related barriers to HIV services, and to enhance rights compliance in health service delivery overall. The principles of human rights, including gender equality, are fundamental to all aspects of Germany's development cooperation efforts, particularly our strategic priority of developing health systems that are specifically aligned to the rights and needs of disadvantaged groups. Therefore, overcoming stigmatisation and discrimination is an important prerequisite for the success of programmes to combat diseases, as well as for building resilient and sustainable health systems.

It is important at all levels of action to create broader awareness of the links between health and human rights, and to further develop the capacity of government and civil society actors to plan, implement and evaluate health strategies

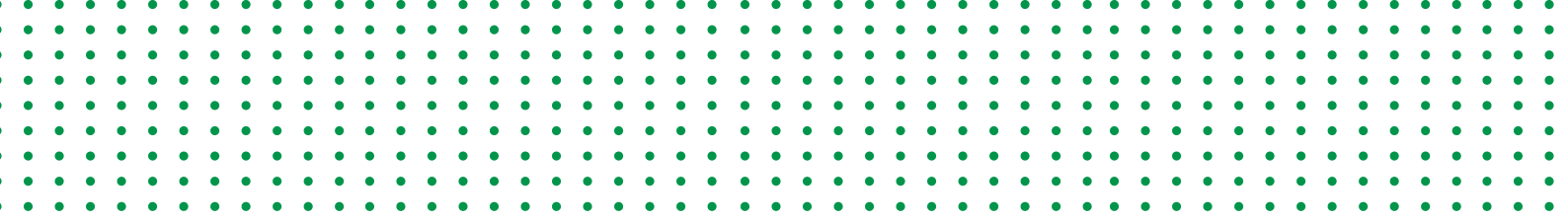
and programmes from a human rights perspective. As a result, the realisation of human rights will be enhanced and, more importantly, health programmes will achieve better health impact.

In order to gain long-term sustainability, we need to think beyond removing human rights-related barriers to HIV, tuberculosis (TB) and malaria services. Now is the time to move toward removing human rights-related barriers to all health services. We are grateful to all partners who collaborated to develop this guide and we strongly believe that it will make an important contribution to the global development goal of universal health access that leaves no one behind.



**Birgit Pickel**  
Deputy Director General  
Human Rights, Gender and Social Development  
Federal Ministry for Economic Cooperation  
and Development (BMZ)





**The Global Fund** is pleased to partner with GIZ BACKUP Health and Frontline AIDS to produce this guidance for those implementing and scaling up programmes to remove human rights-related barriers to HIV, TB and malaria services. The Global Fund has long promoted the right to health and a rights-based approach to the three diseases, and continues to do so. As one essential part of this, the Global Fund has committed in its strategy, *Investing to End Epidemics, 2017-2022*, to make human rights practical and programmatic in national responses to HIV, TB and malaria. This means that countries benefit from funding that is specifically aimed at the removal of human rights-related obstacles to health services, and that affected communities benefit from greater and more equitable access to the health services they need. This not only increases the effectiveness of Global Fund grants, it is also imperative if states and the global community are to reach national targets for ending the diseases as public health threats, leaving no one behind. Further, putting in place and taking to scale the programmes described in this guide helps countries to meet their Sustainable Development Goals (SDGs) concerning health, inequality and gender.

As you will see, this guidance is practical and organised around the Investment Approach to HIV. It helps implementers to understand the programmatic components of evidence-informed and quality interventions to remove barriers to services; to be able to integrate them into national strategies and prevention, treatment and

key population services so as best to support those services, and to take them to scale so that they have the level of impact needed to significantly increase access to health services.

Much has been achieved in the AIDS response, but in 2020, it is clear that those still not sufficiently benefiting from HIV services are the marginalised and vulnerable. Depending on local circumstances, these may include women and adolescent girls, men who have sex with men, people who inject drugs, sex workers, prisoners, transgender people, people with disabilities, refugees, migrants and the internally displaced. It is hoped that this guidance, together with the increased funding and other efforts to support implementation and expansion of programmes to remove human rights-related barriers to services, will result in a sea change where finally all those in need of HIV prevention, treatment and support services are able to access them and continue to access them, resulting in healthy and discrimination-free lives.



**Kate Thomson**  
Head  
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The Global Fund to Fight AIDS, Tuberculosis  
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# INTRODUCTION

## A CRITICAL MOMENT IN THE GLOBAL HIV RESPONSE



“ The axes of poverty, gender, sexual orientation, race, age and class intersect. Some are getting the benefit of science, but others are not. Some are getting quality people-centered services, but others are not. We must therefore focus our efforts on addressing inequality in access and inequality in outcome...”

UNAIDS Executive Director, Winnie Byanyima, at the opening of the UNAIDS Programme Coordinating Board, 10 December 2019.

This guide has been developed to support implementers to plan, roll out and scale up effective, evidence-informed programmes to remove human rights-related barriers to HIV services. In 2020 this cannot be more critical or timely, as countries move forward, for the first time in the history of the AIDS response, to apply significant resources to resolving the human rights challenges that have impeded the response since the beginning of the epidemic, some 40 years ago.

Much has been achieved to overcome the HIV epidemic. As of the end of June 2019, 24.5 million people were accessing antiretroviral therapy (ART). New HIV infections have been reduced by 40% since their peak in 1997. AIDS-related deaths have been reduced by more than 56% since their peak in 2004.<sup>1</sup> But much more must be done to truly end HIV and AIDS.

The most marginalised and under-served people continue to be disproportionately affected. Every week, some 6,000 young women aged 15–24 years contract HIV; in 2018, 770,000 people died from AIDS-related illnesses. Key populations, including gay, bisexual and other men who have sex with men, sex workers of all genders, transgender people, and people who use drugs

and their sexual partners now account for 54% of new HIV infections globally.<sup>2,3</sup> Since the 90-90-90 targets were set, it has become even clearer that success will not be achieved without addressing the social, legal and economic barriers to services – the human rights-related barriers – that still prevent many people from accessing the prevention and treatment services they need.<sup>4</sup>

This guide describes the barriers to HIV services that many people continue to face; why concrete programmes are needed to remove them and the evidence-informed programmes that can achieve this. It provides step-by-step guidance to enable implementers to plan, implement and evaluate programmes to remove human rights-related barriers to services. These programmes are not new in the response to HIV. Since the beginning of the epidemic, civil society and networks of affected populations have put their best efforts into establishing programmes to enable those most vulnerable to HIV to avoid infection, or those living with HIV to continue to lead full, productive lives in their communities. However, a lack of political commitment and funding has meant these were often *ad hoc* and not implemented strategically or at a scale that resulted in significant impact.

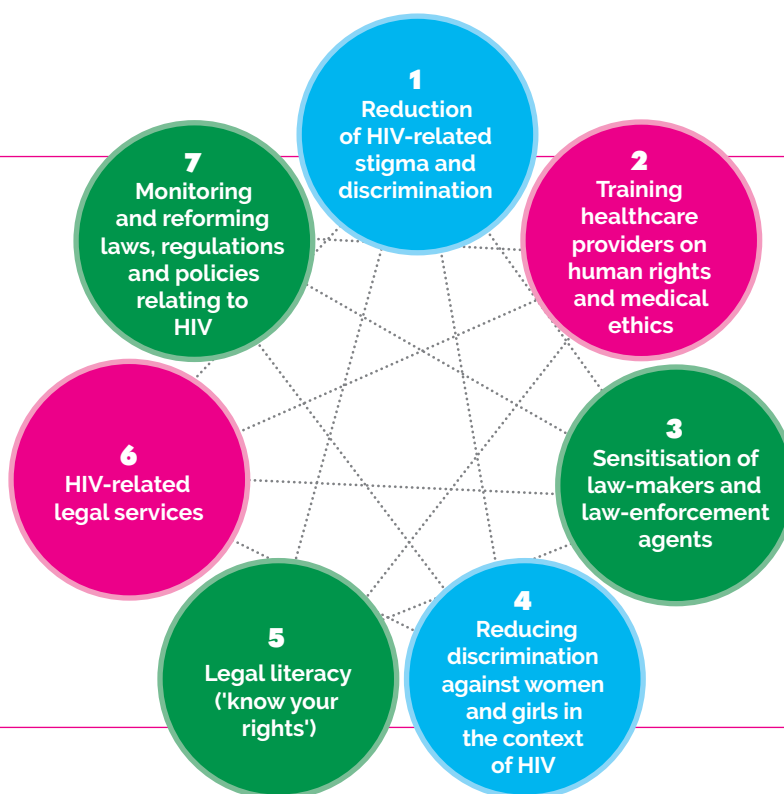
1. UNAIDS (2019), 'Global HIV and AIDS Statistics – 2019 fact sheet', Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/fact-sheet](http://www.unaids.org/en/resources/fact-sheet)  
2. *Ibid.*  
3. UNAIDS considers gay men and other men who have sex with men, sex workers, transgender people and people who inject drugs as the four main key population groups, but it acknowledges that prisoners

and other incarcerated people also are particularly vulnerable to HIV and frequently lack adequate access to services. See: [www.unaids.org/sites/default/files/media\\_asset/2015\\_terminology\\_guidelines\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf)

4. UNAIDS (2019), 'Power to the People', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/power-to-the-people\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/power-to-the-people_en.pdf); and UNAIDS (2019), 'Communities at the Centre, Global AIDS Update', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/2019-global-AIDS-update\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2019-global-AIDS-update_en.pdf)

## BOX 1: THE SEVEN KEY PROGRAMME AREAS

The seven key programme areas recognised as effective in removing human rights-related barriers to HIV services



This has changed in the last 10 years. Following a consultative process from 2010 to 2012, UNAIDS articulated seven key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses (see *Box 1*).<sup>5</sup> These programmes are cited in its strategies.<sup>6</sup> The World Health Organization (WHO) has promoted these programmes as 'critical enablers' in the investment approach to HIV. UNDP has supported them through its sponsorship of the *Global Commission on HIV and the Law*.<sup>7</sup> Most importantly, states committed to their implementation in the *2011*<sup>8</sup> and *2016 Political Declarations on HIV and AIDS*.<sup>9</sup>

### Now is the time to move forward

Now, the Global Fund has provided unprecedented funding for and commitment to the implementation and scale-up of these programmes. Indeed, the Global Fund now requires that all its grantees put in place programmes to remove human rights-related barriers to services.<sup>10</sup> There has been a huge

paradigm shift in the political commitment and funding available, presenting previously unseen opportunities to implement these programmes strategically, comprehensively, and at scale. Only by doing so will those most vulnerable to and impacted by HIV be reached with vital prevention and treatment services, thereby maximising the impact of national, regional and global responses to HIV.

By implementing these programmes and taking them to scale, states will not only address their HIV epidemic more effectively and accelerate progress towards reaching their 90-90-90 targets,<sup>11</sup> they will also fulfil their obligations under the SDGs;<sup>12</sup> in particular, Goal 3 to ensure healthy lives, Goal 5 to achieve gender equality, and Goal 10 to reduce inequality. This will also fulfil their obligations under the *Political Declaration on Universal Health Coverage*, whereby Paragraph 70 reflects the principles of equality and non-discrimination and commits governments to ensuring that no one is left behind.<sup>13</sup>

5. UNAIDS (2012), 'Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses, Guidance Note', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012\\_0.pdf](http://www.unaids.org/sites/default/files/media_asset/Key_Human_Rights_Programmes_en_May2012_0.pdf).

6. UNAIDS (2010), 'Getting to Zero 2011-2015 Strategy', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/JC2034\\_UNAIDS\\_Strategy\\_en\\_1.pdf](http://www.unaids.org/sites/default/files/media_asset/JC2034_UNAIDS_Strategy_en_1.pdf).

7. See Global Commission on HIV and the Law: <https://hivlawcommission.org/>.

8. UNAIDS (2011), 'Political Declaration on HIV/AIDS', Geneva: UNAIDS. Available at: [www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids](http://www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids).

9. UNAIDS (2016), 'Political Declaration on HIV/AIDS', Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2016/2016-political-declaration-HIV-AIDS](http://www.unaids.org/en/resources/documents/2016/2016-political-declaration-HIV-AIDS).

10. Global Fund (2016), 'Sustainability, Transition and Co-Financing Policy', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/4221/bm35\\_04-sustainabilitytransitionandcofinancing\\_policy\\_en.pdf](http://www.theglobalfund.org/media/4221/bm35_04-sustainabilitytransitionandcofinancing_policy_en.pdf).

11. UNAIDS (2017) '90-90-90: An ambitious treatment target to help end the AIDS epidemic', Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/909090](http://www.unaids.org/en/resources/909090).

12. See UN Sustainable Development Goals: [www.un.org/sustainabledevelopment/development-agenda/](http://www.un.org/sustainabledevelopment/development-agenda/).

13. United Nations General Assembly (UNGA), 'Political declaration of the high-level meeting on universal health coverage, 2019, Resolution adopted by the General Assembly on 10 October 2019, A/RES/74/2'. Available at: <https://undocs.org/en/A/RES/74/2>.

## Removing human rights-related barriers is crucial to further global progress on HIV

At the end of the last decade, it was clear from years of experience, as well as ever-accumulating data, that adolescent girls and young women continue to acquire HIV, in large part due to gender inequality, poverty and gender-based violence (GBV). Key populations continue to acquire HIV, mainly due to the criminalisation, marginalisation and violence that they experience. Prisoners, refugees, migrants and people with disabilities suffer from limited or no access to HIV prevention and treatment services, and people living with HIV are discouraged from accessing HIV prevention and treatment interventions for fear of stigma and discrimination, or even arrest should their status become known.<sup>14</sup>

The programmes described in this guide cannot address all the challenges facing those most vulnerable to HIV and to the impact of AIDS, but they have been shown to be a pragmatic and effective means by which to support these populations to navigate the social, legal and economic challenges that make uptake and adherence to HIV prevention and treatment difficult.

These programmes support those vulnerable to and living with HIV to know their rights to health, non-discrimination, and freedom from violence; to organise around these rights and the protective laws and policies in their countries, and to get support and assistance to overcome the stigma and discrimination, punitive policies, police abuses and other risks and harms that prevent them from accessing services. These programmes also support healthcare workers, police, judges and parliamentarians to work against stigma, discrimination and violence, and to support national HIV strategies and programmes through protective healthcare, policing, policy and legislation.

## The Global Fund *Breaking Down Barriers* initiative

The Global Fund's Strategy, *Investing to End Epidemics, 2017–2022*, commits the Global Fund, under Strategic Objective 3, to: 'introduce and scale up programmes that remove human rights barriers to accessing HIV, tuberculosis (TB) and malaria services'.<sup>15</sup> In order to operationalise this objective and meet its key performance indicators, in 2017, the Global Fund launched its *Breaking Down Barriers* initiative.<sup>16</sup> The initiative aims to dramatically scale up programmes to remove human rights-related barriers to HIV, TB and malaria services in 20 countries,<sup>17</sup> while at the same time the Global Fund supports all its grantees to implement and scale up these programmes.

In partnership with country stakeholders, civil society, technical partners (including Frontline AIDS) and other donors, the initiative has:

- developed programmatic guidance on the most effective ways to reduce or remove human rights-related barriers to HIV, TB and malaria services<sup>18</sup>
- conducted baseline assessments in 20 countries to describe such barriers, document existing programmes and investments to address these barriers, and identify opportunities for developing more comprehensive responses, including estimating investment needs<sup>19</sup>
- held meetings with country stakeholders and partners to put together comprehensive, longer-term plans to remove the barriers
- increased available resources to fund comprehensive responses, reaching a total of USD 74.81 million by end 2019.

### Increased commitments from other partners

Other partners are also making valuable financial and technical contributions:

14. UNAIDS (2019), 'Power to the People', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/power-to-the-people\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/power-to-the-people_en.pdf). And UNAIDS (2019), 'Communities at the Centre. Global AIDS Update', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/2019-global-AIDS-update\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2019-global-AIDS-update_en.pdf).
15. Global Fund, 'Global Fund Strategy 2017–2022: Investing to end epidemics', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/2531/core\\_globalfundstrategy2017-2022\\_strategy\\_en.pdf?u=637066531950000000](http://www.theglobalfund.org/media/2531/core_globalfundstrategy2017-2022_strategy_en.pdf?u=637066531950000000).
16. Global Fund (2018), 'Breaking Down Barriers to Access: Scaling up programs to remove human rights-related barriers to health services in 20 countries and beyond'. Available at: [www.theglobalfund.org/media/1213/humanrights\\_2016-removingbarrierspart2\\_qa\\_en.pdf?u=637166000090000000](http://www.theglobalfund.org/media/1213/humanrights_2016-removingbarrierspart2_qa_en.pdf?u=637166000090000000).
17. Benin, Botswana, Cameroon, Democratic Republic of Congo (province-level), Côte d'Ivoire, Ghana, Honduras, Indonesia (selected cities), Jamaica, Kenya, Kyrgyzstan, Nepal, Mozambique, Philippines, Senegal, Sierra Leone, South Africa, Tunisia, Uganda and Ukraine. See Global Fund (2016), 'Step up the fight: Focus on human rights', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/8119/publication\\_humanrights\\_focuson\\_en.pdf?u=637146788050000000](http://www.theglobalfund.org/media/8119/publication_humanrights_focuson_en.pdf?u=637146788050000000).
18. Global Fund (2019), 'Global Fund Technical Brief: HIV, Human Rights, and Gender Equality', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/6348/core\\_hivhumanrightsgenderequality\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/6348/core_hivhumanrightsgenderequality_technicalbrief_en.pdf); Global Fund (2019), 'Technical Brief: Gender Equity', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/5728/core\\_gender\\_infonote\\_en.pdf](http://www.theglobalfund.org/media/5728/core_gender_infonote_en.pdf); Global Fund (2017), 'Global Fund Technical Brief on Tuberculosis, Gender and Human Rights', GENEVA: Global Fund. Available at: [www.theglobalfund.org/media/6349/core\\_tbhhumanrightsgenderequality\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/6349/core_tbhhumanrightsgenderequality_technicalbrief_en.pdf), and Global Fund (2019) 'Global Fund Technical Brief: Malaria, Gender and Human Rights', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/5536/core\\_malariagenderhumanrights\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/5536/core_malariagenderhumanrights_technicalbrief_en.pdf).
19. Global Fund (2020), 'Baseline Assessments of Human Rights-related Barriers to Services', Geneva: Global Fund. Available at: [www.theglobalfund.org/en/publications/](http://www.theglobalfund.org/en/publications/).



- UNAIDS, UNDP, United Nations (UN) Women, and the Global Network of People Living with HIV (GNP+) have convened the *Global Partnership for Action to Eliminate All Forms of HIV-related Stigma and Discrimination*, which promotes evidence-based programmes and policies to remove stigma and discrimination in six settings: healthcare, education, the workplace, the justice system, household and community, and emergencies and humanitarian settings.<sup>20</sup>
- UNDP is supporting action under the findings and recommendations of the *Global Commission on HIV and the Law*, including support for legal environment assessments (LEAs), judges' forums, and other actions to improve the legal and policy frameworks around HIV at national and regional levels.<sup>21</sup>
- Many non-governmental organisations (NGOs) and community-based organisations (CBOs) are engaged in legal empowerment efforts, human rights training and monitoring, and strengthening and expanding community-based responses to human rights challenges, including gender inequality and GBV.
- Charities and private trusts and foundations including the Ford Foundation, Open Society Foundations (OSF), M·A·C AIDS Fund, Robert Carr Foundation and Aidsfonds Netherlands.
- Governmental international development agencies, including the United States, the United Kingdom and The Netherlands.

20. UNAIDS, 'Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/global-partnership-hiv-stigma-discrimination\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/global-partnership-hiv-stigma-discrimination_en.pdf).

Together, these collective efforts represent a huge paradigm shift in terms of increased financial and political commitment and the technical and operational resources to enable significant scale-up and to sustain efforts to reduce human rights-related barriers in national responses to HIV, as well as the linked epidemics of TB and malaria.

## WHY THIS GUIDE?

Although unprecedented resources and opportunities are now available, there are still challenges to overcome. The first is to consistently implement interventions of quality and to move beyond *ad hoc*, one-off efforts. The second challenge is the urgent need to take these efforts to scale, to the level of national and comprehensive responses that are fully integrated into national HIV strategies and disease programmes at all levels.

This guide aims to address these challenges by providing practical guidance in understanding human rights-related barriers to services; who is affected by them; the programmes that can remove them, and in designing and implementing quality interventions. It also focuses on taking such interventions to scale in order to achieve a comprehensive response that results in the maximum impact in terms of increased access, uptake and retention in services; impact that can be sustained, ensuring no one is left behind in efforts to end AIDS by 2030.

21. See Global Commission on HIV and the Law: <https://hivlawcommission.org/>.

## Who is this guide for?

This guide is for organisations, networks and communities involved in designing, implementing and scaling up comprehensive programmes to remove human rights-related barriers to HIV and other health services. This includes those from government, civil society, affected populations, technical partners and donors. Although this guide focuses primarily on HIV programming, the epidemics of HIV, TB and malaria, and the populations affected by them, often overlap, and therefore the content of this guide may also inform programmes addressing barriers in these other contexts.

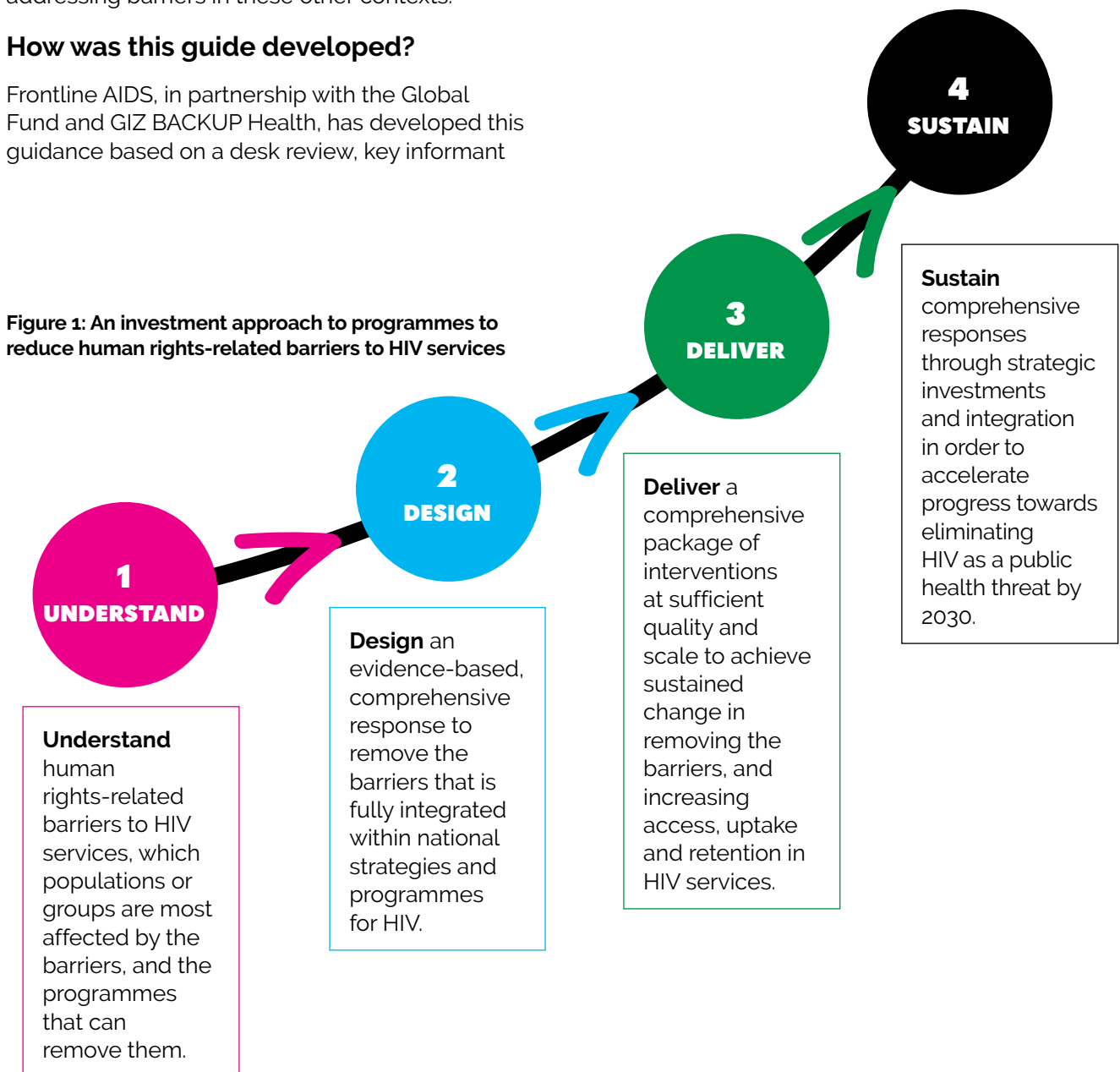
## How was this guide developed?

Frontline AIDS, in partnership with the Global Fund and GIZ BACKUP Health, has developed this guidance based on a desk review, key informant

interviews and workshops carried out in 2019. The guide was piloted with practitioners in two regional workshops held in August 2019 in Anglophone and Francophone Africa, and through key informant interviews with implementers in Eastern Europe and Central Asia in September 2019.

## What is in this guide?

The guide is structured around the four components of the Global Fund's Investment Approach to HIV responses, which includes programmes to reduce human rights-related barriers (see *Figure 1*).



## MODULE 1

### **UNDERSTAND HUMAN RIGHTS-RELATED BARRIERS TO HIV SERVICES AND THE PROGRAMMES TO REMOVE THEM**

This module introduces the core concepts in removing human rights-related barriers to HIV services, and guides you through the preparation for programme design.

- **Unit 1: Understand human rights-related barriers to HIV services and the need to remove them:** Describes the main human rights- and gender-related barriers that currently impede access to, uptake and retention in HIV services in many parts of the world.
- **Unit 2: Understand the seven key programme areas that can reduce or remove human rights-related barriers to HIV services:** Describes the seven evidence-informed programmes and the activities under them.
- **Unit 3: Understand your country context:** Guides you through the important first stage in designing and implementing a comprehensive response, and helps you to: engage with the right stakeholders; map national HIV services, strategies and barriers, and map current programmes to remove human rights-related barriers to services.

## MODULE 2

### **DESIGN PROGRAMMES TO REMOVE HUMAN RIGHTS-RELATED BARRIERS TO HIV SERVICES**

This module provides information and guidance on designing programmes so that they have a high standard of quality, achieve comprehensiveness, are sustainable and create impact.

- **Unit 4: Essential components for quality, comprehensiveness, sustainability and impact**
- **Unit 5: Design programmes: Four key steps**
  - Step 1: Map the process of change
  - Step 2: Combine interventions
  - Step 3: Coordinate implementation
  - Step 4: Select indicators and monitoring process
- **Unit 6: Design programmes: Using the seven key programme areas**
  - Getting started and activities
  - Step 1: Map the process of change
  - Step 2: Combine interventions
  - Step 3: Coordinate implementation
  - Step 4: Select indicators and monitoring process
  - Key enablers and additional resources
- **Unit 7: Cross-cutting issues**
  - Keeping communities at the centre of programmes
  - Addressing safety and security across programme areas
  - Sustaining programmes to achieve impact

## MODULE 3

### **DELIVER PROGRAMMES AT SCALE TO REMOVE HUMAN RIGHTS-RELATED BARRIERS TO HIV SERVICES**

This module provides guidance on scaling up and delivering combined programmes.

#### **Unit 8: Deliver at scale: Four key steps**

- Step 1: Develop the scale-up plan
- Step 2: Develop the monitoring, evaluation and learning plan
- Step 3: Cost the scale-up plan and mobilise resources
- Step 4: Implement the scale-up plan

## How to use this guide

It is strongly recommended that users read all the modules, however, they can be used separately or together, according to the national context. Countries are at different stages in their efforts to address human rights-related barriers to services. Some of the countries supported by the Global Fund, under the *Breaking Down Barriers* initiative, may have already put in place significant programming and/or have developed or are developing multi-year strategies to remove human rights-related barriers to services. Others are considering efforts as part of their action plans resulting from LEAs, or through their participation in the *Global Partnership for Action to Eliminate All Forms of HIV-related Stigma and Discrimination*.

### ESSENTIAL READING

- **HIV Information Note** – Global Fund.<sup>22</sup>
- **Technical Brief on HIV, Human Rights and Gender Equality** – Global Fund.<sup>23</sup>
- **Technical Brief on Gender Equity** – Global Fund.<sup>24</sup>
- **Good Practice Guide: HIV and Human Rights** – Frontline AIDS and ARASA.<sup>25</sup>
- **Rights–Evidence–ACTION (REAct)** – Frontline AIDS – a tool to record human rights violations that happen when accessing HIV and health services.<sup>26</sup>
- **Good Practice Guide: Gender-transformative HIV Programming** – Frontline AIDS.<sup>27</sup>
- **Safety and Security Toolkit: Strengthening the Implementation of HIV Programs for and with Key Populations** – Frontline AIDS and the LINKAGES Project.<sup>28</sup>
- **Fast-Track and human rights: Advancing human rights efforts to accelerate the HIV response** – UNAIDS – outlines the role of human rights programming in achieving Fast-Track targets.<sup>29</sup>
- **Sustaining the human rights response to HIV: Funding Landscape and Community Voices** – UNAIDS.<sup>30</sup>

22. Global Fund (2019), 'HIV Information Note', Geneva: Global Fund. [www.theglobalfund.org/media/4765/core\\_hiv\\_infonote\\_en.pdf](http://www.theglobalfund.org/media/4765/core_hiv_infonote_en.pdf).

23. Global Fund (2019), 'Global Fund Technical Brief: HIV, Human Rights, and Gender Equality', Geneva: Global Fund. [www.theglobalfund.org/media/6348/core\\_hivhumanrightsgenderequality\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/6348/core_hivhumanrightsgenderequality_technicalbrief_en.pdf).

24. Global Fund (2019), 'Technical Brief: Gender Equity', Geneva: Global Fund. [www.theglobalfund.org/media/5728/core\\_gender\\_infonote\\_en.pdf](http://www.theglobalfund.org/media/5728/core_gender_infonote_en.pdf).

25. Frontline AIDS and ARASA (2014), 'Good Practice Guide: HIV and Human Rights', Brighton: IHAA. <https://frontlineaids.org/resources/good-practice-guide-hiv-and-human-rights/>.

26. Frontline AIDS (2019), 'Rights–Evidence–ACTION (REAct)', Brighton: Frontline AIDS. <https://frontlineaids.org/resources/react-user-guide/>.

27. Frontline AIDS (2018), 'Good Practice Guide: Gender-transformative HIV Programming', <https://frontlineaids.org/resources/good-practice-guide-gender-transformative-hiv-programming/>.

28. Frontline AIDS and the LINKAGES Project (2018), 'Safety and Security Toolkit: Strengthening the Implementation of HIV Programs for and with Key Populations', Durham, NC: FHI 360. [www.fhi360.org/sites/default/files/media/documents/resource-linkages-safety-security-toolkit.pdf](http://www.fhi360.org/sites/default/files/media/documents/resource-linkages-safety-security-toolkit.pdf).

29. UNAIDS (2017), 'Fast-Track and human rights: Advancing human rights efforts to accelerate the HIV response', Geneva: UNAIDS. [www.unaids.org/en/resources/documents/2017/fast-track-human-rights](http://www.unaids.org/en/resources/documents/2017/fast-track-human-rights)

30. UNAIDS (2015), 'Sustaining the human rights response to HIV: Funding Landscape and Community Voices', [www.unaids.org/sites/default/files/media\\_asset/JC2769\\_humanrights\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/JC2769_humanrights_en.pdf)



**MODULE 1**

# UNDERSTAND

**HUMAN RIGHTS-RELATED BARRIERS TO HIV SERVICES AND THE PROGRAMMES TO REMOVE THEM**

## ABOUT THIS MODULE

This module introduces the core concepts in removing human rights-related barriers to HIV services, and prepares you for the first step in programme design.

**Unit 1** describes the main human rights- and gender-related barriers that currently impede access to, uptake and retention in HIV services in many parts of the world.

**Unit 2** describes the seven evidence-informed programmes and the activities under them that can reduce or remove human rights-related barriers to HIV services.

**Unit 3** guides you through the important first stage in designing and implementing a comprehensive response, and helps you to: engage with the right stakeholders; map national HIV services, strategies and barriers, and map current programmes to remove human rights-related barriers to services.

Completing the steps in this unit will provide you with the essential information that will form the basis of your process of change, covered in *Module 2*.

**Unit 1: Understand human rights-related barriers to HIV services and the need to remove them** 17

**Unit 2: Understand the seven key programme areas that can reduce or remove human rights-related barriers to HIV services** 21

**Unit 3: Understand your country context** 25

## UNIT 1: UNDERSTAND

### HUMAN RIGHTS-RELATED BARRIERS TO HIV SERVICES AND THE NEED TO REMOVE THEM

Global progress in understanding how to prevent HIV infection, and how to maintain the long-term health of those living with HIV, now enables us to contemplate ending the AIDS epidemic as a major public health challenge by 2030. However, it is increasingly clear that this will only be possible if we remove the human rights-related barriers to access, uptake and retention in HIV and other health services. These barriers remain as key drivers of vulnerability to HIV infection and to its impact on the lives of those living with HIV.

This is especially the case for people from key and vulnerable populations, whose health and human rights continue to be compromised in many countries. Key populations include gay men and other men who have sex with men, sex workers, transgender people, people who inject drugs, prisoners and other incarcerated people. Vulnerable populations can include adolescent girls and young women, people with disabilities, migrants, refugees and displaced people.<sup>31</sup>

The difficulties key populations face in accessing HIV services not only negatively impact on their health and well-being, but also impede on progress towards political commitments (see *Box 2*) and global targets such as the 2030 Agenda and the SDGs.<sup>32</sup> Therefore, it is critical that renewed efforts and stronger accountability for removing human rights-related barriers continue to be global priorities.

The Global Fund has broadly defined **three overall categories of human rights-related barriers to HIV services** based on years of research by technical

#### BOX 2: POLITICAL COMMITMENTS

All UN Member States recognised and committed to the realisation of human rights as an essential element of a successful HIV response in the *2001 Declaration of Commitment on HIV/AIDS*<sup>33</sup> and the *2006*,<sup>34</sup> *2011*<sup>35</sup> and *2016 Political Declarations on HIV and AIDS*. In particular, in 2016, they committed to implement:

“... national AIDS strategies that empower people living with, at risk of and affected by HIV to know their rights and to access justice and legal services to prevent and challenge violations of human rights, including strategies and programmes aimed at sensitising law-enforcement officials and members of the legislature and judiciary, training healthcare workers in non-discrimination, confidentiality and informed consent, and supporting national human rights learning campaigns, as well as monitoring the impact of the legal environment on HIV prevention, treatment, care and support.”<sup>36</sup>

partners, universities and governments, as well as the lived experiences of affected populations:<sup>37</sup>

1. Stigma and discrimination
2. Gender inequality and gender based-violence
3. Punitive laws, policies and practices.

Often, these barriers are compounded by other factors, particularly socio-economic inequality, as the many facets of exclusion drive individuals and groups towards poverty (see *Figure 2*).

31. See UNAIDS, 'Key Populations': [www.unaids.org/en/topic/key-populations](http://www.unaids.org/en/topic/key-populations) and Global Fund, 'Key Populations': [www.theglobalfund.org/en/key-populations/](http://www.theglobalfund.org/en/key-populations/).

32. See: 'UN Sustainable Development Goals': <https://sustainabledevelopment.un.org/?menu=1300>.

33. UNAIDS (2001), 'Declaration of Commitment on HIV/AIDS'. Geneva: UNAIDS. Available at: [www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2001declarationofcommitmentonhivaids](http://www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2001declarationofcommitmentonhivaids)

34. UNAIDS (2006), 'Political Declaration on HIV/AIDS'. Geneva: UNAIDS. Available at: [www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2006politicaldeclarationonhivaids](http://www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2006politicaldeclarationonhivaids)

35. UNAIDS (2011), 'Political Declaration on HIV/AIDS'. Geneva: UNAIDS. Available at: [www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids](http://www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids).

36. UNAIDS (2016), 'Political Declaration on HIV/AIDS'. Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2016/2016-political-declaration-HIV-AIDS](http://www.unaids.org/en/resources/documents/2016/2016-political-declaration-HIV-AIDS).

37. Global Fund (2017), 'Breaking Down Barriers to Access: Scaling up programs to remove human rights-related barriers to health services in 20 countries and beyond'. Geneva: Global Fund. Available at: [www.theglobalfund.org/media/1213/humanrights\\_2016-removingbarrierspart2\\_qa\\_en.pdf](http://www.theglobalfund.org/media/1213/humanrights_2016-removingbarrierspart2_qa_en.pdf).

“ When I went to the clinic, the security guard refused to let me in because I am a transgender woman. Now, I have nowhere to go.”

#### BARRIERS

- Stigmatising and discriminatory attitudes towards key populations
- Denial of services and support

#### PROGRAMMES

- Sensitisation training for healthcare workers and staff
- Rights literacy training and peer support
- Strengthening community mobilisation
- Advocating for a sector-wide commitment to change

## 1.1 Stigma and discrimination

'HIV-related stigma is evident in irrational or fear-driven negative attitudes, behaviours and judgements towards people living with HIV, their partners and families and key populations. HIV-related discrimination is unfair and unjust treatment of a person or group of people based on their real or perceived HIV status. Discrimination also includes the unfair treatment of key populations, including gay men and other men who have sex with men, transgender people, sex workers, people who inject drugs, women and girls and other groups at higher risk of acquiring HIV, such as mobile and migrant populations, and prisoners and other people in closed, institutional settings.

Discrimination can become institutionalised in laws, policies and practices that negatively focus on people and marginalised groups living with HIV, including criminalised populations. HIV-specific laws, such as those criminalising HIV non-disclosure, exposure and transmission, further entrench stigma and discrimination. Restrictive laws and policies, such as the requirement for parental consent for adolescents and young people to access services, discourage people from seeking services and support. HIV-related discrimination can be compounded by other forms of discrimination, including discrimination based on race, sex, socio-economic status, sexual orientation, age, gender identity or national origin.<sup>38</sup>

Stigma and discrimination create a hostile environment and can negatively affect an individual's motivation to be tested for HIV or, if HIV

positive, can decrease the likelihood that someone will disclose his or her status or access HIV-related prevention, care, treatment and support services. It can also result in the direct denial of services. The *Global Partnership for Action to Eliminate All Forms of HIV-related Stigma and Discrimination* focuses on stigma and discrimination in six settings: healthcare, education, the workplace, the justice system, household and community, and emergencies and humanitarian settings.<sup>39</sup>

In addition to stigma from others, 'self-stigma' occurs when a person who belongs to a stigmatised group, for example a sex worker or person living with HIV, internalises negative public attitudes and accepts them as valid. Self-stigma is characterised by profound feelings of shame and worthlessness. Various forms of marginalisation can contribute to self-stigma, including discrimination, poverty, punitive laws and policies, and violence.

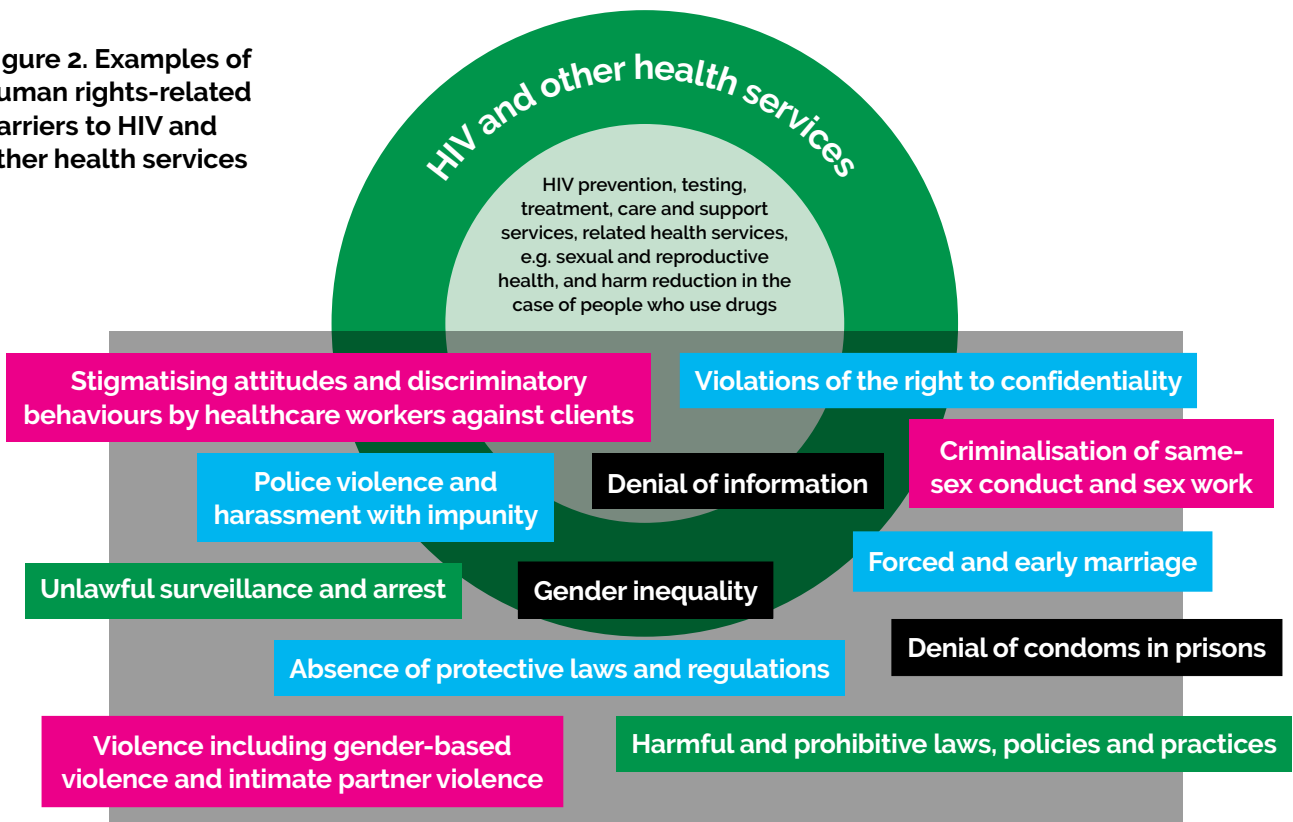
## 1.2 Gender inequality and gender-based violence

Inequality and discrimination based on sex, gender and gender identity and expression cause major vulnerability to HIV infection and increase the negative impact of living with HIV. The forms and effects of gender inequality and inequity are different for men and women, boys and girls, and gender non-conforming communities. Health and community systems that respond to the gender-specific needs of individuals, in where and how they receive services, are more effective. Health programmes should promote gender equality and gender equity, so that the different needs

38. UNAIDS (n.d), 'Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/global-partnership-hiv-stigma-discrimination\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/global-partnership-hiv-stigma-discrimination_en.pdf).

39. *Ibid.*

**Figure 2. Examples of human rights-related barriers to HIV and other health services**



and vulnerabilities of women, girls, men, boys, transgender women and gender non-conforming individuals are identified and addressed.

Women's economic, political and social subordination is deeply entrenched in harmful cultural norms, attitudes, beliefs and practices, as well as in retrogressive laws. Depending on the context, these gender-specific vulnerabilities for women and girls may comprise: lack of autonomy; unequal access to educational and economic opportunities; forced or early marriage; third party authorisation requirements limiting their access to healthcare, and various forms of violence in private or public spaces, including laws and policies that condone various forms of GBV and harmful cultural practices.

In many communities, women are afraid to reveal their HIV status or seek treatment because they

fear rejection, blame, loss of property and custody rights, and/or violence if their HIV status becomes known. Many women and girls cannot negotiate for safer sex with their intimate partners, nor make decisions on use of contraceptives. In many settings, women do not have access to sexual health services, including comprehensive family planning and contraceptive choice. In addition, early or forced marriage constitutes a serious human rights violation, posing risks of HIV infection and significant reproductive health problems.

In almost all contexts, women and girls face high rates of GBV, and there is a proven link between GBV and HIV.<sup>40,41,42</sup> Such violence, and fear of it, can undermine their capacity to negotiate safer sex or leave an abusive relationship. Violence not only increases risk of infection, but also negatively influences adherence to HIV treatment and access to other health services.

40. Jewkes R., Dunkle K., Nduna M., Shai N. (2010). 'Intimate partner violence, relationship power inequity, and incidence of HIV infection in young women in South Africa: a cohort study', *The Lancet*, 376: 41-48. [www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)60548-X/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)60548-X/fulltext).

41. Kouyoumdjian F.G., Calzavara L.M., Bondy S.J. et al (2013), 'Intimate partner violence is associated with incident HIV infection in women in Uganda', *AIDS*, 27(8). [www.ncbi.nlm.nih.gov/pubmed/23925380](http://www.ncbi.nlm.nih.gov/pubmed/23925380).

42. WHO and UNAIDS (2013), '16 Ideas for addressing violence against women in the context of the HIV epidemic: A programming tool'. [www.who.int/reproductivehealth/publications/violence/vaw\\_hiv\\_epidemic/en/](http://www.who.int/reproductivehealth/publications/violence/vaw_hiv_epidemic/en/).

Criminalised communities, including sex workers, people who inject drugs and lesbian, gay, bisexual and transgender (LGBT) communities are at higher risk of violence. Sex workers and transgender women also face higher risk of sexual violence, including rape, at the hands of clients, police, and sometimes vigilantes, and others in the community.

Men and boys also experience gender-related vulnerability to HIV, including violence. Gender norms and notions of masculinity may push men and boys into avoiding health-seeking behaviour, and engaging in activities that put them at risk of HIV infection, such as high alcohol and drug use and having multiple and concurrent sexual partners. Because of these gender-related vulnerabilities, a disproportionate number of men discontinue treatment, and there is a disproportionately higher death rate of men from AIDS than women. While women and girls face higher rates of violence, there are communities of men, including those who use drugs and male sex workers, who are also vulnerable to high levels of violence.<sup>43</sup>

### 1.3 Punitive laws, policies and practices

In many countries and communities, there are laws, policies and practices that drive people away from healthcare. Within health services, these may include:

- Lack of informed consent and confidentiality
- Mandatory testing
- Demands for bribes or high fees
- Policies allowing for discriminatory treatment of particular groups
- Laws requiring healthcare providers to report certain groups to law-enforcement.

In the community, police may engage in harsh policing and illegal practices against people who use drugs, sex workers and LGBT communities. Such

#### BOX 3: LAWS AFFECTING ACCESS TO HIV SERVICES

In 75 countries, HIV non-disclosure, exposure or transmission, including unintentional transmission, is criminalised.<sup>45</sup> Thirty countries outlaw sex work explicitly, and at least 47 others criminalise some aspect of sex work, including penalising the clients of sex workers or operators of brothels, while not criminalising sex work *per se*.<sup>46</sup> Sixty-eight countries criminalise consensual same-sex conduct, punishable by death in six of those countries.<sup>47</sup> Most countries criminalise some aspect of drug use or possession for personal use, and at least 35 countries maintain the death penalty for some drug-related crimes.<sup>48</sup>

illegal police practices involve harassment, extortion, arbitrary arrests and violence, including sexual violence. These may send sex workers and their clients, LGBT people and people who use drugs underground, discouraging them from accessing health services and/or engaging in safer practices.

Other forms of punitive law-enforcement directly undermine HIV prevention and treatment efforts. Police may arrest people who use drugs as they try to enter harm reduction service sites; or harm reduction may be altogether denied due to criminalisation of drug use. Sex workers may be arrested and condoms in their possession be used as evidence against them. Overly-broad laws criminalising transmission of HIV may make people fearful of getting tested or informing their sexual partners of their HIV status. Those in police custody, prisons, or other closed settings, may be denied access to condoms, harm reduction measures and other forms of HIV and TB prevention, as well as treatment. Migrants and refugees may be denied access to HIV prevention and treatment that is available to other citizens.<sup>44</sup>

43. Global Fund (2019), 'Global Fund Technical Brief: HIV, Human Rights, and Gender Equality', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/6348/core\\_hivhumanrightsgenderequality\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/6348/core_hivhumanrightsgenderequality_technicalbrief_en.pdf).

44. *Ibid.*

45. HIV Justice Network (2019), 'Advancing HIV Justice 3: Growing the global movement against HIV criminalisation', Amsterdam: HIV Justice Network. Available at: [www.hivjustice.net/advancing3/](http://www.hivjustice.net/advancing3/).

46. ProCon.Org (2018), 'Countries and their prostitution policies'. Available at: <https://prostitution.procon.org/view.resource.php?resourceID=000772>.

47. International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA World) (2019), 'State-Sponsored Homophobia report 2019: Global Legislation Overview Update', Geneva: ILGA World. Available at: <https://ilga.org/state-sponsored-homophobia-report>.

48. Harm Reduction International (HRI) (updated 2019), 'The Death Penalty for Drug Offences: Global Overview 2018', London: HRI. Available at: [www.hri.global/death-penalty-drugs-2018](http://www.hri.global/death-penalty-drugs-2018). See also, UNAIDS Laws and Policies Analytics at <http://lawsandpolicies.unaids.org>.

**UNIT 2: UNDERSTAND****THE SEVEN KEY PROGRAMMES THAT CAN REDUCE OR REMOVE HUMAN RIGHTS-RELATED BARRIERS TO HIV SERVICES**

Based on evidence, country experiences and best practice, governments have committed to, and the Global Fund, UNAIDS and Frontline AIDS recommend, seven key programme areas to remove human rights-related barriers to HIV services (see *Figure 3*).<sup>49</sup>

These programme areas are recognised as 'critical enablers' by the Global Fund, UNAIDS, WHO and other technical partners.<sup>50</sup> They are critical because they improve access, uptake and retention in health services by those living with, affected by and most at risk of HIV.



49. UNAIDS (2012), 'Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses, Guidance Note', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012\\_0.pdf](http://www.unaids.org/sites/default/files/media_asset/Key_Human_Rights_Programmes_en_May2012_0.pdf).

50. WHO (2014), 'Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations', Geneva: WHO. Available at [www.who.int/hiv/pub/guidelines/keypopulations/en/](http://www.who.int/hiv/pub/guidelines/keypopulations/en/). UNDP (2012), 'Understanding and acting on critical enablers and development synergies for strategic investments', New York: UNDP. Available at: [www.undp.org/content/dam/undp/library/hiv/aids/English/UNAIDS\\_UNDP\\_Enablers\\_and\\_Synergies\\_ENG.pdf](http://www.undp.org/content/dam/undp/library/hiv/aids/English/UNAIDS_UNDP_Enablers_and_Synergies_ENG.pdf).



The seven key programmes help to ensure that:

- health and other related services reach all those most affected
- human rights are protected
- key and vulnerable populations are enabled to navigate difficult social and legal challenges blocking access to HIV-related health services
- uptake and retention are supported
- community and health systems are strengthened.

Therefore, these interventions are most effective when they are integrated into or 'follow' existing national prevention and treatment services, so as to support these efficiently. (See *Unit 3: Understand your country context* for guidance on mapping national HIV services, strategies and barriers).

A range of activities and interventions can be incorporated and implemented under each of these programme areas. These approaches are flexible, can take many cost-effective forms, and be tailored and combined to address different issues and contexts, as well as different key and vulnerable populations (see *Module 2, Unit 6: Design programmes: Using the seven key programme areas*).

**Table 1: Seven key programme areas for removing human rights-related barriers and increasing access to services**

PROGRAMME AREA	WHY	WHAT
 <p><b>1</b> Reduction of HIV-related stigma and discrimination</p>	<p>Addressing stigma and discrimination can positively influence a range of outcomes that are critical to the HIV response, including behaviours and uptake of HIV services and support services, all of which ultimately influence individual quality of life and HIV incidence and prevalence.</p>	<ul style="list-style-type: none"> <li>● Community mobilisation/sensitisation on HIV/TB stigma and discrimination, including community dialogues</li> <li>● Public engagement of people living with HIV and HIV/TB, religious and community leaders and celebrities</li> <li>● Media campaigns; edu-tainment; TV and radio shows</li> <li>● Anti-discrimination programmes/policies in work, health and education, championed by key influencers and heads of staff</li> <li>● Roll out of the <i>HIV Stigma Index</i> and other measurement tools for stigma</li> <li>● Peer mobilisation and support groups to promote health and non-discrimination.</li> </ul>
 <p><b>2</b> Training healthcare providers on human rights and medical ethics</p>	<p>Human rights and ethics training for healthcare providers focuses on:</p> <ul style="list-style-type: none"> <li>● ensuring that healthcare providers know about their own human rights to health and non-discrimination, as well as their human rights and ethical obligations in the context of HIV</li> </ul>	<ul style="list-style-type: none"> <li>● Development of curricula on HIV-related human rights and medical ethics for healthcare personnel and staff embedded in pre- and in-service training courses for staff</li> <li>● Training of and on-going support to healthcare providers (inside and outside facilities), administrators and other staff on non-discrimination, duty to treat, informed consent and confidentiality, violence prevention and treatment</li> </ul>



## PROGRAMME AREA

## WHY

## WHAT

- reducing stigmatising attitudes and discrimination in healthcare settings
- providing healthcare staff with the skills and tools necessary to ensure the rights of patients to informed consent, confidentiality, treatment and non-discrimination.

- Collaboration between healthcare points and community organisations for patient support and quality control
- Development of institutional policies and accountability mechanisms for healthcare facilities that ensure stigma- and discrimination-free service delivery and access to justice and/or conflict resolution for clients through administrative pathways.

## 3

## Sensitisation of law-makers and law-enforcement agents

These programmes seek to inform and sensitise those who make the laws (parliamentarians) and those who enforce them (e.g. ministers of interior and justice, police, prosecutors, judges, lawyers, and traditional and religious leaders) about the ways the law can and should protect people in the context of HIV and support national HIV prevention, treatment and key population programming strategies.

- Information/sensitisation for parliamentarians, ministers of justice, judges, prosecutors, police, traditional and religious leaders on legal, health and human rights of people living with HIV and HIV/TB, including gender- and age-based discrimination, inequality and violence prevention and intimate partner violence
- Facilitation of discussions and joint activities among service providers, law-enforcement and key and vulnerable populations to gain police support for health programmes
- Training of prison personnel (in prisons for women and men) on public health, human rights and HIV and HIV/TB responses
- HIV and HIV/TB in the workplace programmes for law-makers and enforcers.

## 4

## Reducing discrimination against women and girls in the context of HIV

Programmes under this area address gender inequality, harmful gender norms and GBV, both as causes and as consequences of HIV infection. The activities described in all the other programme areas can also be rolled out for and by women, including young women and adolescent girls.

- Developing or reforming laws and law-enforcement practices on age of consent, spousal consent, domestic violence, sexual consent and child marriage
- Community consultations to identify specific gender-related barriers to accessing HIV services
- Reform of family law, marriage, property, inheritance and custody laws
- Development of age-appropriate curriculum for sexuality and life-skills education, including HIV and gender equality issues
- Roll out of HIV-informed programmes to address harmful gender norms and traditional practices, and GBV.

PROGRAMME AREA	WHY	WHAT
 <p><b>5</b> Legal literacy ('know your rights')</p>	<p>Legal literacy programmes teach those living with or vulnerable to HIV about their human rights and about the national and local laws and policies that advance such rights in the context of HIV. This knowledge enables people to demand their individual rights, and provides them with knowledge and expertise to empower them to advocate for and organise around group rights (e.g. sex worker rights, the rights of young people).</p>	<ul style="list-style-type: none"> <li>● Legal and patients'-rights literacy trainings, including through peer human rights educators</li> <li>● Support to mobilisation and advocacy around HIV-related rights, laws and policies</li> <li>● Establishment of crisis response mechanisms to respond to abuse and violence, including GBV, and to use the data gathered to inform mitigation strategies to be built into programmes and policies.</li> </ul>
 <p><b>6</b> HIV-related legal services</p>	<p>HIV-related legal services can facilitate access to justice and redress in cases of HIV-related discrimination or other human rights violations. It can also provide mediation in disputes, including those involving property and child custody. They can enable people to plan estates, get medication, and navigate social services.</p>	<ul style="list-style-type: none"> <li>● Support to individuals to access legal information, referral services, advice and representation, including through hotlines, radio, professional law firms and peer paralegal community systems</li> <li>● Support to individuals in arbitration, dispute settlement, and community mediation, including engagement of traditional leaders and customary law in support of affected individuals</li> <li>● With the informed consent of litigants, their cases can also be used in support of strategic litigation/law reform efforts.</li> </ul>
 <p><b>7</b> Monitoring and reforming laws, regulations and policies relating to HIV</p>	<p>Laws, regulations and policies relating to HIV can negatively or positively impact a national HIV epidemic and the lives and human rights of those living with and affected by HIV. Therefore, it is critical to monitor and reform laws, regulations and policies so that they protect and promote human rights, and support (rather than hinder) access to HIV and health services.</p>	<ul style="list-style-type: none"> <li>● Assessing policies/practices on informed consent and confidentiality and their impact on access to services</li> <li>● LEAs</li> <li>● Community-based monitoring of laws and policies and their implementation</li> <li>● Advocacy and mobilisation for law and policy reform to increase access to HIV services.</li> </ul>

Source: UNAIDS, 2019

## UNIT 3: UNDERSTAND YOUR COUNTRY CONTEXT

The crucial first step in designing and implementing programmes to remove human rights-related barriers to services is to *understand* your country context, that is: the national HIV prevention and treatment strategies and services; the specific barriers to these services in your national context; who is affected by them; what is currently being done to address those barriers and how those barriers impact the national response to HIV.

The following process will enable you to: engage with the right stakeholders; map national HIV services, strategies and barriers and map current programmes to remove human rights-related barriers to services.

This important information will form the basis of your '**process of change**', which is critical for understanding, planning, scaling up, and monitoring and evaluating results (see *Module 2, Step 1: Map the process of change*), i.e. 'If I put in place these programmes, they will remove these barriers, resulting in this increase in access to prevention, treatment, and key population programming, for these populations, in this locale'.

### 3.1 Sources of information

In countries included in the *Breaking Down Barriers* initiative, this information will be available through the baseline assessments conducted in 2017 and 2018.<sup>51</sup> Countries may already have additional information available through other efforts by governments, the UN system and civil society to document relevant barriers.

In other settings, this information may need to be gathered with the help of data and evidence from various national sources. At this stage, it is important

### BOX 4: MAIN SOURCES OF INFORMATION

- National Strategic Plans (NSPs). Even if not comprehensive, most NSPs and/or Investment Cases/concept notes will already have a focus and some data on key populations and vulnerable populations at risk, and will set out a strategy for how to reach them with HIV prevention, treatment and retention services
- LEAs<sup>52</sup>
- UNAIDS National Commitments and Policy Instruments
- HIV Stigma Index<sup>53</sup>
- UNAIDS Global AIDS Monitoring (GAM)<sup>54</sup>
- Integrated Biological and Behavioral Surveillance (IBBS) surveys
- REAct<sup>55</sup>
- Universal Periodic Review reports<sup>56</sup>
- Data bases, gender assessments, measurements of stigma and discrimination in healthcare and in communities, human rights reporting, and community-based monitoring.

to engage with networks and representatives of the populations you are aiming to support. (For more detailed information on engaging with communities see *Module 2, Unit 7, 7.1: Keeping communities at the centre of programmes*)

For the purpose of understanding the barriers, so you can plan for, implement and scale up programmes to remove them, the focus should be on priority barriers in a country, those that:

- contribute significantly to the epidemiological situation of particular populations

51. Global Fund (2020), '*Baseline Assessments of Human Rights-related Barriers to Services*', Geneva: Global Fund. Available at: [www.theglobalfund.org/en/publications/](http://www.theglobalfund.org/en/publications/).

52. See: [www.undp.org/content/dam/undp/library/HIV-AIDS/Governance of HIV Responses/UNDP Practical Manual LEA FINAL web.pdf](http://www.undp.org/content/dam/undp/library/HIV-AIDS/Governance%20of%20HIV%20Responses/UNDP%20Practical%20Manual%20LEA%20FINAL%20web.pdf).

53. Global Network of People Living with HIV (GNP+), '*People Living with HIV Stigma Index*', Amsterdam: GNP+. Available at: [www.stigmaindex.org/](http://www.stigmaindex.org/).

54. See UNAIDS website: [www.unaids.org/en/global-aids-monitoring](http://www.unaids.org/en/global-aids-monitoring).

55. See Frontline AIDS website: <https://frontlineaids.org/our-work-includes/react/>.

56. See: United Nations Human Rights Council, Office of the High Commissioner (OHCHR) website: [www.ohchr.org/en/hrbodies/upr/pages/basicfacts.aspx](http://www.ohchr.org/en/hrbodies/upr/pages/basicfacts.aspx).

- directly lead to greater vulnerability to HIV and/or less willingness or ability to access treatment and stay on it
- can and should be overcome by programmes that are funded by HIV/health funding (i.e. some barriers may be more logically addressed by broader development funding).

### 3.2 Understand your country context: Getting started

#### Engage important stakeholders at the start in an inclusive process

It is important to engage all relevant actors and stakeholders in the process of identifying and understanding human rights-related barriers to HIV services. The expertise and experience of stakeholders from affected communities, civil society, government and donors is critical. A diverse and inclusive partnership will help all participants to understand the barriers and the best programmes or combination of programmes by which to address them. (See *Module 2, Unit 7, 7.1: Keeping communities at the centre of programmes.*)

#### Map national HIV services, strategies and barriers

It is essential to understand the context, particularly the national HIV strategy, in which human rights-related programming will be scaled up and sustained. The programmes to remove human rights-related barriers to HIV services are to become part of the national HIV strategy, and should seek to increase access to existing services, as well as push for greater access for populations that have been underserved. The following types of information should be gathered and reviewed:

- ✓ **Review national strategies**, for example, HIV prevention, testing, treatment and retention strategies, gender, sexual and reproductive health and rights, prevention of mother-to-child transmission, GBV, and other strategies relevant to specific groups and populations. Assess whether and to what extent they include a focus on human rights and gender equality. Consider if there are any gaps in the inclusion of key and vulnerable

populations or barriers they face that are not considered.

- ✓ **Map national HIV programme data** provided by government, public sector, private sector, civil society or communities. Include prevention, testing, treatment and care and retention, and other packages of services that are HIV-related, for example, sexual and reproductive health services, programmes for adolescent girls and young women, harm reduction services for people who use drugs, and other key population programming. If the data is sufficiently disaggregated, try to determine what HIV prevention and treatment services are being delivered, where, by whom and for whom.

- ✓ **Review national data on uptake, access and retention in HIV prevention, treatment and retention services.** Include all available disaggregation: sex, gender, key population group, age, and location. Review and compare data from different locations/regions/districts to ensure any variation between different places in the country, not just a national aggregate, is taken into account. National data may include a 'cascade analysis', showing percentages of people not having access to or dropping out at various points of the cascade (prevention, testing, treatment, retention). Review any national strategies to increase uptake, access and retention. These national strategies should be supported by programmes to remove human rights-related barriers to services.

- ✓ **Assess human rights-related barriers.** Review existing data on stigma and discrimination gathered through the *HIV Stigma Index* or through other assessments of stigma and discrimination, for example in healthcare settings or through the GAM, or any IBBS surveys that have been conducted for key populations at higher risk of HIV infection. Review any existing gender assessments. The HIV and human rights situation in-country may also have been reported on by regional or national NGOs. Review available assessments of laws, policies and practices, for example in existing LEAs. The recommendations by the Global Commission on HIV and the Law in *HIV and the Law: Risks, Rights & Health* provide a good framework to shape the review of law, policy and practice.<sup>57</sup>

57. UNDP (2012). Global Commission on HIV and the Law, '*HIV and the Law: Risks, Rights & Health*', Geneva: UNDP. Available at: <https://hivlawcommission.org/wp-content/uploads/2017/06/FinalReport-RisksRightsHealth-EN.pdf>

✓ **Consult with communities on barriers and recommendations for change.** Meet with networks of people living with HIV and other key and vulnerable populations, as well as with the NGOs and CBOs working with them, to discuss the nature of the barriers faced by these populations; the root causes of the barriers, and what would be needed to remove them using the seven key programme areas as a framework.

### Map current programmes to remove human rights-related barriers to services

It is also important to know and assess any activities and programmes that are already being implemented to address human rights-related barriers; who is responsible for delivering these activities; how much they cost; how effective they have been, and what the potential is to scale up existing efforts. This will help ensure that your programme builds on and integrates existing quality programmes and avoids duplication and working in silos. Knowing about existing programmes also helps to identify the national and local expertise that is already available.

✓ **Hold an open, inclusive consultation with implementers of existing programmes** to find out: Who are the key actors and stakeholders? What are their roles and what power do they have? What work is currently being done to remove human rights-related barriers? What is working? (Assess this at different levels for different groups and across programme areas.) What are the gaps in current programming? What are the opportunities?

✓ **Assess the potential for scale-up based on the mapping:** Which existing programmes have potential for scale-up? Have any of these been evaluated? Are there programmes that could be

delivered in more places or reach more people? Have projects with evidence of impact been piloted in different locations or with different participants, or can pilots be implemented? Could different actors work together to scale up their capacity? Could existing programmes add more activities or integrate with other programmes? It is important to think about potential for referrals and building the capacity and reach of existing programmes, not just creating new ones.

✓ **Consider investment and costs:** Add existing levels of investments, costs and funding sources to the mapping: What are the opportunities for synergy and maximising existing funding? Are existing human rights programmes, run by other organisations, effectively integrated into, and ensuring support for, prevention and treatment activities and the populations that benefit from them? Are there opportunities for cost-saving through integration? Is new funding needed? What sources are available? How can activities be sustained beyond current funding opportunities?

### Bring together all the evidence from the previous step

What are the barriers that need to be addressed? What impact do these barriers have, and for whom? What is being done and what more needs to be done to address these barriers? Are there duplications and gaps in existing programmes to reduce human rights-related barriers to services? How best can these be addressed?

### Hold a further consultation to validate what the analysis has found

Are there any gaps? Are the experiences of all key and vulnerable populations, urban and rural areas and different genders and age groups represented?



### BOX 5: HUMAN RIGHTS AND GENDER PROGRAMMING IN CHALLENGING OPERATING ENVIRONMENTS

Global Fund guidance on challenging operating environments (COEs) highlights the need for human rights and gender programming to also be implemented in these contexts. This guide has not been designed specifically for use in COEs, but those who are implementing human rights programmes to remove human rights-related barriers to services in these settings should use this guide.<sup>58</sup> It can also be used alongside the Global Fund Guidance Brief on [Human rights and gender programming in challenging operating environments \(COEs\)](#).<sup>59</sup>

Barriers faced by key and vulnerable populations, including women, girls and adolescents, may be worse in COEs, and the need for services may be heightened.

Those involved in planning and implementing programmes to address human rights-related barriers to HIV services in COEs can adapt them to the environments, including by working with security forces and other authorities to ensure non-discriminatory access to health services and basic needs; working inclusively with refugees, linguistic minorities and vulnerable people in host communities, and addressing the increased risk of violence against women and girls in such contexts.

### ESSENTIAL READING

- [Avert website](#) for data and introductory overviews on HIV and key issues including human rights.<sup>60</sup>
- [The Right to the Highest Attainable Standard of Health: The International Covenant on Economic, Social, and Cultural Rights](#) – Office of the United Nations High Commissioner for Human Rights (OHCHR).<sup>61</sup>
- [Technical brief: HIV, Human Rights and Gender Equality](#) – Global Fund.<sup>62</sup>
- [HIV Information Note](#) – Global Fund.<sup>63</sup>
- [Good Practice Guide: HIV and Human Rights](#) – Frontline AIDS and ARASA – provides detailed and practical guidance on HIV and human rights.<sup>64</sup>
- [Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses](#) – UNAIDS.<sup>65</sup>
- [Guidance Note: Human Rights and the Law](#) – UNAIDS.<sup>66</sup>
- [Fast-Track and human rights: Advancing human rights efforts to accelerate the HIV response](#) – UNAIDS – outlines the role of human rights programming in achieving Fast-Track targets.<sup>67</sup>
- [International Guidelines on HIV/AIDS and Human Rights](#) – OHCHR and UNAIDS.<sup>68</sup>
- [Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030](#) – UN General Assembly.<sup>69</sup>

58. For example, three countries in the Global Fund Breaking Down Barriers initiative are defined as challenging operating environments by the Global Fund: DRC, Sierra Leone and Ukraine.

59. Global Fund (2017), *Human rights and gender programming in challenging operating environments (COEs): Guidance Brief*, Geneva: Global Fund. Available at: [www.theglobalfund.org/media/6346/fundingmodel\\_humanrightsgenderchallengingoperatingenvironments\\_guidance\\_en.pdf?u=637066568310000000](http://www.theglobalfund.org/media/6346/fundingmodel_humanrightsgenderchallengingoperatingenvironments_guidance_en.pdf?u=637066568310000000).

60. See Avert website: [www.avert.org/human-rights-and-hiv](http://www.avert.org/human-rights-and-hiv).

61. OHCHR (16 December 1966), Committee on Economic, Social and Cultural Rights. General Comment No. 14: *The Right to the Highest Attainable Standard of Health in: The International Covenant on Economic, Social, and Cultural Rights*. A/RES/2200. Available at: [www.ohchr.org/en/professionalinterest/pages/cescr.aspx](http://www.ohchr.org/en/professionalinterest/pages/cescr.aspx).

62. Global Fund (2019), *Global Fund Technical Brief: HIV, Human Rights, and Gender Equality*, Geneva: Global Fund. Available at: [www.theglobalfund.org/media/6348/core\\_hivhumanrightsgenderequality\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/6348/core_hivhumanrightsgenderequality_technicalbrief_en.pdf).

63. Global Fund (2019), *HIV Information Note*, Geneva: Global Fund. Available at: [www.theglobalfund.org/media/4765/core\\_hiv\\_infonote\\_en.pdf](http://www.theglobalfund.org/media/4765/core_hiv_infonote_en.pdf).

64. Frontline AIDS and ARASA (2014), *Good Practice Guide: HIV and Human Rights*, Brighton: Frontline AIDS. Available at: <https://frontlineaids.org/resources/good-practice-guide-hiv-and-human-rights/>.

65. UNAIDS (2012), *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses, Guidance Note*, Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2012/Key\\_Human\\_Rights\\_Programmes](http://www.unaids.org/en/resources/documents/2012/Key_Human_Rights_Programmes).

66. UNAIDS (2014), *Guidance note: human rights and the law*. Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/2014unaidsguidancenote\\_humanrightsandthelaw\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_humanrightsandthelaw_en.pdf).

67. UNAIDS (2017), *Fast-Track and human rights: Advancing human rights efforts to accelerate the HIV response*, Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2017/fast-track-human-rights](http://www.unaids.org/en/resources/documents/2017/fast-track-human-rights).

68. UNAIDS and OHCHR (2006), *International Guidelines on HIV/AIDS and Human Rights*, Geneva: UNAIDS. Available at: [www.ohchr.org/Documents/Publications/HIVAIDSGuidelinesen.pdf](http://www.ohchr.org/Documents/Publications/HIVAIDSGuidelinesen.pdf).

69. UN General Assembly (2016), *Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030*, Available at: [www.unaids.org/sites/default/files/media\\_asset/2016-political-declaration-HIV-AIDS\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2016-political-declaration-HIV-AIDS_en.pdf).


**ADDITIONAL RESOURCES**

- **Working together: a community-driven guide to meaningful involvement in national responses to HIV** – International Council of AIDS Service Organizations (ICASO) – provides guidance on effective community consultation and involvement.<sup>70</sup>
- **Practical Field Guide for Community-based Human Rights Documentation** – Asia Catalyst – provides helpful guidance on how to carry out an inclusive consultation.<sup>71</sup>
- **Unity in Diversity: Achievements, Good Practices, and Lessons Learned** – Global Forum on MSM & HIV (MSMGF) – provides examples of key populations mobilising in hostile environments, building capacity and regional partnerships.<sup>72</sup>
- **Legal environment assessment for HIV – An operational guide to conducting national legal, regulatory and policy assessments for HIV** – UNDP.<sup>73</sup>
- **HIV and the Law: Risks, Rights & Health – Global Commission on HIV and the Law**.<sup>74</sup>
- **Sexual orientation, gender identity, HIV and human rights: An advocacy toolkit** – ARASA – A useful and practical toolkit for advocates.<sup>75</sup>

70. ICASO (2015), *Working together: a community-driven guide to meaningful involvement in national responses to HIV*, Toronto: ICASA. Available at: <http://icaso.org/wp-content/uploads/2015/06/Working-Together-EN.pdf>.

71. Asia Catalyst (2016), *Practical Field Guide for Community-based Human Rights Documentation*, Available at: [https://asiacatalyst.org/wp-content/uploads/2014/09/Field-Guide-June\\_forWeb.pdf](https://asiacatalyst.org/wp-content/uploads/2014/09/Field-Guide-June_forWeb.pdf).

72. MSMGF (2018), *Unity in diversity: Achievements, Good Practices, and Lessons Learned from the Consortium of MSM and Transgender Networks*, MSMGF. Available at: <https://msmgf.org/wp-content/uploads/2018/05/Unity-in-Diversity.pdf>.

73. UNDP (2014), *Legal Environment Assessment for HIV – An operational guide to conducting national legal, regulatory and policy assessments for HIV*, New York: UNDP. Available at: [www.undp.org/content/dam/undp/library/HIV-AIDS/Governance of HIV Responses/UNDP Practical Manual LEA FINAL web.pdf](http://www.undp.org/content/dam/undp/library/HIV-AIDS/Governance%20of%20HIV%20Responses/UNDP%20Practical%20Manual%20LEA%20FINAL%20web.pdf).

74. UNDP Global Commission on HIV and the Law (2018), *HIV and the Law: Risks, Rights and Health*, New York: UNDP. Available at: <https://hivlawcommission.org/>.

75. ARASA (2015), *Sexual orientation, gender identity, HIV and human rights. An advocacy toolkit*. Available at: [www.arasa.info/media/arasa/Resources/user%20manuals/arasa-toolkit-full-web.pdf](http://www.arasa.info/media/arasa/Resources/user%20manuals/arasa-toolkit-full-web.pdf).



**MODULE 2**

**DESIGN**

**PROGRAMMES TO REMOVE  
HUMAN RIGHTS-RELATED  
BARRIERS TO HIV SERVICES**



## ABOUT THIS MODULE

This module covers designing programmes to reduce human rights-related barriers to services so that they have a high standard of quality, achieve comprehensiveness, are sustainable, and have impact in terms of increasing access, uptake and retention in HIV services.

**Unit 4** describes the nine essential components integral to programmes to remove barriers to HIV services.

**Unit 5** describes the four key steps in developing effective programmes. It takes you through mapping a process of change to match interventions to specific barriers and the populations they affect; combining programme areas for greater effectiveness and impact; coordinating implementation; monitoring progress, and ensuring that national efforts to remove human rights-related barriers to services are comprehensive.

**Unit 6** guides you through each of the seven key programme areas using the four steps described in *Unit 5*.

**Unit 7** highlights three important cross-cutting areas that need to be considered throughout the design process:

- Keeping communities at the centre of programmes
- Addressing safety and security across programme areas
- Sustaining programmes to achieve impact.

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## UNIT 4: ESSENTIAL COMPONENTS

### FOR QUALITY, COMPREHENSIVENESS, SUSTAINABILITY AND IMPACT

A growing body of evidence shows that aiming to achieve quality, comprehensiveness, sustainability and impact must be integral to programmes to remove barriers to HIV prevention and treatment services. Programmes should be designed to support those services, and where possible be integrated into them. Designing programmes involves taking what is known about the barriers and those experiencing

them, and rolling out programmes that will remove them as part of the national HIV strategy and the HIV prevention, treatment and key population services provided under it.

Programmes should be designed to be gender-responsive, that is, designed in a way that also responds to the gendered dimensions of risk and access to services. Finally, remember the goal is to achieve **comprehensive** programmes, that is, **quality** programmes that are recognised as effective, reach the majority of those affected by the barriers, and that are implemented at a scale that will have **impact** and be **sustainable** in terms of reducing and removing the barriers in the long-term. To achieve this goal a number of essential components must be present.

Figure 4: Essential components for quality, comprehensiveness, sustainability and impact



- 1 Understand:** Achieving quality, comprehensiveness and impact begins with understanding human rights-related barriers to services and the need to remove them; understanding the seven key programme areas; understanding your country context in terms of knowing national HIV prevention and treatment strategies, the HIV services and the nature of the barriers and populations that you are seeking to support by implementing programmes (see *Module 1*).
- 2 Use a process of change:** Completing *Unit 3* in *Module 1* will provide you with important information that will form the basis of your process of change, enabling you to identify the programmes that will be most effective in removing the barriers, i.e. 'If I put in place these programmes, they will remove these barriers, resulting in this increase in access to prevention, treatment, key population programming, for these populations in this area'. Using a process of change is critical for understanding, planning, scaling up, and monitoring and evaluating results (see *Unit 5, Step 1: Map the process of change*).
- 3 Integrate programmes:** To be effective and to be most cost-efficient, programmes to remove human rights-related barriers should be integrated, wherever possible, into the HIV prevention, treatment and key population services they seek to benefit. For example, where there is training of healthcare workers on treatment, it should also include training on human rights and ethics. Where there are community health outreach workers or community testing, some of those involved can also be trained as peer paralegals and/or provide human rights education and legal literacy. Where there cannot be actual integration into prevention and treatment, the programmes to remove human rights-related barriers should be targeted in a way to support a key and vulnerable population in a given area to access nearby prevention and treatment services (*Module 1, Unit 3*, guides you through the process of mapping these services, interventions and their locations).
- 4 Avoid stand-alone and one-off activities:** To be effective and sustainable, programmes should not be stand-alone or one-off. In the past, many efforts involved organising a meeting or producing human rights materials. Whereas these

may be important components of a wider strategy or programme, they in themselves will not be sufficient to change the attitudes, levels of knowledge or behaviours that are at the core of barriers to services.

- 5 Use and build on local expertise and existing programmes:** It is important and efficient to use and build on local expertise and existing quality programmes to remove human rights-related barriers to services. In most countries, NGOs, CBOs, and networks of affected populations have been implementing such programmes for many years, but have not had sufficient funding or political support to sustain or expand them. They have important local capacity and expertise both in terms of knowledge of the barriers and of the programmes. Ways should be found to link them to increased funding so as to expand and incorporate their work into national efforts. (See *Unit 7, 7.1: Keeping communities at the centre of programmes*.)

- 6 Programmes should be combined or linked up for greater effectiveness and impact:** The interventions in the seven programme areas can and should be combined within one programme area or across programme areas for greater effectiveness. The population or geographic area would then benefit from this combination, leading to greater impact. For example, programmes to reduce barriers to services experienced by people who inject drugs could include:

- efforts to improve policies and laws supporting harm reduction
- legal literacy for people who inject drugs
- work with police to end abuses against people who inject drugs, including arbitrary arrest and detention and confiscation of clean needles and syringes
- training and deployment of individuals as peer paralegals among people who inject drugs.

In some cases, a single organisation may implement several combined programmes, but in most cases, combining programmes and doing so at scale is achieved by well-coordinated linking up of different interventions within programmes that are implemented by several different organisations. (See *Unit 5, Step 2: Combine interventions*. *Unit 6* also provides information on combining interventions and programmes under each of the programme areas).

**7** It is important to take into consideration and respond to contextual enabling/inhibiting factors, such as working environments or institutional practices, when developing or implementing programmes. Poor service delivery on the part of healthcare workers may be a result of low pay, inadequate facilities, or low moral, as much as it may be about specific attitudes or beliefs about a population. Individual police officers may benefit from training and sensitisation interventions and genuinely desire to make change. However, the institutional practices, particularly the chain of command, may prevent them from achieving such change if their superiors are not engaged to become supportive.

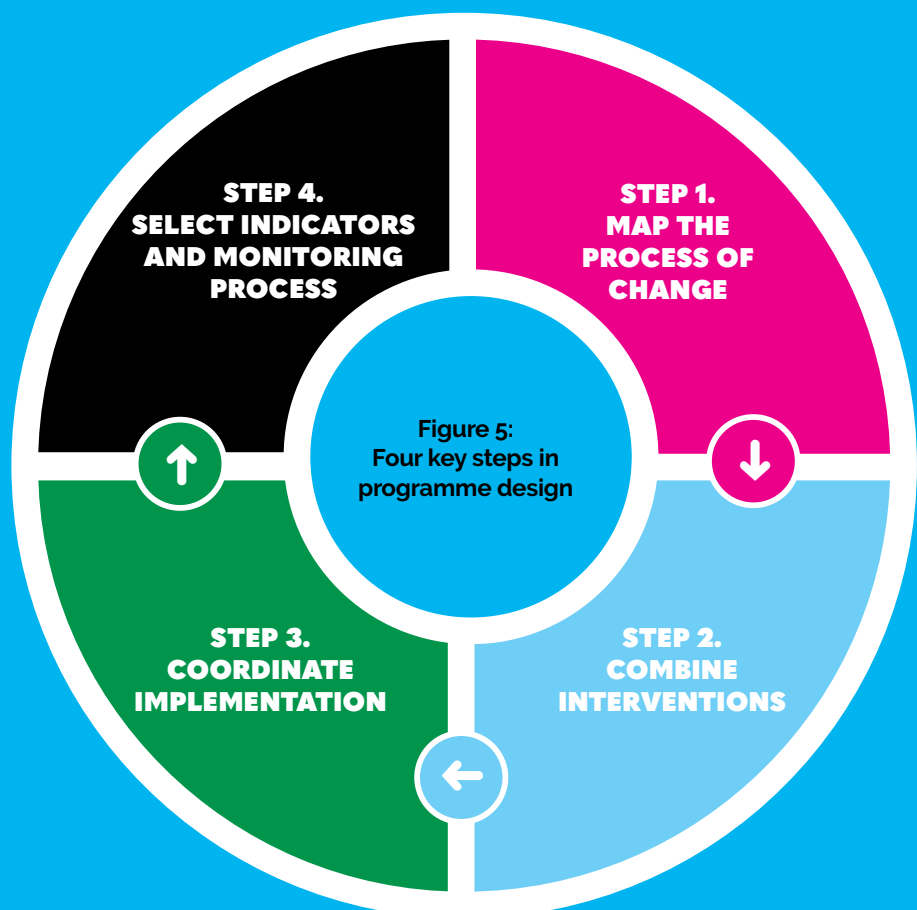
**8** Build cadres of local expertise among service providers and affected populations for longer-term capacity and sustainability. This involves such things as: a) investment in institutionalised pre-service and in-service human rights and ethics education for healthcare workers; b) increasing legal and patients'-rights literacy; c) mobilisation and advocacy through

trained and remunerated outreach workers who also act as peer human rights educators and peer paralegals; d) sustained sensitisation of police and prison staff in ways that address the pressures of their workplaces. (See Unit 7, 7.1: *Keeping communities at the centre of programmes.*)

**9** Measure, monitor, learn, improve: Finally, it is important to create systems and processes for continuous monitoring, evaluation and learning. For many implementers, designing and delivering programmes to reduce barriers at sufficient scale and scope to achieve impact is a relatively new responsibility. Having robust systems for measuring progress and for continuous learning and quality assurance is crucial, and should be established from the beginning of the project. (See Unit 5, Step 4: *Select indicators and monitoring process.* In Unit 6, information on choosing indicators and monitoring processes is given under each of the programme areas. See Module 3, Unit 8 for in-depth guidance on selecting indicators and developing a monitoring, evaluation and learning plan.)

## UNIT 5: DESIGN PROGRAMMES: FOUR KEY STEPS

The four key steps in developing combined programmes for quality, comprehensiveness, sustainability and impact



## Step 1: Map the process of change

The implementation and scale-up of programmes to remove human rights-related barriers need to show clear results over a set period of time. Mapping the process of change links programme success with health outcomes and indicators to help track progress along the path of implementation. Indicators need to be aligned to the monitoring and evaluation (M&E) framework of the programme. It is the combination of interventions that leads to change (see *Figure 6*).

“The theory of change for removing human rights barriers to HIV services needs to be very clearly defined. That leads to the indicators – it’s very hard to measure impact without a very clear theory of change.”

Key Informant, AIDS Foundation South Africa (AFSA),  
*Breaking Down Barriers* meeting, Durban, 2019.



### The *Breaking Down Barriers* process of change recognises:

1. Important human rights barriers to HIV, TB and malaria services exist at the national and regional level.
2. These barriers affect people living with or affected by one or more of the three diseases, and members of key and vulnerable groups, as identified in national strategic plans for HIV, TB and malaria and other relevant documents.
3. As a result of these barriers, these populations and groups have less access to the continuum of services to prevent infection or to obtain treatment, care and other curative services, therefore they experience greater vulnerability to infection or to a higher burden or prevalence of disease.
4. Evidence-based, best-practice approaches and interventions have been identified.
5. Implementing these interventions in a comprehensive manner will contribute towards reducing or removing the barriers. As a result of the reduction or removal of the barriers, access, uptake and retention in services will improve.

6. Finally, by reducing or removing human rights-related barriers, progress towards ending AIDS, TB and malaria as public health threats by 2030 will accelerate, and health equity will be improved for all.

A sample process of change is provided under each programme area in the next section of this module. However, a process of change for a specific intervention does not stand alone. If we were to look at the combination of interventions in a comprehensive human rights programme, we would need a theory of change (ToC), where each process of change in each intervention interacts with the other processes of change in other interventions to make a holistic change.

The ToC and process of change maps are context specific and living tools that should be revised periodically to:

- make sure that our assumptions about how change happens are correct
- incorporate unforeseen changes in the context where we set our ToC (e.g. changes in government or legislative change we did not anticipate)
- assess how our programming is contributing to the changes stated in the ToC.

#### BOX 6: COMPREHENSIVE PROGRAMMES

Programmes to remove human rights-related barriers to services are comprehensive when the **right programmes** are implemented for the **right people** in the **right combination** at the **right level of investment** to remove human rights-related barriers and increase access to HIV, TB and malaria services.<sup>76</sup>

<sup>76</sup> Paper available on request from the Global Fund.

## Step 2: Combine interventions

One important component of a comprehensive approach is combining interventions and programme areas so that they mutually reinforce each other to remove barriers and increase access to services for a given population and/or in a given location.

Activities can be combined from *within* a programme area or *across* programme areas. For example, when stigma and discrimination are high in healthcare settings, four interventions could be put in place that would reinforce each other:

- Training healthcare workers on human rights, gender equality and equity, and medical ethics related to HIV, and enhancing their accountability
- Providing gender-responsive patient's-rights and human rights literacy to affected populations so that they know how they should be treated in the clinic and can deal with any discrimination they face
- Supporting CBOs to monitor and document human rights-related barriers to services, including alleged human rights violations against people affected by HIV, and discrimination and other human rights abuses in healthcare

settings, and to monitor and feed back on the quality of healthcare provision

- Providing community- and peer-based legal services and supporting those discriminated against so that they continue to access and stay in healthcare.

In this way, the barrier is addressed from a number of different directions, and builds knowledge and capacity among a number of community stakeholders. In addition to combining programmes to address a specific barrier, comprehensiveness also involves a set of combined programmes addressing a number of different barriers that affect access to services for a specific population. Examples of combined interventions are provided under each programme area in the next section of this module.

Combining interventions and programmes to address the interconnected web of barriers experienced by a population in a certain location is one aspect of a comprehensive response. To be comprehensive, however, these interventions need to be taken to scale in locations where these barriers are a significant problem: to reach the majority of the population that is experiencing

### **BOX 7: AN EXAMPLE OF A COMPREHENSIVE RESPONSE TO REMOVING HUMAN RIGHTS BARRIERS FOR SEX WORKERS THAT COMBINES DIFFERENT INTERVENTIONS ACROSS PROGRAMME AREAS**

Sex workers experience many social and legal barriers that reduce their ability to access and remain in HIV prevention and treatment services. These include overly-broad criminal laws; illegal policing that includes harassment, extortion, arbitrary arrest, violence and rape; stigma and discrimination in the community and from healthcare workers; violence from clients; poverty; low levels of literacy, and low levels of community empowerment.

To begin to address these barriers comprehensively, interventions need to focus on tackling the impact of criminalisation and police abuse, reducing stigma and discrimination in healthcare services, and assisting sex workers

to mobilise in communities for personal and collective empowerment. A wide range of interventions is needed, including:

- **Addressing stigma, discrimination and violence** (community dialogues, advocacy and sensitisation training, law and policy reform)
- **Addressing self-stigma and low motivation to use services** (peer education and support, community mobilisation and empowerment)
- **Promoting access to justice** (human rights literacy, peer paralegals and legal representation, sensitisation training for judges and prosecutors)
- **Supporting scale-up and sustainability** (capacity-building and institutional strengthening for NGOs and sex worker-led networks)
- **Continuously monitoring and improving comprehensive responses** (*HIV Stigma Index*, M&E and operational research).

them as well other stakeholders key to removing the barrier; be sustained over sufficient time to change attitudes, behaviours and harmful policies. Going to scale is discussed in detail in *Module 3*. Some considerations for **sustaining** responses are discussed in *Unit 7* at the end of this module.

### Step 3: Coordinate implementation

Combined programmes need well-coordinated implementation and collaboration at all stages of the programme cycle to be effective at achieving and sustaining change. Such programmes often involve different sectors (e.g. government and civil society) as well as different levels and types of actors (from senior parliamentarians to individuals in communities). While critical, putting in place structures for coordination may not always be straightforward, particularly where there has not previously been a need for collaboration. Establishing a national human rights technical working group is one example of how to coordinate efforts. The terms of reference for such a group need to be clear in terms of roles and responsibilities, processes and procedures for monitoring and reporting, and accountability for results.

### Step 4: Select indicators and monitoring process

Identifying indicators is a core part of developing a monitoring, evaluation and learning (MEL) plan (see *Module 3, Step 2*). As investment has increased for programmes to reduce human rights-related barriers to HIV services, there has been an increase in technical guidance on how to monitor and evaluate these programmes. For example, UNAIDS has recently released its guidance on *Rights-Based Monitoring and Evaluation of National HIV Responses*. Similarly, the Global Fund has revised its monitoring and evaluation tools and requirements to be more comprehensive and inclusive of programmes to reduce barriers (see *Box 8*).

A good process of change guides the selection of indicators and when designing indicator

#### BOX 8: MAIN SOURCES FOR INDICATORS TO MONITOR PROGRAMMES TO REDUCE HUMAN RIGHTS-RELATED BARRIERS

- Rights-Based Monitoring and Evaluation of National HIV Responses – UNAIDS.<sup>77</sup>
- Modular Framework Handbook and core set of indicators – Global Fund.<sup>78</sup>
- Indicator Registry, Stigma and Discrimination.<sup>79</sup>
- Compendium of Gender Equality and HIV Indicators – MEASURE Evaluation.<sup>80</sup>
- Tool for strengthening gender-sensitive national HIV and SRH monitoring and evaluation systems – WHO and UNAIDS.<sup>81</sup>

frameworks and monitoring processes, be aware of the different levels where change occurs. Such change commonly occurs at the individual or community level (e.g. reduction in self-stigma or community levels of stigma and discrimination); the service-delivery level (e.g. improved attitudes and practices of healthcare workers); and the institutional or structural level (e.g. changes in laws or policies). Indicators and monitoring processes should be inclusive of all levels.

When selecting indicators, especially at the outcome level, they should be drawn as much as possible from the existing indicators in the sources in *Box 8*, as these have been globally validated and standardised. It is important not to propose new indicators unless absolutely necessary and unless sufficient resources are available to carry out baseline data collection and validation. This is not to say that indicators should not be specific to contexts and programmes, only that existing sources should be considered first.

As the goal of programmes to reduce human rights-related barriers is to increase access, uptake

77. UNAIDS (2019), '*Rights-Based Monitoring and Evaluation of National HIV Responses*'. Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/JC2968\\_rights-based-monitoring-evaluation-national-hiv-responses\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/JC2968_rights-based-monitoring-evaluation-national-hiv-responses_en.pdf).

78. Global Fund (2019), '*Monitoring and Evaluation Framework*', Geneva: Global Fund. Available at: [www.theglobalfund.org/en/monitoring-evaluation/framework/](http://www.theglobalfund.org/en/monitoring-evaluation/framework/).

79. See Indicator Registry, Stigma and Discrimination: [www.indicatorregistry.org/tags/stigma-and-discrimination](http://www.indicatorregistry.org/tags/stigma-and-discrimination).

80. Bloom S.S and Negroustoueva S.(2014), '*Compendium of Gender Equality and HIV Indicators*', MEASURE Evaluation. Available at: [www.measureevaluation.org/resources/publications/ms-13-82](http://www.measureevaluation.org/resources/publications/ms-13-82).

81. WHO and UNAIDS (2016), '*A tool for strengthening gender-sensitive national HIV and SRH monitoring and evaluation systems*'. Available at: [www.unaids.org/sites/default/files/media\\_asset/tool-SRH-monitoring-eval-systems\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/tool-SRH-monitoring-eval-systems_en.pdf).



and retention in HIV services, and to improve HIV-related health and well-being more broadly, monitoring processes should also be linked to systems tracking the core elements of the HIV response, for example, prevention, treatment, and key population programming. Finally, to be comprehensive and sustainable, human rights-related indicators and monitoring processes should be integrated into national M&E frameworks

and processes for HIV responses, and not place separate or parallel requirements on implementers. Indicators not only monitor progress, they also ensure accountability for coordination between stakeholders involved in delivering combined programmes, and for delivering sustainable results.

Example indicators are provided under each programme area in the next section of this module.

## UNIT 6: DESIGN PROGRAMMES: USING THE SEVEN KEY PROGRAMME AREAS

When working through this unit, there are a number of points to note that are common to all programme areas:

### ACTIVITIES

The activities under each programme area are provided as examples and the lists are not exhaustive.

### PROCESS OF CHANGE

A sample process of change is given under each programme area, however, within a comprehensive programme, each intervention will not stand alone, neither will its corresponding process of change. Removing barriers to access to health services involves different interventions and, therefore, each will interact as part of a combination of changes and interventions to make a holistic change.



### SELECTING INDICATORS

The selection of indicators cannot be done in isolation and should be part of the wider process of developing your MEL plan. This plan needs to ensure that you can collect the necessary data required by the indicator. The indicators need to tell us if the programme is indeed effecting the change we anticipate. Routinely monitoring progress through regular review of the different results according to the indicator will require collaboration.



## 1

## Programme Area 1: Reduction of HIV-related stigma and discrimination

### Getting started

The science of stigma and discrimination is advancing and providing important insights into how stigma happens, why it happens, where it happens, and how and who it affects most. To design effective responses for reducing stigma and discrimination, it is critical to understand this evidence of 'what works' and to have detailed knowledge of the country context of 'how, why, where, and who' is being affected. If it has not already been done, it is important to measure levels of stigma and discrimination in the community and in healthcare settings. There are a number of tools to do this, for example the *HIV Stigma Index*,<sup>82</sup> the *TB Stigma Assessment*<sup>83</sup> and/or *TB Communities, Rights and Gender (CRG) Assessment*.<sup>84</sup>

### Activities to reduce HIV-related stigma and discrimination include:

- Community mobilisation/sensitisation on HIV stigma and discrimination, including community dialogues
- Public engagement of people living with HIV, religious and community leaders, and celebrities
- Media campaigns; edu-tainment; TV and radio shows
- Anti-discrimination programmes and policies in the workplace, healthcare, and education
- Peer mobilisation and support groups to promote health and non-discrimination.



82. See GNP+, HIV Stigma Index; [www.stigmaindex.org/](http://www.stigmaindex.org/).

83. See Stop TB, TB Stigma Assessment Tool; [www.stoptb.org/news/stories/2019/ns19\\_031.html](http://www.stoptb.org/news/stories/2019/ns19_031.html).

84. See Stop TB, Communities, Human Rights and Gender; [www.stoptb.org/communities/](http://www.stoptb.org/communities/).

### Step 1: Map the process of change

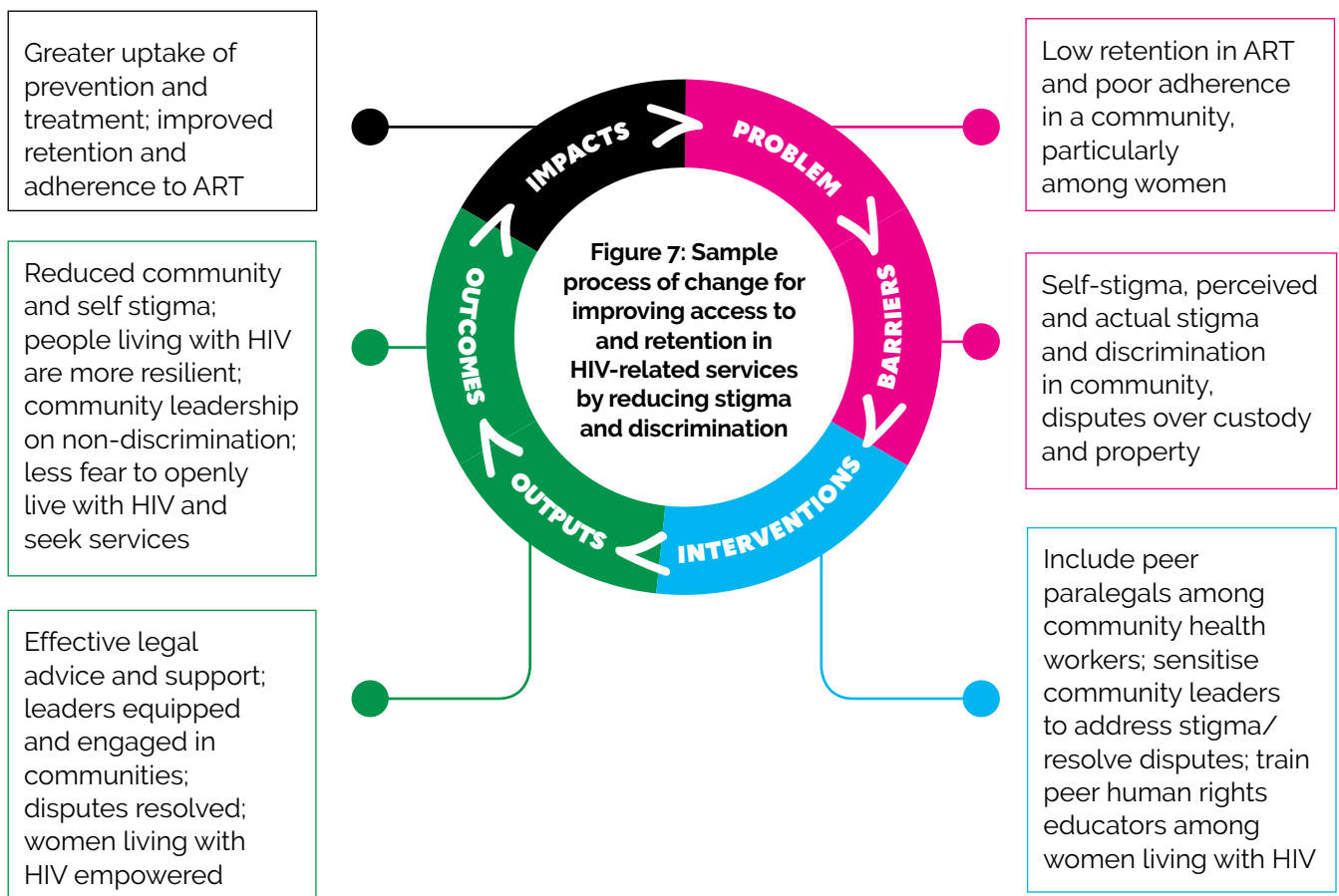
Based on an understanding of the types of stigma and discrimination, who is affected and prevalence in a given location, the next step is to map a process of change. This will illustrate the overall change objective (zero discrimination), the pathways for change and the drivers or facilitators of change. See *Figure 7* for an example of a process of change for reducing HIV-related stigma and discrimination.

This example illustrates the problem of low uptake of and retention in HIV treatment linked to specific manifestations and effects of stigma and discrimination (self-stigma, community stigma and discrimination against women living with HIV – i.e property-grabbing, loss of child custody). In mapping the process of change, these should be addressed by relevant interventions and linked

to anticipated outputs, outcomes and impacts, which would be measured (greater uptake of and adherence to treatment, which improves quality of life, keeps people living with HIV alive and reduces ongoing HIV transmission).

### Step 2: Combine interventions

Reducing stigma and discrimination can be achieved through a well-coordinated, combined set of interventions within and across programmes. *Table 2* illustrates an example of a combined approach to reduce HIV-related stigma and discrimination. In this example, HIV-related stigma and discrimination are addressed at the individual level (empowering people living with HIV and members of other key populations to confront and become resilient to stigma); the community level (changing social norms), the services level (improving legal literacy



and access to legal services and support); and at the institutional level (law and policy change and strategic litigation). Because different country contexts will merit different choices, it is crucial to identify and combine a range of interventions needed to comprehensively address the mechanisms, manifestations and effects of stigma and discrimination across the population and in relation to specific key and vulnerable populations.

### Step 3: Coordinate implementation

Combined approaches to stigma and discrimination require well-coordinated implementation arrangements to be effective and to achieve impact. How will different implementers work together and be accountable for the same result, which is sustained reduction in stigma and discrimination? Some options include establishing a stigma reduction working group; having memorandums of understanding (MoUs), or performance agreements between different levels of implementers (e.g. Global Fund Principal Recipient and Sub-Recipients).

Table 2: Example of combined interventions to reduce HIV-related stigma and discrimination

ZERO STIGMA, DISCRIMINATION AND VIOLENCE IN THE CONTEXT OF HIV, TB AND MALARIA	
Interventions	Activities
Monitoring and reforming laws and policies	<ul style="list-style-type: none"> <li>● Law and policy developed to increase protections against discrimination</li> <li>● Strategic litigation to ensure HIV is included as a category of 'disability' within existing legal/policy protection frameworks</li> </ul>
Legal services	<ul style="list-style-type: none"> <li>● Lawyers and legal aid providers trained to represent people living with HIV and other key populations on discrimination cases</li> <li>● People living with HIV trained as peer paralegals to provide advice and mediation in communities</li> </ul>
Legal literacy	<ul style="list-style-type: none"> <li>● Legal/human rights literacy information and activities included in community mobilisation against stigma and discrimination</li> <li>● Information on human rights and redress mechanisms included as part of social counselling for people living with HIV and other key populations in health services</li> </ul>
Community interventions to change social norms	<ul style="list-style-type: none"> <li>● Local cultural and religious leaders sensitised and engaged to champion community acceptance of people living with HIV and other key populations</li> <li>● People living with HIV and key populations in communities equipped to participate in public events and activities</li> </ul>
Community interventions to empower people living with HIV and key populations to challenge and become resilient to stigma	<ul style="list-style-type: none"> <li>● Community radio shows and local theatre supported to provide messages against stigma and discrimination</li> <li>● Community-based monitoring by networks of people living with HIV and other key populations of quality of healthcare and supplies at health points</li> </ul>

## Step 4: Select indicators and monitoring process

As discussed, stigma and discrimination should be measured to understand the extent and nature of the problem as a barrier to services; to guide the selection of interventions to address it and to establish a baseline against which progress can be measured. Routine measurement can then occur to ascertain success in reducing stigma and discrimination. As part of programme design, it is important to determine when, how and what is to be monitored over the course of programme implementation, and how these measurements will be used to guide further programming.

### Key enablers

The following evidence-based key enablers should be considered in the design and implementation of programmes to reduce stigma and discrimination:

- ✓ **Support community-led efforts and meaningful involvement** of people living with HIV and members of other key and vulnerable populations – such participation is a human rights principle in itself. This is shown to increase the effectiveness of initiatives, including training on

stigma and discrimination, particularly if members of these populations are part of supportive community organisations.<sup>85</sup>

- ✓ **Address stigma and discrimination as a core aim across all programme areas:** For example, including a focus on stigma and discrimination in all trainings for healthcare workers can successfully challenge stigmatising attitudes, which can increase the uptake of health services.
- ✓ **Understand and address the drivers and manifestations of stigma and discrimination** so that approaches are better tailored to the context. The *HIV Stigma Index* is a tool to collect data on levels of stigma and discrimination. Findings from the *HIV Stigma Index* need to be embedded in the programme as a mechanism to monitor any change in the levels of stigma and to advocate for change.<sup>86</sup>
- ✓ **Understand the gendered dimensions of stigma and discrimination.** Women and adolescent girls face different forms of stigma and discrimination than men, based on gender norms that influence how women/men should and should not behave. Discrimination against women may result in divorce and in loss of property, child custody and income. LGBT communities face other forms of

**Table 3: Example indicators linked to a combined programme to reduce HIV-related stigma and discrimination**

INDICATOR LEVEL	INDICATOR	DATA SOURCE
Coverage	Percentage of people living with HIV and on ART who have a suppressed viral load at 12 months (<1000 copies/ml)	Programme data
Outcome	Percentage of people living with HIV reporting their rights were violated who sought legal redress	Reports from community monitoring
Outcome	Percentage of men and women reporting discriminatory attitudes against people living with HIV	District Health Information Software (DHIS) surveys, community surveys
Output	Number of legal literacy sessions conducted	Project data
Output	Number of paralegals trained and deployed	Project data

85. Csete (2016), 'Human rights-based training of health workers related to HIV: Theory of change and review of evaluations' Global Fund Draft. Cited in Global Fund (2017), 'HIV, Human Rights and Gender Equality', Geneva: Global Fund. Available at: [https://hivlawcommission.org/wp-content/uploads/2017/07/core\\_hivhumanrightsgenderequality\\_technicalbrief\\_en.pdf](https://hivlawcommission.org/wp-content/uploads/2017/07/core_hivhumanrightsgenderequality_technicalbrief_en.pdf).

86. Global Network of People Living with HIV (GNP+), 'People Living with HIV Stigma Index', Amsterdam: GNP+. Available at: [www.stigmaindex.org/](http://www.stigmaindex.org/).

gendered stigma and discrimination. Different approaches should be developed for different forms of stigma and discrimination, designed and led by members of the communities affected.

✓ **Interventions, such as training, will be more effective if there is supportive leadership and wider institutional changes**, including accountability mechanisms such as complaints procedures (e.g. within the health, education, workplace and justice sectors). This includes embedding training on stigma and discrimination in the ongoing training of the sector, as well as including in policies and procedures a commitment to address stigma and discrimination, a description of what stigma and discrimination look like, how to report them, and what the sanctions for them will be.<sup>87,88</sup> Management and supervisors should always be engaged and included in training.

✓ **Take a multi-strategy approach.** For example, combining edu-tainment, media campaigns, community mobilisation and peer outreach (as well as within health and other sectors) – or including those already working on these different approaches in discussion and planning forums.

✓ **Address self-stigma with empowerment, human rights literacy and skills-building** programmes and opportunities to mobilise. This consistently results in reductions in self-stigma. Combining self-stigma reduction programmes with economic strengthening interventions, such as savings schemes, support for nutrition and housing and income-generation activities, also results in significant reductions.<sup>89</sup>

87. ICRW and LSHTM (2010), '*Scaling Up the Response to HIV Stigma and Discrimination*', Washington: International Center for Research on Women (ICRW); London: London School of Hygiene & Tropical Medicine (LSHTM). Available at: [www.icrw.org/publications/scaling-up-the-response-to-hiv-stigma-and-discrimination/](http://www.icrw.org/publications/scaling-up-the-response-to-hiv-stigma-and-discrimination/).
88. Pulerwitz J. et al. (2015), 'Improving hospital-based quality of care by reducing HIV-related stigma: evaluation results from Vietnam', *AIDS Behavior*, Vol 19(2), pp. 246-56.
89. Frontline AIDS (2019), '*What works: Addressing self-stigma among people affected by HIV*', Brighton: Frontline AIDS. Available at: [https://frontlineaids.org/wp-content/uploads/2019/07/FrontlineAIDS-SelfStigma-Report-A5-AW\\_Web-singlepages.pdf](https://frontlineaids.org/wp-content/uploads/2019/07/FrontlineAIDS-SelfStigma-Report-A5-AW_Web-singlepages.pdf).
90. Frontline AIDS, AED and ICRW. (2013). 'Understanding and Challenging HIV Stigma: Toolkit for Action', Washington DC. Available at: [www.icrw.org/publications/understanding-and-challenging-hiv-stigma-toolkit-for-action/](http://www.icrw.org/publications/understanding-and-challenging-hiv-stigma-toolkit-for-action/).

## ADDITIONAL RESOURCES

- **Understanding and Challenging HIV Stigma: Toolkit for Action** – Academy for Educational Development (AED), International Center for Research on Women (ICRW) and Frontline AIDS.<sup>90</sup>
- **Scaling Up the Response to HIV Stigma and Discrimination** – ICRW and London School of Hygiene & Tropical Medicine (LSHTM).<sup>91</sup>
- **HIV Stigma Index** – GNP+.<sup>92</sup>
- **Comprehensive Package for Reducing Stigma and Discrimination in Health Facilities** – Health Policy Project – A package of best practice tools.<sup>93</sup>
- **Act to change laws that discriminate** – UNAIDS.<sup>94</sup>
- **Global Partnership for Action to Eliminate all Forms of HIV-Related Stigma and Discrimination** – UNAIDS.<sup>95</sup>

91. ICRW and LSHTM (2010), '*Scaling Up the Response to HIV Stigma and Discrimination*', Washington DC; London: ICRW; LSHTM. Available at: [www.icrw.org/publications/scaling-up-the-response-to-hiv-stigma-and-discrimination/](http://www.icrw.org/publications/scaling-up-the-response-to-hiv-stigma-and-discrimination/).
92. GNP+, '*People Living with HIV Stigma Index*', Amsterdam: GNP+. Available at: [www.stigmaindex.org/](http://www.stigmaindex.org/).
93. Carr, D., R. Kidd, M. Fitzgerald, and L. Nyblade. (2015), '*Comprehensive Package for Reducing Stigma and Discrimination in Health Facilities*', Washington DC: Futures Group, Health Policy Project. Available at: [www.healthpolicyproject.com/index.cfm?id=publications&get=pubID&pubID=281](http://www.healthpolicyproject.com/index.cfm?id=publications&get=pubID&pubID=281).
94. UNAIDS (2019), '*Act to Change Laws that Discriminate*', Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2019/20190215\\_ZDD2019\\_brochure](http://www.unaids.org/en/resources/documents/2019/20190215_ZDD2019_brochure).
95. UNAIDS (2018), '*Global Partnership for Action to Eliminate all Forms of HIV-Related Stigma and Discrimination*', Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2018/global-partnership-hiv-stigma-discrimination](http://www.unaids.org/en/resources/documents/2018/global-partnership-hiv-stigma-discrimination).

## 2 Programme Area 2: Training healthcare providers on human rights and medical ethics

### Getting started

The way that healthcare services are provided is critical to peoples' access, uptake and retention in HIV services. Whether healthcare providers are welcoming and compassionate and offer quality care, or whether they are stigmatising and abusive, has huge consequences for individuals in terms of whether they use the services at all and/or remain in them. Abusive healthcare provision takes the form of dismissive or critical attitudes; refusal of care or offering substandard care; making disparaging remarks and belittlement; segregation into 'HIV sections' where confidentiality of status is lost, and denying the use of bathrooms. It can be suffered at the hands of guards, receptionists, nurses, doctors, laboratory assistants and others. It can take the form of individual behaviour on the part of staff or can be part of institutional policy.

As for Programme Area 1, it is important to measure stigma and discrimination in healthcare services and

to learn from people living with HIV (women, men and adolescents) as well as sex workers, men who have sex with men, transgender people and people who use drugs, how they are treated in healthcare facilities. Within this analysis, it is important to know:

- whether it is only specific groups of healthcare staff that are problematic (e.g. receptionists/guards and not nurses)
- specific populations that are affected (e.g. men who have sex with men, sex workers or drug users, but not people living with HIV more generally)
- where the problems are occurring (e.g. in specific facilities in specific locations, in clinics in one region, or across regions).

### Activities for training healthcare workers on human rights and medical ethics include:

- Development of training curricula for health service staff on non-discrimination, duty to treat, informed consent and confidentiality, violence prevention and treatment, as well as on how healthcare workers can and should be protected from HIV infection and from HIV-related discrimination

### LESSONS FROM PRACTICE

#### IMPROVING QUALITY OF CARE BY REDUCING HIV-RELATED STIGMA IN HOSPITALS IN VIETNAM

Research at four hospitals in Vietnam sought to reduce HIV-related stigma and discrimination among staff. The research team identified five major intervention components to address barriers to quality care and to reduce stigma in both the hospital and in the behaviours and attitudes of staff members:

- Hospital steering committees to oversee quality of care
- Staff training and follow-up discussions at monthly staff meetings
- Hospital policy development
- Provision of material supplies to facilitate the practice of universal precautions

- Educational materials to reinforce key messages from the training.

Both intervention arms received all five components. However, the type and intensity of the training differed. The training for arm 1 addressed 'fear-based' stigma stemming from lack of knowledge, while arm 2 addressed both fear-based and social stigma stemming from moral judgements. At baseline, reported stigma was substantial, for example, about half of hospital workers indicated fear of casually touching people living with HIV, and felt HIV was a punishment for bad behaviour. By end-line, measures had improved significantly for both intervention groups with the combined intervention group showing much greater effects. Clearly communicated anti-stigma policies at the hospital level and the participation in the training of people living with HIV were important success elements.<sup>96</sup>

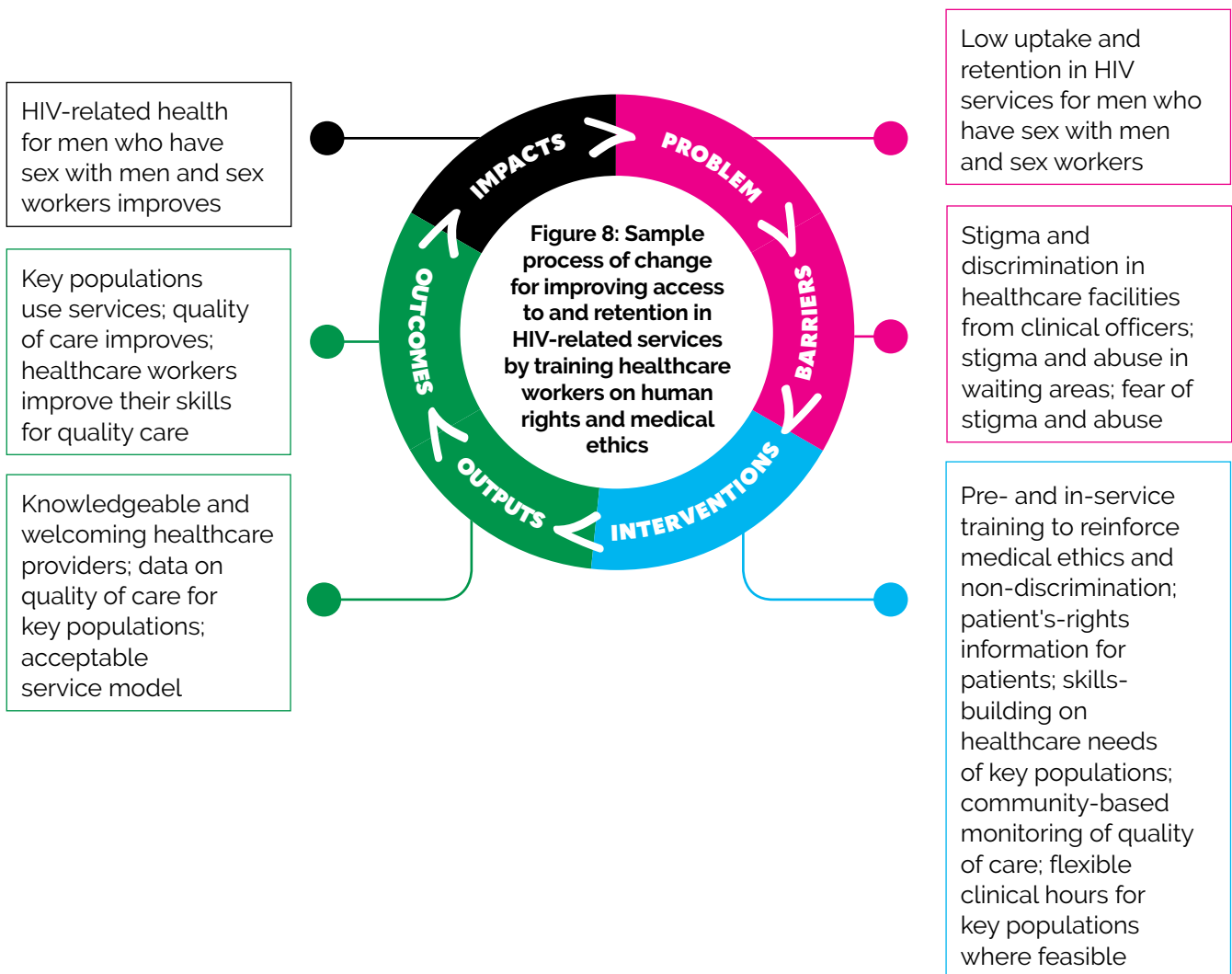
96. Pulerwitz J, Oanh KT, Akinwolemiwa D, Ashburn K, Nyblade L. (2015) Improving hospital-based quality of care by reducing HIV-related stigma: evaluation results from Vietnam. *AIDS Behavior* 2015;19(2):246-56.

- Pre-service and/or in-service training on human rights and medical ethics of healthcare providers (inside and outside facilities), administrators and other staff
- Collaboration between healthcare points and community organisations for training, patient support and quality control
- Development of institutional policies and accountability mechanisms for healthcare facilities.

barriers involving the attitudes and behaviours of specific types of healthcare workers (clinical officers). The interventions address not only short-term fixes (in-service training) but longer-term issues, such as ensuring that pre-service healthcare training institutions have relevant curricula on non-discrimination, as well as on the specific needs of key populations; communities are equipped with patient's-rights information and materials (also posted in the clinic); CBOs have a formal role in community-based monitoring of the quality of the care. The result is improved healthcare provision leading to improved health for men who have sex with men and sex workers through increased uptake and retention in public health services.

**Step 1: Map the process of change**

The example in *Figure 8* illustrates how low uptake and retention in HIV programmes for men who have sex with men and sex workers is driven by particular





## Step 2: Combine interventions

Table 4 shows an example of combined interventions to address challenges of ethics and human rights in the delivery of healthcare services for key populations. This combined approach addresses the root causes of poor quality service delivery, and the reluctance of certain groups to use services, by addressing both institutional and community-level challenges. For healthcare workers, it institutionalises human rights training and provides refresher training in select facilities where there are problems. It also ensures that patients are aware of their rights and responsibilities and that they know about and use existing mechanisms to challenge poor service delivery and to seek redress. Finally, the programme addresses the regulatory framework for healthcare providers so that there are stronger accountability

mechanisms (including disciplinary procedures) for healthcare workers, but there are also better workplace protections for healthcare providers who may experience stigma and discrimination themselves, if living with HIV, or may need workers' compensation if they contract HIV at work.

It is important to ensure that efforts are gender- and age-responsive. Pregnant women may face challenges in healthcare efforts to prevent mother-to-child transmission of HIV – for example, forced sterilisation, abortion, or notification of status to husband/family without consent. Adolescents may have little or no ability to access prevention modalities, testing or treatment on their own, with adolescent girls facing greater stigma and rejection. These groups may need the patient's-rights materials to be tailored to their particular realities and needs.

**Table 4: Example of combined interventions for training healthcare workers on human rights and medical ethics**

### ZERO STIGMA, DISCRIMINATION AND VIOLENCE IN THE CONTEXT OF HIV, TB AND MALARIA

Interventions	Activities
<b>Monitoring and reforming laws and policies</b>	<ul style="list-style-type: none"> <li>Strengthen regulatory mechanisms for healthcare workers to address stigma and discrimination in services</li> <li>Support the development and implementation of patient charters, complaints procedures and workers' compensation</li> </ul>
<b>Legal services</b>	<ul style="list-style-type: none"> <li>Develop and roll out healthcare complaints mechanism</li> <li>Support individuals to file and pursue formal complaints regarding poor service delivery</li> </ul>
<b>Legal literacy</b>	<ul style="list-style-type: none"> <li>Develop and disseminate patients'-rights information for people living with HIV and key populations as well as information on responsibilities of healthcare providers</li> <li>Support community-based monitoring and engagement with health facilities</li> </ul>
<b>Training healthcare providers on human rights and medical ethics</b>	<ul style="list-style-type: none"> <li>Revise pre-service training to address issues of human rights and medical ethics in the context of HIV, provide in-service training in select facilities</li> <li>Engage supervisors to develop and enforce non-discrimination policy in healthcare institution</li> </ul>

### Step 3: Coordinate implementation

Different sectors and institutions need to collaborate for effective implementation in order to achieve the desired level of change. In some cases, this may be the first time that key population-led organisations, government entities, training institutions and councils of health professionals, for example, have collaborated for a common goal. Time will need to be spent at the beginning for key population-led organisations to learn about how healthcare workers are regulated or governed, for example. Representatives of healthcare training institutions may also need time to improve their understanding of the issues and challenges faced by key populations.

### Step 4: Select indicators and monitoring process

An example of relevant indicators is shown *Table 5*.

### Key enablers

- ✓ **Provide comprehensive training of healthcare workers at different levels within health services.** Trainings that explore values and address moral and judgemental attitudes are more effective than just improving knowledge about HIV. Training to promote universal human rights principles should be adapted to local contexts.<sup>97</sup> The medical ethics framework provides similar protections to the human rights framework. It should be standard in any medical education, but may need to be enhanced and the particular issues around HIV and affected populations made explicit.
- ✓ **Address prevention and treatment of violence against women,** including women living with HIV, sex workers, women who use drugs, transgender women and adolescent girls. It is important healthcare workers understand the violence that key and vulnerable groups may face.

**Table 5: Example of indicators linked to a combined programme for training healthcare workers on human rights and medical ethics**

INDICATOR LEVEL	INDICATOR	DATA SOURCE
Coverage	Percentage of men who have sex with men and sex workers (disaggregated) on ART who have a suppressed viral load at 12 months (<1000 copies/ml)	Programme data
Outcome	Percentage of men who have sex with men and sex workers (disaggregated) who avoid healthcare because of stigma and discrimination	Reports, stigma studies and community monitoring
Outcome	Percentage of healthcare workers (disaggregated by cadre) who express discriminatory attitudes towards men who have sex with men or sex workers	Special survey administered every two years
Output	Percentage of healthcare workers trained on medical ethics and human rights	Project data
Output	Percentage of men who have sex with men and sex workers reached with outreach activities, including on patients' rights and responsibilities	Project data

97. Csete (2016) Draft, 'Human rights-based training of health workers related to HIV: Theory of change and review of evaluations'. Global Fund.

how, among other things, it increases their vulnerability to HIV, and how they can benefit from medical, legal and psychosocial counselling to be better able to deal with it. For example, sex workers of diverse gender identities experience violence from both clients and the police. This violence prevents them from accessing and using services, including referrals, to mitigate the direct impact of violence on health.

✓ **Support institutional change.** Training embedded in curricula (with in-service training repeated periodically) should be supported by institutional changes, with senior supervisors sensitised and engaged to lead the change. These can include procedures and policies outlining a commitment to the human rights of key populations, messaging around intent, and complaints

mechanisms, as well as reporting and response mechanisms for any violations.

- ✓ **Use indicators that focus not only on stigma and discrimination reduction,** but also on informed consent and confidentiality.
- ✓ **Address the specific needs of people from key and vulnerable populations.** For example, there is specific guidance developed by young people on how health services can better meet the needs of young people living with HIV.<sup>98</sup>
- ✓ **Establish formal links between healthcare facilities and community support groups.** These groups can support individuals to access services and stay connected to them (retention) while also monitoring the quality of the services and providing feedback to the facility for improvements.

#### ADDITIONAL RESOURCES

- **READY to care: Improving health services for young people living with HIV** – Global Network of Young People Living with HIV (Y+) – Includes a health charter for health facilities and scorecard to assess the quality of services for young people.<sup>99</sup>
- **Eliminating discrimination in healthcare: Stepping stone towards ending the AIDS epidemic** – UNAIDS.<sup>100</sup>
- **The Consolidated guideline on sexual and reproductive health and rights of women living with HIV and A checklist for community engagement to implement the WHO guideline on sexual and reproductive health and rights of women living with HIV** – WHO – offer guidance on addressing violence against women in the health sector.<sup>101</sup>

98. Y+ (2019), 'READY to Care: Improving Health Services for Young People Living with HIV', Amsterdam: Y+. Available at: [www.yplusnetwork.org/resource/ready-to-care/](http://www.yplusnetwork.org/resource/ready-to-care/).

99. *Ibid.*

100. UNAIDS (2016), 'Eliminating discrimination in healthcare: Stepping stone towards ending the AIDS epidemic', Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2016/eliminating-discrimination-in-health-care](http://www.unaids.org/en/resources/documents/2016/eliminating-discrimination-in-health-care).

101. WHO (2017), 'Consolidated guideline on sexual and reproductive health and rights of women living with HIV', Geneva: WHO. Available at: [www.who.int/reproductivehealth/publications/gender\\_rights/Ex-Summary-srhr-women-hiv/en/](http://www.who.int/reproductivehealth/publications/gender_rights/Ex-Summary-srhr-women-hiv/en/); and WHO (2019), 'Translating community research into global policy reform for national action: a checklist for community engagement to implement the WHO consolidated guideline on the sexual and reproductive health and rights of women living with HIV', Geneva: WHO. Available at: <https://apps.who.int/iris/bitstream/handle/10665/325776/9789241515627-eng.pdf?ua=1>.

## 3 Programme Area 3: Sensitisation of law-makers and law-enforcement agents

### Getting started

This programme area encompasses a number of different stakeholders, including:

- Law-makers who are members of parliaments and their staff
- Law-enforcement agents, including judges, police, prison officials, immigration officials and other security forces.

Each of these types of professionals has very different professional responsibilities and obligations, requires different forms of training, and engages in different types of professional activities. For example, training and sensitisation that works for police officers will probably not be relevant or effective for parliamentarians or judicial officers. It is critical to be clear and specific about which groups of stakeholders are to be included in interventions and to design them specifically to achieve change for that group.

It is also important to determine what the objectives are when working with these groups. Some interventions will achieve fairly immediate impact in the lives of those living with or vulnerable to HIV. Other interventions will only achieve longer-term impact and will need to be strategic and sustained over longer periods. For example, setting up programmes and activities with and for police in a particular city or location is likely to have a fairly immediate impact on the lives of key populations who interact with these police in this location. On the other hand, interventions with parliamentarians or judges are likely to require more time to have impact if they are to result in more protective laws and policies and greater judicial protection and access to justice. (See more on this in *Programme Area 7: Monitoring and reforming laws, regulations and policies*).

### Activities for sensitising law-makers and law-enforcement agents include:

- Information/sensitisation for parliamentarians, ministers of justice, judges, prosecutors, police, traditional and religious leaders on legal, health and human rights of HIV and



HIV/TB, including gender- and age-based discrimination, inequality and violence prevention, including intimate partner violence

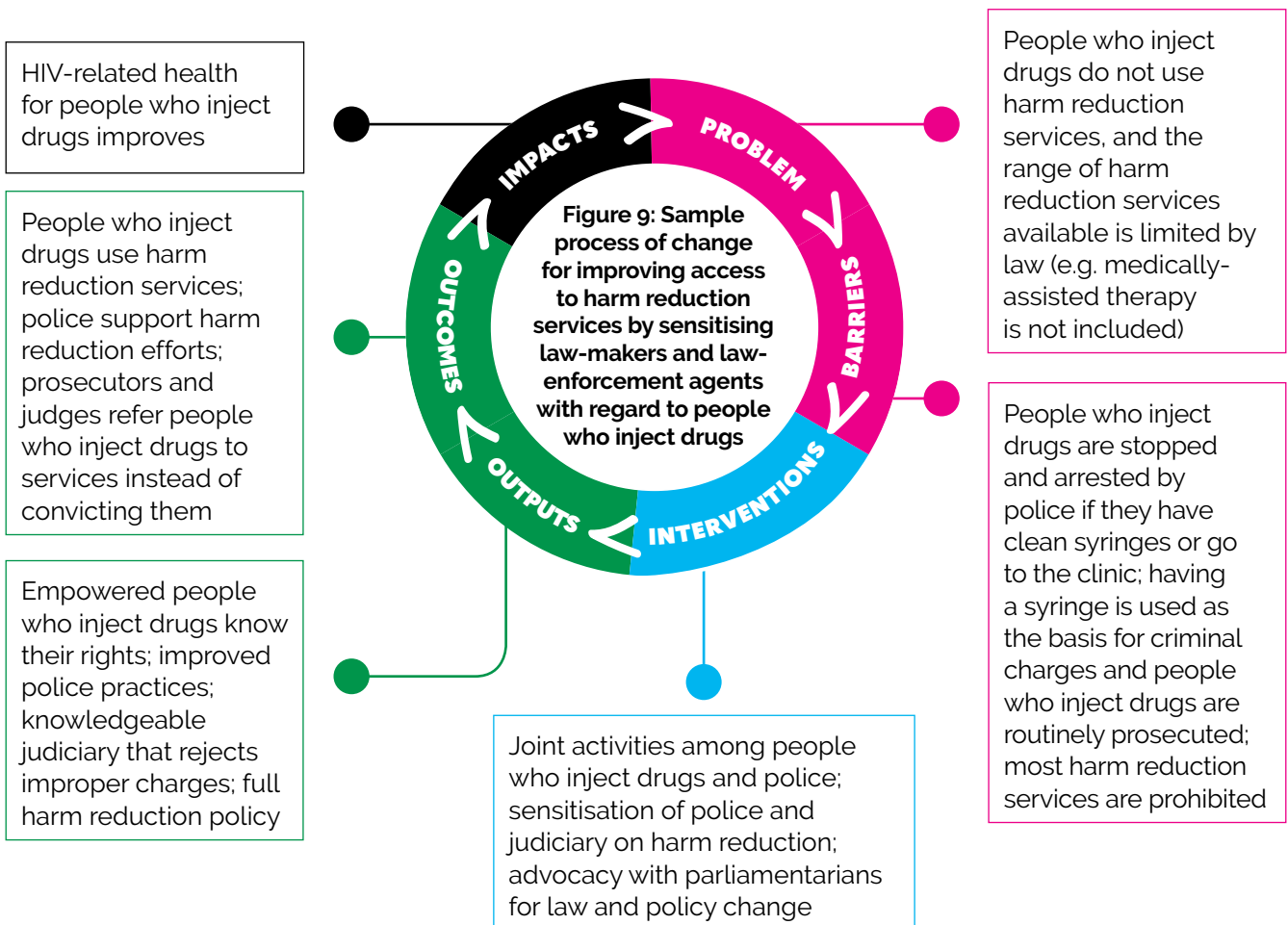
- Facilitation of discussions and joint activities among service providers, law-enforcement agents and key and vulnerable populations to gain police support for HIV programmes and protective policing
- Training of prison personnel (in prisons for women and men) on public health, human rights and HIV and HIV/TB responses
- HIV and HIV/TB in the workplace programmes for law-makers and enforcers.

**Step 1: Map the process of change**

Figure 9 shows a sample process of change for sensitising law-makers and law-enforcement agents regarding harm reduction for people who inject

drugs. In this example, comprehensive change is needed to improve uptake and retention in harm reduction services for people who inject drugs. Interventions address specific barriers among a number of stakeholders: people who inject drugs receive capacity-building to be effective advocates and work with police and judges; police and judges are sensitised about drug use as a health issue (including the particular needs of women who inject drugs) and to understand harm reduction; police and the judiciary engage in less punitive approaches against people who inject drugs and stop interfering with harm reduction services.

The longer-term outcomes include working with parliamentarians to create a more effective harm reduction legal and policy framework which can, in turn, further guide law-enforcement practices and the judiciary by positioning drug use as a public health concern rather than an issue of law and order.



## Step 2: Combine interventions

An example of combining interventions to address barriers to services for people who use drugs is shown in *Table 6*. In this example, components of the law-enforcement and justice sectors, as well as the community sector and people who inject drugs, are engaged to use peer paralegals and legal literacy. This combination of interventions across programme areas provides legal support for people who inject drugs; works to change attitudes and behaviours of the police; and supports eventual legal reform through efforts to build a core group of parliamentarians that will lead this process of reform. The aim is that they will do this by using a public health argument leading judges to consider alternative sentencing for people who use drugs, diverting them from prison into health and community programmes.

## Step 3: Coordinate implementation

Different sectors and institutions need to collaborate for effective implementation and sustained change. Some of the challenges are clear, particularly where organisations led by or working with people who inject drugs may have difficult relationships with the police or the judiciary. At the start of the process to design a combined programme, views on harm reduction may be far apart. Skills in evidence-based advocacy, conflict resolution, mediation, and knowing when to accept some compromises for the sake of moving forward will likely be needed.

## Step 4: Select indicators and monitoring process

As the process of change maps out, sensitising law-makers and law-enforcement agents

**Table 6: Example of combined interventions for sensitising law-makers and law-enforcement agents with regard to people who inject drugs**

### ZERO STIGMA, DISCRIMINATION AND VIOLENCE IN THE CONTEXT OF HIV, TB AND MALARIA

Interventions	Activities
<b>Monitoring and reforming laws and policies</b>	<ul style="list-style-type: none"> <li>● Develop and implement a strategy for decriminalisation of possession of small amounts of drugs for personal use</li> <li>● Advocate for policy for the delivery and scale-up of harm reduction interventions</li> </ul>
<b>Legal services</b>	<ul style="list-style-type: none"> <li>● Represent people who inject drugs who have been charged with criminal offenses</li> <li>● Provide rapid response mechanisms for people who inject drugs who are illegally detained</li> </ul>
<b>Legal literacy</b>	<ul style="list-style-type: none"> <li>● Equip people who inject drugs and outreach workers with knowledge regarding laws and policies relating to drug use and arrestable offences</li> <li>● Train outreach workers/counsellors/peers as paralegals to provide information and referral</li> </ul>
<b>Sensitisation of law-makers and law-enforcement agencies</b>	<ul style="list-style-type: none"> <li>● Train and equip police units to refer people who inject drugs to healthcare service providers (in line with harm reduction policy)</li> <li>● Engage parliament on harm reduction and the health benefits of decriminalisation; engage judiciary on policy of diversion</li> </ul>

Table 7: Example of indicators linked to a combined programme for sensitising law-makers and enforcement agents

INDICATOR LEVEL	INDICATOR	DATA SOURCE
Coverage	Percentage of people who inject drugs reached with HIV prevention programmes, including harm reduction	Programme data
Outcome	Percentage of people who inject drugs who avoid healthcare because of stigma and discrimination	Reports and stigma studies and from community monitoring system
Outcome	Percentage of people who inject drugs who report that their rights were violated and who sought redress	Reports from community monitoring system
Output	Percentage of law-enforcement agents trained on harm reduction	Project data
Output	Percentage of outreach workers trained and deployed as paralegals	Project data

to improve uptake and retention in harm reduction services crosses a number of different stakeholders and intervention areas. Routinely monitoring progress through regular review of the different results according to the indicators will depend on a structure and a process for collaboration. For example, a national harm reduction technical working group may be an opportunity for coordination, monitoring progress, sharing lessons learnt, and negotiating and maintaining mutual accountability for achieving the overall outcome of improving the HIV-related health of people who use drugs.

### Key enablers

- ✓ **Ensure a multi-activity and sustained effort that has high-level support from leaders in the security and justice sectors.** The understanding and support from supervisors and chiefs of both judges and police will be critical to change professional behaviour.
- ✓ **In the interventions with police, judges and parliamentarians, include efforts to reduce their own vulnerability to HIV infection.** Among these professional groups, there continues to be many misperceptions and lack of information

regarding how HIV is transmitted, and how treatment reduces infectiousness and increases long-term health. Understanding HIV vulnerability from a personal point of view will help raise empathy and support among these professional groups for addressing the HIV vulnerabilities in other populations.

- ✓ **One-off trainings alone are not sufficient** to ensure that any reduction in stigmatising and discriminatory attitudes among law-enforcement personnel is sustained and translates into changes in practice.<sup>102</sup> Trainings need to occur regularly, as well as other things such as professional focus groups on HIV, and study groups that travel to see how other police, judges or parliamentarians are addressing HIV-related legal challenges in the country or in the region.
- ✓ **Support joint activities between law-enforcement agents and key and vulnerable populations.** If these groups work together on training, monitoring and reporting violations, and creating mechanisms of reporting and redress, this will more effective than just holding training workshops. This kind of collaboration can also address the mistrust that exists between key populations and police.<sup>103</sup>

102. Csete (2016), 'Police training to improve HIV responses: Theory of change, methods and results of a review of the literature'. Global Fund, Draft.

103. *Ibid.*

## CASE STUDY

**COLLABORATIVE HUMAN RIGHTS TRAINING FOR SOUTH AFRICAN POLICE FORCE MEMBERS**

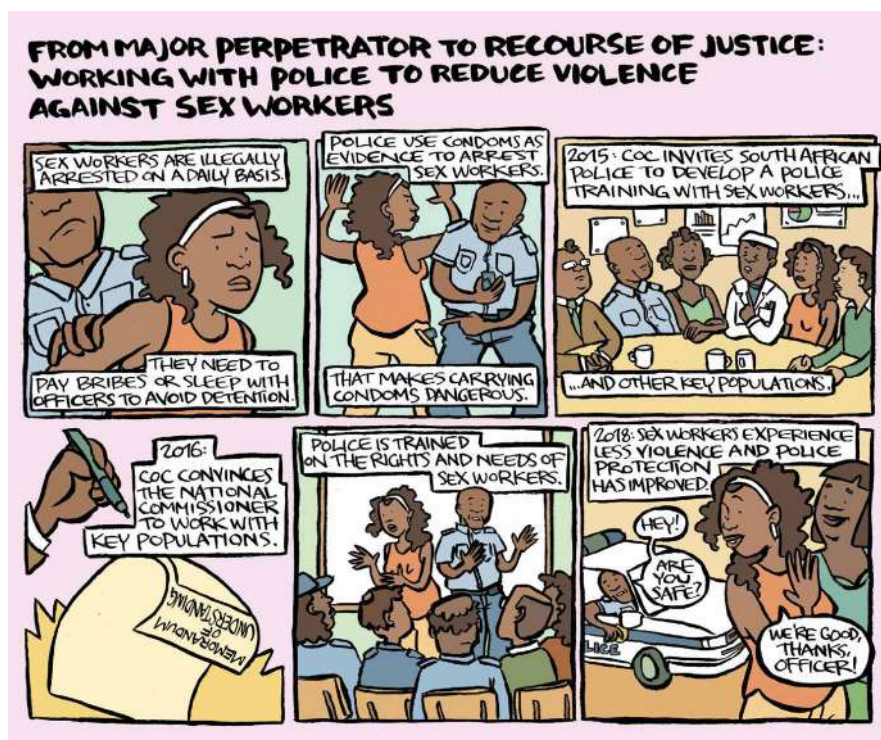
"Police have been very rude to sex workers, abusing us, throwing us in the river, taking all of our money, taking our condoms. They will smack us around and even tell you to go to the back of the van where they would have sex with us." Sex worker, South Africa

In 2015 and 2016, a participatory process led by COC Netherlands resulted in the development of the *Dignity, Diversity and Policing Training Manual* to address the stigmatising and discriminatory attitudes of South African Police Services (SAPS) against sex workers. After years of lobbying, COC and local partners succeeded in SAPS and key population networks formalising their relationship through a ground-breaking MoU. Building rapport and trust between these two very different groups of stakeholders was critical. During the project, partners learned that SAPS is a complex, hierarchical organisation whose processes are protocol-driven and time-consuming, involving seven or eight levels of management, and that engaging with SAPS on different levels therefore required patience.

SAPS and civil society partners (including key population members and experts) came together to develop the *Dignity, Diversity and Policing Training Manual* through a participatory process that recognised police systems, strategies and needs. Once the manual was approved by SAPS, Employee Health and Wellness police officers, civil society and key population

representatives were trained as trainers, with all parties serving as mentors. The SAPS Human Resource Department adapted the manual for in-service training, which has resulted in both intended and unintended benefits, including:

- Police understand that their actions impact on the vulnerability of sex workers and other key populations to HIV.
- Violence against sex workers from law-enforcement has decreased.
- Sex workers are more able to report crimes perpetrated against them to police and to receive protection and redress.
- The training is being integrated into the police college curricula, which will result in training for roughly 153,000 police cadets.





### ADDITIONAL RESOURCES

- **HIV and the Law: Risks, Rights & Health** – UNDP Global Commission on HIV and the Law.<sup>104</sup>
- **HIV and the Law: Risks, Rights and Health Supplement** – UNDP Global Commission on HIV and the Law.<sup>105</sup>
- **Legal environment assessment for HIV – An operational guide to conducting national legal, regulatory and policy assessments for HIV** – UNDP.<sup>106</sup>
- **Effective Laws to End HIV and AIDS: Next Steps for Parliaments** – Inter-Parliamentary Union and UNDP.<sup>107</sup>
- **Guidance note: Human Rights and the Law** – UNAIDS.<sup>108</sup>
- **Advancing the Human Rights and Inclusion of LGBTI People: A Handbook for Parliamentarians** – UNDP.<sup>109</sup>

### PROGRAMMES

- Sensitisation training with law-enforcement agents and judiciary
- Legal hotline
- Media engagement to promote harm reduction
- Advocacy for law and policy reform

### BARRIERS

- Punitive laws criminalising drug use
- Harmful attitudes and practices in law-enforcement

“ The police arrest us if they find us carrying needles, so we end up using other people's.”

104. UNDP Global Commission on HIV and the Law (2018), '*HIV and the Law: Risks, Rights and Health*', New York: UNDP. Available at: <https://hivlawcommission.org/>.

105. UNDP Global Commission on HIV and the Law (2018), '*HIV and the Law: Risks, Rights and Health Supplement*'. New York: UNDP. Available at: <https://hivlawcommission.org/wp-content/uploads/2018/09/HIV-and-the-Law-supplement-FINAL.pdf>.

106. UNDP (2014), '*Legal Environment Assessment for HIV – An operational guide to conducting national legal, regulatory and policy assessments for HIV*', New York: UNDP. Available at: [www.undp.org/content/dam/undp/library/HIV-AIDS/Governance of HIV Responses/UNDP Practical Manual LEA FINAL web.pdf](http://www.undp.org/content/dam/undp/library/HIV-AIDS/Governance%20of%20HIV%20Responses/UNDP%20Practical%20Manual%20LEA%20FINAL%20web.pdf).

107. Available at: [www.ipu.org/resources/publications/reference/2016-07/effective-laws-end-hiv-and-aids-next-steps-parliaments](http://www.ipu.org/resources/publications/reference/2016-07/effective-laws-end-hiv-and-aids-next-steps-parliaments).

108. UNAIDS (2014), '*Guidance note: human rights and the law*'. Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/2014unaidsguidancenote\\_humanrightsandthelaw\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_humanrightsandthelaw_en.pdf).

109. UNDP (2017), '*Advancing the Human Rights and Inclusion of LGBTI People: A Handbook for Parliamentarians*'. New York: UNDP. Available at: [www.undp.org/content/undp/en/home/librarypage/democratic-governance/parliamentary\\_development/advancing-the-human-rights-and-inclusion-of-lgbti-people--a-hand.html](http://www.undp.org/content/undp/en/home/librarypage/democratic-governance/parliamentary_development/advancing-the-human-rights-and-inclusion-of-lgbti-people--a-hand.html).

## 4 Programme Area 4: Reducing discrimination against women and girls in the context of HIV

### Getting started

Women and girls continue to face gender-related issues of vulnerability to HIV infection and to the impact of living with HIV. As their realities have long been over-looked, this programme area highlights the need to take particular steps to address the discrimination that women and girls face in the context of HIV, and the impact it has on their health and lives. However, it should also be highlighted that all the key programme areas and the activities under them can and should be implemented by and for women and girls. Examples include:

- Peer paralegals among women living with HIV
- Peer human rights educators among adolescent girls and young women
- Community-based monitoring of laws and policies by women's groups
- Law and policy reform addressing laws

and policies that do not sufficiently protect women or that entrench inequality

- Training of healthcare workers and police so that they can successfully support women living with HIV, survivors of violence, and women members of key populations, for example, sex workers, women and girls who inject drugs, and gay and transgender women.

### Relevant activities for reducing discrimination against women and girls in the context of HIV include:

- Developing or reforming of laws and law-enforcement practices on age of consent, spousal consent, domestic violence, sexual consent, or child marriage
- Reform of family law, marriage, property, inheritance and custody laws
- Inclusion of gender equality teaching for girls and boys in age-appropriate curriculum for sexuality and life-skills education
- Roll-out of programmes to address harmful gender norms and traditional practices, and GBV.

### LESSONS FROM PRACTICE

#### INTEGRATING HUMAN RIGHTS STANDARDS AND COMMUNITY PARTICIPATION INTO ELIMINATION OF MOTHER-TO-CHILD TRANSMISSION

In 2014, WHO published guidance for validation of the elimination of mother-to-child transmission (EMTCT) of HIV and syphilis. Initiated by the International Community of Women Living with HIV (ICW), GNP+ and supported by UNAIDS, the process introduced norms and approaches grounded in human rights, gender equality, and community engagement.

This human rights-based validation process serves as a key opportunity to enhance accountability for human rights protection by evaluating EMTCT programmes against human rights norms and standards, including in

relation to gender equality, and by ensuring the provision of discrimination-free quality services. The process also involves the assessment of participation of affected communities in EMTCT programme development, implementation, and monitoring and evaluation. It brings awareness to the types of human rights abuses and inequalities faced by women living with, at risk of, or affected by HIV and syphilis, and commits governments to eliminate those barriers.

This process demonstrates the importance and feasibility of integrating the human rights of women and women's leadership into key public health interventions in a manner that increases health outcomes, legitimises the participation of affected communities of women, and advances the human rights of women living with HIV.<sup>110</sup>

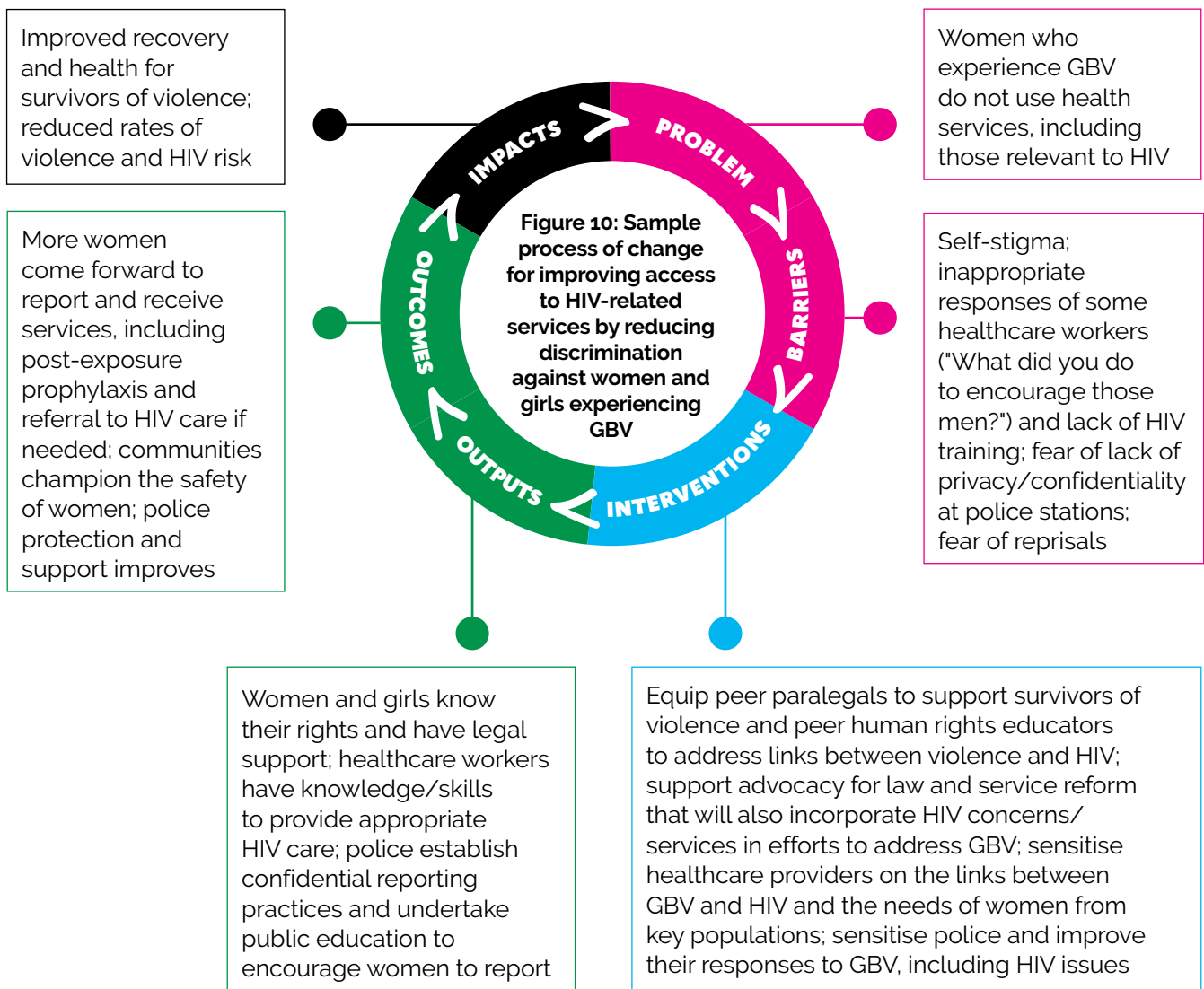
110. Kismödi, Kiragu, Sawicki et al (2017) 'Where Public Health Meets Human Rights: Integrating Human Rights into the Validation of the Elimination of Mother-to-Child Transmission of HIV and Syphilis', *Health and Human Rights Journal*, December 2017. Available at: [www.hhrjournal.org/2017/12/where-public-health-meets-human-rights-integrating-human-rights-into-the-validation-of-the-elimination-of-mother-to-child-transmission-of-hiv-and-syphilis/](http://www.hhrjournal.org/2017/12/where-public-health-meets-human-rights-integrating-human-rights-into-the-validation-of-the-elimination-of-mother-to-child-transmission-of-hiv-and-syphilis/).

### Step 1: Map the process of change

Figure 10 illustrates a process of change for improving utilisation of GBV support services, which also serve as entry points for HIV care, by women and girls who experience this particular human rights violation.

In addressing the relationship between GBV and HIV, it is important to assess the best entry points. For example, if strong national or community efforts against GBV already exist, it may be best to ensure that these efforts include sufficient advocacy,

information and services linking GBV and HIV, and to ensure that women and members of key populations who experience violence are not excluded from GBV advocacy and services. Where there are existing strong efforts for the rights of women living with HIV, it may be best to work to integrate issues around GBV into these efforts. In this example, a number of opportunities for change and improvement are identified that ensure that women get legal support; that survivors of violence, police and healthcare workers know the links and appropriate responses to GBV and HIV, and that there are improved policing and other protective systems in communities.



## Step 2: Combine interventions

Table 8 shows an example of how interventions can be combined to improve uptake and retention in services for women who experience GBV. In this example, the combined programmes are cross-cutting, for example, building human rights capacity and awareness of women and girls (both living with HIV and from other key populations) regarding GBV and HIV; equipping them as leaders and advocates; supporting efforts to change harmful gender norms; providing legal support to survivors; advocacy for law and policy reform for stronger preventive and protective measures. Such a combined approach has greater potential for more substantive change in terms of barriers to services than undertaking only one or two interventions on their own.

## Step 3: Coordinate implementation

Addressing the cross-cutting individual-, community- and institutional-level drivers of gender-related discrimination in the context of HIV requires extensive coordination and collaboration across different sectors. Gender-focused technical working groups or sectoral working groups exist in a number of countries and may be effective as coordinating entities. In many settings, there are strong groups working on the rights of women and other gender-related issues, but they have not engaged in, and perhaps are not willing, to take on HIV-related issues or to support women of HIV-affected key populations. Working with these women's groups to incorporate HIV issues is important, as is strengthening the gender equality capacities of women living with HIV and women and girl members of key and vulnerable populations.

**Table 8: Example of combined interventions for reducing discrimination against women in the context of HIV and GBV**

ZERO STIGMA, DISCRIMINATION AND VIOLENCE IN THE CONTEXT OF HIV	
Interventions	Activities
<b>Monitoring and reforming laws and policies</b>	<ul style="list-style-type: none"> <li>Develop and implement an advocacy strategy for strengthening legal and social responses to GBV and links to HIV</li> <li>Document and report rates of GBV, its social harms and its links to HIV</li> </ul>
<b>Legal services</b>	<ul style="list-style-type: none"> <li>Ensure that HIV concerns are among the skills and knowledge of lawyers/peer paralegals providing legal services to survivors of GBV</li> <li>Include GBV and HIV issues in any 'crisis response' hotline to encourage more women to report GBV</li> </ul>
<b>Legal literacy</b>	<ul style="list-style-type: none"> <li>Include GBV issues in legal literacy campaigns in communities</li> <li>Undertake community campaigns to promote health and HIV services for survivors of GBV</li> </ul>
<b>Sensitisation of law-makers and law-enforcement agencies</b>	<ul style="list-style-type: none"> <li>Educate parliamentarians on links between GBV and HIV and advocate for a strong legal framework to prevent GBV</li> <li>Work with national police force to improve capacity to respond to GBV, including stronger privacy and confidentiality arrangements, as well as more community protections</li> </ul>
<b>Reducing discrimination against women and girls in the context of HIV</b>	<ul style="list-style-type: none"> <li>Support programmes to change harmful gender norms around GBV and its links to HIV; include HIV issues in sexuality, life skills and gender equality training for young people</li> <li>Train and support women living with HIV and women from other key populations to advocate against GBV and related harmful gender norms</li> </ul>

## Step 4: Select indicators and monitoring process

The example indicators in *Table 9* show there are a number of interlinked actions to monitor on a continuous basis, including the progress of law reform at the institutional level; the response of police in supporting survivors of violence; the capacity of women living with HIV to get legal support and be leaders and advocates against GBV; the capacity of healthcare workers to recognise and address important linkages between GBV and HIV.

### Key enablers

✓ **Integrate gender-transformative approaches into all the seven key programme areas** and roll out the other six areas by and for women and adolescent girls.

- ✓ **Support women's rights and LGBT organisations with financial, institutional and technical assistance.** They play a fundamental role in addressing gender inequality and gender-related discrimination and violence against women and girls, including on the grounds of sexual orientation or gender identity.
- ✓ **Survey and try to engage national and local groups working for gender equality,** as well as the rights of LGBT people, to get them to take on and champion HIV concerns and populations affected by HIV.
- ✓ **Adopt an intersectional approach** that recognises the multiple overlapping factors that may lead to compound discrimination against women and girls. In addition, create, invest in and expand spaces for the meaningful participation of women and girls in all their diversity.

**Table 9: Example of indicators linked to a combined programme for reducing discrimination against women and girls in the context of HIV**

INDICATOR LEVEL	INDICATOR	DATA SOURCE
Outcome	Percentage of ever-married or partnered women (aged 15–49 years) who experienced physical and/or sexual violence by a current or former intimate partner in the last 12 months	DHIS or other similar population-based surveys
Outcome	Existence of policies and laws relating to gender inequality and violence that impact HIV vulnerability for women and girls	LEAs
Output	Number of primary healthcare facilities with functioning referral systems for survivors of GBV	Project data
Output	Number of CSOs trained and equipped to provide comprehensive psychosocial and practical support, including HIV-related support	Community monitoring systems



## LESSONS FROM PRACTICE

## THE TATHMINI GENDER-BASED VIOLENCE STUDY

The Tathmini gender-based violence study was a cluster-randomised trial conducted in Tanzania. It assessed the impact of a comprehensive health facility and a community-based programme on reduction in GBV and improved care for survivors. Twelve health facilities and surrounding communities in Mbeya Region were randomly assigned to the intervention or as control arms.

The programme was found to contribute to positive community-wide changes, including less tolerance for certain forms of violence, more gender-equitable norms, better knowledge about GBV, and increased community actions to address violence. The programme also led to increased utilisation of GBV services at health facilities. Nearly three times as many client visits for GBV were recorded at intervention compared to control facilities over a 16-month period. These visits were more likely to include an HIV test.<sup>111</sup>

## ADDITIONAL RESOURCES

- **RESPECT Women, Preventing violence against women: A framework for policy-makers** – WHO.<sup>112</sup>
- **INSPIRE: Seven strategies for ending violence against children** – WHO.<sup>113</sup>
- **Action Linking Initiatives on Violence Against Women and HIV Everywhere, ALIVHIE Framework** – Salamander Trust, Athena, UNAIDS et al.<sup>114</sup>
- **Case Study Collection** – Community for Understanding Scale Up (CUSP).<sup>115</sup>
- **Scaling up interventions to prevent and respond to gender-based violence** – USAID.<sup>116</sup>

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111. Settergren S.K., Mujaya S. Rida W., Kajula L.J., Kamugisha H., Kilonzo Mbwambo J. et al. (2018), 'Cluster randomized trial of comprehensive gender-based violence programming delivered through the HIV/AIDS program platform in Mbeya Region, Tanzania: Tathmini GBV study', *PLoS ONE* 13(12): e0206074. <https://doi.org/10.1371/journal.pone.0206074>.

112. WHO (2019), 'RESPECT Women: Preventing violence against women: A framework for policy-makers', Geneva: WHO. Available at: [www.who.int/reproductivehealth/publications/preventing-vaw-framework-policy-makers/en/](http://www.who.int/reproductivehealth/publications/preventing-vaw-framework-policy-makers/en/).

113. WHO (2016), INSPIRE: 'Seven strategies for ending violence against children', Geneva: SHO. Available at: [www.who.int/violence\\_injury\\_prevention/violence/inspire/en/](http://www.who.int/violence_injury_prevention/violence/inspire/en/).

114. Salamander Trust, Athena, UNAIDS, AIDS Legal Network, Project Empower, HEARD and University of KwaZulu-Natal (2017), 'Action Linking Initiatives on Violence Against Women and HIV Everywhere, ALIVHIE framework'. Available at: [www.unaids.org/en/resources/documents/2017/ALIVHE\\_Framework](http://www.unaids.org/en/resources/documents/2017/ALIVHE_Framework).

115. CUSP (2018), 'Case Study Collection'. Available at: [www.comminit.com/srhr/africa/content/cusp-2018-case-study-collection](http://www.comminit.com/srhr/africa/content/cusp-2018-case-study-collection).

116. USAID (2015), 'Scaling up interventions to prevent and respond to gender-based violence: An analytical report', Washington DC: USAID. Available at: [www.usaid.gov/sites/default/files/documents/1865/Scaling-up-Interventions-to-Prevent-and-Respond-to-GBV.pdf](http://www.usaid.gov/sites/default/files/documents/1865/Scaling-up-Interventions-to-Prevent-and-Respond-to-GBV.pdf).

## 5 Programme Area 5: Legal literacy ('know your rights')

### Getting started

People living with or vulnerable to HIV should know about their health-related human rights, as well as the laws and policies that protect them and provide them with support. This is 'legal literacy' in the context of HIV. This knowledge is also a form of demand creation and supports community mobilisation around concrete health needs. As people know and mobilise around their rights and the laws and policies relevant to HIV, they are better enabled to ask for and take up prevention and treatment, whether at the individual level, or as a group. They are also enabled to take action to address barriers to HIV services and to seek redress in cases of violations of their rights in health, justice or other settings.

Before designing programmes to improve HIV-related legal and human rights literacy, it is important to know what the current levels of knowledge are and where opportunities exist to integrate rights literacy activities. Legal and rights literacy can involve national laws and policies, local laws (for example, district budgets for health), health regulations and patients' rights and charters. Knowing about these things enables people to translate their needs into concrete demands/asks that are supported by law, policy, regulation and rights.

#### Activities for legal or human rights literacy include:

- Legal and patients'-rights literacy trainings, including through the development and deployment of peer human rights educators
- Support to mobilisation and advocacy around HIV-related rights, laws and policies
- Establishment of crisis response mechanisms to prevent abuse and violence, including GBV.



### Step 1: Map the process of change

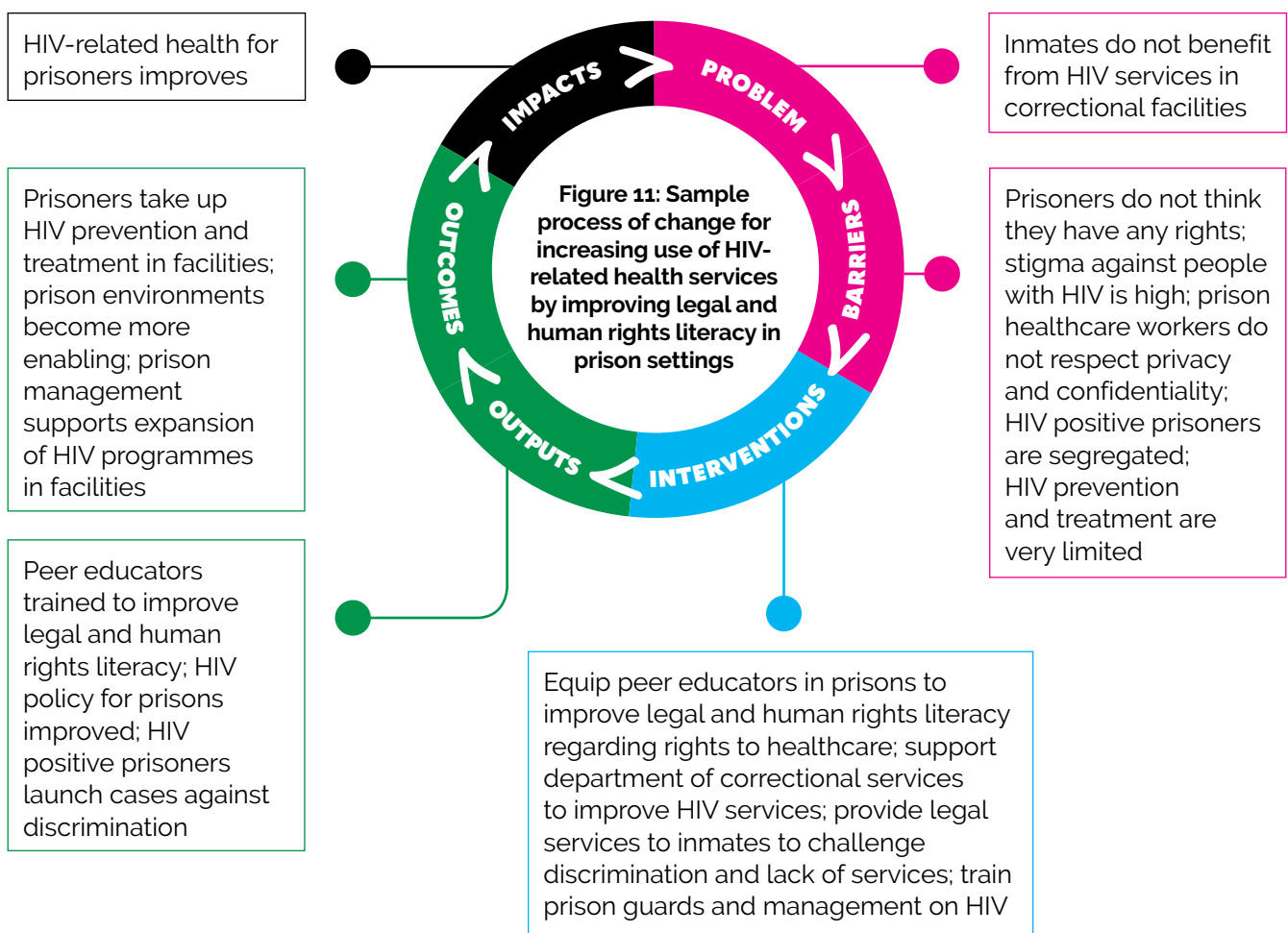
While legal and human rights literacy is valuable on its own, in the context of removing barriers to HIV services it is important to identify how improving such knowledge and skills will contribute to increasing access and uptake in HIV services. In particular, knowledge should result in action – usually in the form of mobilisation, advocacy and/or seeking health services. The sample process of change in *Figure 11* suggests how improving legal and human rights literacy could achieve this in prisons.

In this example, providing legal and human rights literacy through peer educators in prisons empowers inmates to know that they have health-related rights (i.e. inmates have a right to the same

standard of care as found in the community outside the prison) and to advocate for these rights in prison. In a combined approach, this is supported by sensitising prison management and staff to the need for non-discriminatory provision of HIV prevention and treatment. Also, combining legal literacy with access to legal services is a pathway to drive institutional change by using the justice system to get individual redress and possibly to change prison policies. The result is that the barriers are reduced and more inmates have access to HIV prevention and treatment services.

### Step 2: Combine interventions

*Table 10* shows an example of a combined programme that links improved legal and human rights literacy to other opportunities for reducing





and removing barriers in prisons. In this example, legal and human rights literacy for inmates regarding minimum standards and entitlements for health services is linked to other interventions to ensure that such knowledge and skills can be effectively used to achieve change. At the same time, there are efforts to make changes at the institutional level regarding policies and practices, using the legal system as a way to accelerate change and enforce accountability, and aiming towards a more permanent solution, which is to locate the responsibility for health service provision within the ministry of health.

### Step 3: Coordinate implementation

Different sectors and institutions need to collaborate for effective implementation and for the achievement of sustained change. The first step is to determine whether there are existing mechanisms, such as a prison's oversight body or a prison ombudsman, that could perform the coordination function, or whether a new mechanism will be needed. Prisoners themselves may not be permitted to participate in such coordination groups. An additional mechanism may need to be put in place by non-governmental partners working on the health rights of prisoners, to ensure that inmates are consulted continually throughout the design, implementation and continuous monitoring processes.

**Table 10: Example of combined interventions for improving legal and human rights literacy in prisons**

#### ZERO STIGMA, DISCRIMINATION AND VIOLENCE IN THE CONTEXT OF HIV, TB AND MALARIA

Interventions	Activities
<b>Monitoring and reforming laws and policies</b>	<ul style="list-style-type: none"> <li>● Develop an HIV policy for provision of HIV services in prisons</li> <li>● Undertake advocacy for the ministry of health to be responsible for health services in prisons instead of the prisons service itself</li> </ul>
<b>Legal services</b>	<ul style="list-style-type: none"> <li>● Provide legal services to HIV positive prisoners to challenge discrimination and exclusion</li> <li>● Launch strategic litigation on behalf of prisoners to enforce legal and human rights to health services</li> </ul>
<b>Legal literacy</b>	<ul style="list-style-type: none"> <li>● Equip peer educators in prisons to provide legal and human rights literacy in the prison</li> <li>● Equip civil society organisations (CSOs) working in prisons on health promotion to include legal and human rights literacy in their activities</li> </ul>
<b>Sensitisation of law-makers and law-enforcement agencies</b>	<ul style="list-style-type: none"> <li>● Support the ministry of health to train prison leadership and prison staff on human rights-informed HIV services provision</li> <li>● Engage judicial oversight mechanisms to monitor improvements in the treatment of HIV positive prisoners</li> </ul>

## Step 4: Select indicators and monitoring process

In the example in *Table 11*, progress is monitored across a number of different domains. These include access, uptake and retention in HIV services in prisons; changes in institutional practices, including levels of stigma and discrimination in prison health services; increased mobilisation of inmates themselves to challenge stigma and discrimination and to use services designed to promote and maintain their health and well-being.

### Key enablers

✓ **Support and work with organisations and networks that have strong links to communities**, including networks of key and vulnerable populations, to recruit, train, supervise and provide ongoing support for those teaching others about their rights and the laws and policies relevant in the context of HIV. Where possible, support the development of a cadre of peer human rights educators. Peer educators will:

- have expertise on the rights, laws and policies relevant to their peers

- be able to present these in a form that is accessible to the population and be trusted by that population
- be able to know and use the best means of mobilising the population around the relevant rights and laws.

Existing community and peer workers providing health service and key population programming can be trained to also provide human rights and legal literacy as part of their work.

✓ **Support the development and roll-out of patients'-rights literacy programmes with materials and policies that are:**

- posted in health services and linked to complaints procedures
- promoted in community health and key population programming
- used for community-based monitoring of health provision.

Also focus on development and roll-out of patient's-rights for women and adolescents as they will face different challenges in healthcare settings.

**Table 11: Example of indicators linked to a combined programme for improving legal literacy in prisons**

INDICATOR LEVEL	INDICATOR	DATA SOURCE
Coverage	Number of people in prisons and other closed settings reached with HIV prevention programmes	Programme data
Coverage	Number of people in prisons or other closed settings that have received an HIV test during the reporting period and know their results	Programme data
Coverage	Percentage of people in prisons living with HIV currently receiving ART	Programme data
Outcome	Percentage of people in prisons living with HIV who report experiences of HIV-related discrimination	Stigma studies and reports from community monitoring systems
Output	Number of peer educators trained to improve legal and human rights literacy	Project data
Output	Number of prison staff trained on human rights-informed health service delivery	Project data

✓ **Support a gender-transformative approach.**

Work with women's and human rights organisations to empower women and girls in all their diversities to know their rights and be supported in claiming them, including through peer educators comprised of women and adolescent girls. Ensure that men, boys and community leaders understand what women's and girls' rights to health and equality are, why they are important and how they figure in a broader set of rights for women and girls around choice, decision-making and freedom from violence.

✓ **Use the media to improve understanding of health-related rights and to change attitudes.**

This is particularly effective when combined with community mobilisation. Social media can also be used to significantly increase reach and possibly increase engagement with the messages, even in contexts that do not support the rights of key and vulnerable groups more broadly.

✓ **Use indicators that capture the pathways between knowing and claiming one's rights for different groups,** including mechanisms for accessing redress. Consider how this relates to access to HIV services and health outcomes.

**ADDITIONAL RESOURCES**

- **Bringing Justice to Health: The impact of legal empowerment projects on public health** – OSF – Useful case studies on legal empowerment work.<sup>117</sup>
- **My Justice, Guide to Organizing and Working with Community-based Paralegals** – Namati.<sup>118</sup>
- **SALC Guidebook: Using complaints to address healthcare violations** – Southern Africa Litigation Centre (SALC).<sup>119</sup>
- The guides on developing paralegal programmes listed under Programme Area 6 also give useful advice about rights training.



117. OSF (2013). 'Bringing Justice to Health: The impact of legal empowerment projects on public health'. New York: OSF. Available at: [www.opensocietyfoundations.org/publications/bringing-justice-health](http://www.opensocietyfoundations.org/publications/bringing-justice-health).

118. Namati, My Justice (2019). 'Guide to Organizing and Working with Community-based Paralegals'. Washington DC: Namati. Available at: <https://namati.org/resources/guide-organizing-working-with-community-based-paralegals-eng/>.

119. SALC (2014). 'SALC Guidebook: Using complaints to address healthcare violations'. Johannesburg: SALC. Available at: [www.southernafricalitigationcentre.org/2016/12/24/salc-guidebook-using-complaints-to-address-healthcare-violations/](http://www.southernafricalitigationcentre.org/2016/12/24/salc-guidebook-using-complaints-to-address-healthcare-violations/).



## Programme Area 6: HIV-related legal services

### Getting started

Readily available, accessible and acceptable HIV-related legal services are a key component of improving access to justice for key and vulnerable populations. First, it is important to understand whether they use legal services and, if not, how they can be encouraged to do so. People may not use available legal services due to lack of awareness of them, lack of confidence that their challenges will be resolved by the legal system, and/or fear of further harm due to reprisals. Many people may not relate at all to the formal legal system, but rather use traditional or religious law systems based in the community.

Therefore, it is important to understand and devise legal services that will work in different legal, social, religious and community settings, and will actually be taken up by individuals. As has already been illustrated, improving access to HIV-related legal services, or creating demand for such services, can be helped by combining legal services with other programme areas, such as legal literacy training, and monitoring and reforming laws and policies.

As you begin to design interventions to increase the availability of HIV-related legal services, it is important to first map what might already be available including, for example, publicly-funded

legal aid services. Are HIV issues addressed by those services and, if not, are there interventions that would modify those services so that they would be used by key and vulnerable populations?

### Activities for providing HIV-related legal services include:

- Legal information, referrals, advice and representation regarding HIV and HIV/TB through hotlines, radio shows and peer paralegal community systems
- Publicly-supported legal services and counselling
- Mediation, arbitration and other dispute settlement mechanisms, including support to community forms of dispute resolution
- Engagement of traditional and religious leaders and customary law in support of key and vulnerable populations
- Strategic litigation.

These interventions may be delivered through a variety of modalities and in a variety of settings, including formal and traditional law settings. They can be delivered in conjunction with HIV prevention, treatment, care and support services, including harm reduction services; and/or delivered in communities by peer paralegals who may or may not also be community healthcare workers. They can also be part of general legal services that address a wide range of legal issues (not necessarily HIV-related).

### LESSONS FROM PRACTICE

#### A WEB- AND SMS-BASED DISCRIMINATION REPORTING SYSTEM

In 2012, the Ghana Commission on Human Rights and Administrative Justice (CHRAJ) adapted its well-developed case management systems to the specific needs of people living with HIV and other key populations, including improving privacy and speed of response. CHRAJ staff were trained, mentored and coached on how to provide sensitive services. They conducted outreach to people living with HIV and other key populations in order to build relationships and understand how to relate to different types of clients.

Working closely with CSOs, cases of discrimination in housing, government services, health, education, employment and other relevant areas were reported. As CHRAJ received these cases, it mediated, investigated or adjudicated them. This model proved that three key elements – legal and policy frameworks, institutions that promote access to justice and mechanisms to link people living with HIV and other key populations to legal services – are necessary to ensure that a discrimination reporting system protects the human rights of people living with HIV and key populations.<sup>120</sup>

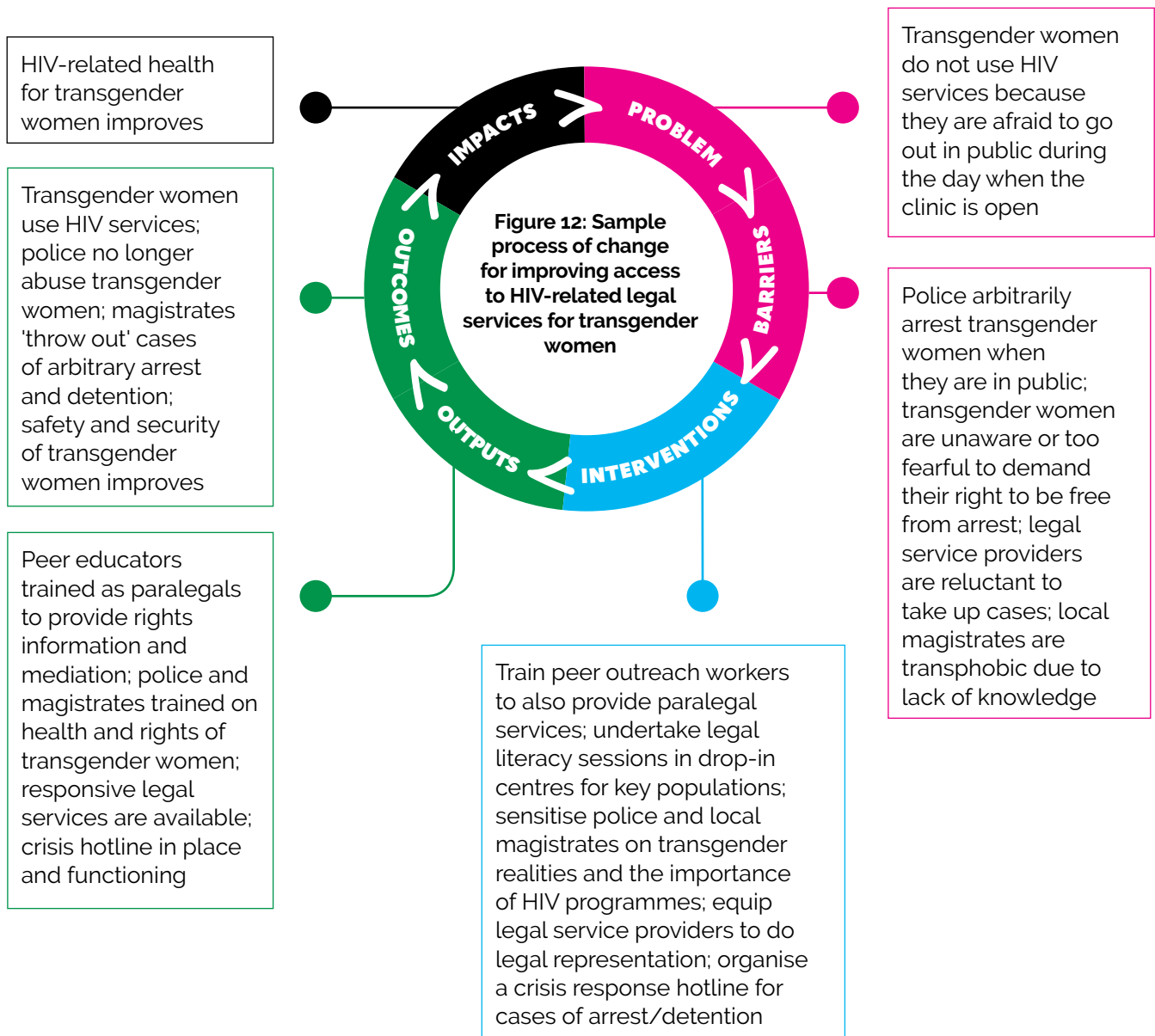
120. Williamson R.T., Fiscian V., Ubuntu Olson R., Nana Poku F. and Whittal J. (2017). A Reporting System to Protect the Human Rights of People Living with HIV and Key Populations. *Health Human Rights*. 2017 Dec; 19(2), pp. 211–222.

### Step 1: Map the process of change

The example process of change in *Figure 12* illustrates how improving access to HIV-related legal services can be an important component of a broader change process aimed at improving uptake and retention in HIV programmes.

In this example, improving access to HIV-related legal services, through peers, and/or in the community, is an important component of resolving safety and security concerns for

transgender women, who have legitimate fears of verbal and physical violence and abuse when attending health facilities. Encouraging individuals to report and pursue legal processes and/or mediation when they experience violence and abuse helps to reinforce other interventions related to legal literacy, such as interventions with law-enforcement agents and the judiciary, and strengthening community empowerment. All of these efforts 'combine' to create a safe and enabling environment for transgender women to use HIV and other health services.



## Step 2: Combine interventions

Table 12 shows an example of a combined programme linking interventions to improve access to HIV-related legal services with other programme areas. When implemented as a package, these interventions can improve access to justice for individuals, as well as strengthen general safety and security in communities. This approach, in turn, creates a safer and more enabling environment for people using health services.

Establishing legal services and a crisis response system increases opportunities for individuals to use the justice system, and provides community

structures to claim and protect legal and human rights against verbal and physical violence and abuse. However, for legal services to be effective, individuals must know about them and be motivated to use them. Similarly, legal processes need to be responsive to the legal and human rights challenges for which individuals are seeking redress. For these reasons, peer paralegals and legal advice in drop-in centres for transgender people may reach this population and be more effective than getting regular legal services to take on transgender issues. Working with judicial officers and the police is as important as improving the availability and use of legal services.

**Table 12: Example of combined interventions for improving access to HIV-related legal services for transgender women**

### ZERO STIGMA, DISCRIMINATION AND VIOLENCE IN THE CONTEXT OF HIV, TB AND MALARIA

Interventions	Activities
<b>Monitoring and reforming laws and policies</b>	<ul style="list-style-type: none"> <li>● Establish a community monitoring system to document and report violence and abuse against transgender people</li> <li>● Undertake advocacy for ending police abuses and developing stronger protection mechanisms for transgender people</li> </ul>
<b>Legal services</b>	<ul style="list-style-type: none"> <li>● Equip peer paralegals to provide legal representation and mediation to transgender people</li> <li>● Put in place a crisis response hotline to support transgender women who are illegally detained</li> </ul>
<b>Legal literacy</b>	<ul style="list-style-type: none"> <li>● Equip peer outreach workers to provide rights literacy to clients</li> <li>● Host regular 'know your rights' sessions in drop-in centres for key populations, including transgender people</li> </ul>
<b>Sensitisation of law-makers and law-enforcement agencies</b>	<ul style="list-style-type: none"> <li>● Include transgender issues in training for local policing units, including their role in protecting transgender women from violence and abuse</li> <li>● Sensitise magistrates on the health and rights of transgender people and the impacts of police violence and abuse</li> </ul>

### Step 3: Coordinate implementation

In this example, lawyers, paralegals, judicial officers, the police and key population networks need to collaborate to achieve change in terms of removing barriers to HIV services. Putting in place a mechanism to facilitate this collaboration (or equipping an existing mechanism to perform this function) is an important step in programme design. Having a national technical working group is one option that could be combined with local-level collaborating mechanisms, such as an 'access to justice' working group comprised of representatives from specific stakeholder groups working in a district or province.

### Step 4: Select indicators and monitoring process

It is important to monitor legal service provision across different dimensions. These include whether or not they are used, the level of satisfaction of both service users and service providers, and the extent to which they increase access to justice for successful resolution of legal or

human rights concerns. Monitoring how they improve safety and security, from the individual and community point of view, is also important.

#### Key enablers

- ✓ **Creating cadres of community paralegals as entry points for legal services** is a highly effective and cost-efficient way to increase knowledge and uptake of legal representation. Peer or community paralegals can come from existing groups of community healthcare workers working with key populations. They should be trained, be backed up by lawyers (for complicated cases and for supervision, the number of lawyers can be low) and be remunerated for their work. Consider creating peer paralegals among women living with HIV as well.
- ✓ **Ensuring confidentiality and privacy**, to the greatest extent possible, and using all procedural options available, is a key enabler of uptake of legal services, as many individuals fear having personal information about them disclosed in settings where it can cause additional harms.

**Table 13: Example of indicators linked to a combined programme for providing HIV-related legal services**

INDICATOR LEVEL	INDICATOR	DATA SOURCE
Coverage	Percentage of transgender people that have received an HIV test during the reporting period and know their results	Programme data
Coverage	Percentage of transgender people living with HIV currently receiving ART	Programme data
Outcome	Percentage of transgender people who avoid healthcare because of stigma and discrimination	Stigma studies and reports from community monitoring systems
Output	Number of lawyers trained to provide legal services	Project data
Output	Number of calls to 'crisis response' hotline and actions taken	Project data

- ✓ **Fostering and sustaining community linkages** is key to the success of expanding the accessibility and acceptability of legal services. Functional links between legal service providers, key-population-led organisations in communities, judicial officers and the police, for example, are important enablers.
- ✓ **Systems and structures for documenting and monitoring the use of legal services**, including the outcomes of cases, are important for a number of reasons, including monitoring the use of services, monitoring the quality of services, and monitoring the outcomes of cases for information and advocacy purposes.

#### ADDITIONAL RESOURCES

- **Toolkit: Scaling up HIV related legal services** – International Development Law Organization (IDLO) and UNAIDS.<sup>121</sup>
- **Equal Rights, Equal Treatment, Ending AIDS: Strengthening and expanding HIV-related legal services and rights** – IDLO.<sup>122</sup>
- **Southern Africa Litigation Centre (SALC) website** for news, ongoing cases and resources.<sup>123</sup>
- **How to develop a community paralegal programme** – Namati.<sup>124</sup>
- **Community-Based Paralegals: A Practitioner's Guide** – OSF.<sup>125</sup>

“ I was fired from work when they found out I have HIV. Now, I have no money to travel to the health clinic.”

#### BARRIERS

- Discriminatory workplace practice
- Denial of information on workplace rights
- Healthcare facilities are far away

#### PROGRAMMES

- Advocacy to strengthen protective workplace practices
- Media campaign
- Rights literacy, peer paralegals and legal services
- Peer educators and outreach services

121. IDLO and UNAIDS (2019), 'Toolkit: Scaling up HIV-related legal services'. Rome: IDLO; Geneva: UNAIDS. Available at: [www.idlo.int/publications/toolkit-scaling-hiv-related-legal-services-english](http://www.idlo.int/publications/toolkit-scaling-hiv-related-legal-services-english).

122. IDLO (2017), 'Equal Rights, Equal Treatment, Ending AIDS: Strengthening and expanding HIV-related legal services and rights'. Rome: IDLO. Available at: [www.idlo.int/publications/equal-rights-equal-treatment-ending-aids-strengthening-and-expanding-hiv-related-legal](http://www.idlo.int/publications/equal-rights-equal-treatment-ending-aids-strengthening-and-expanding-hiv-related-legal).

123. See SALC website: [www.southernafricalitigationcentre.org/](http://www.southernafricalitigationcentre.org/)

124. See Namati website: <https://namati.org/resources/developing-a-community-paralegal-program/>.

125. OSF (2010), Community-Based Paralegals: A Practitioner's Guide'. New York: OSF. Available at: [www.justiceinitiative.org/publications/community-based-paralegals-practitioners-guide](http://www.justiceinitiative.org/publications/community-based-paralegals-practitioners-guide).



## LESSONS FROM PRACTICE

**PROVIDING LEGAL SERVICES AND TAKING PARALEGAL WORK TO SCALE**

In Mozambique, Namati is building a global movement of grassroots legal advocates who give people the power to understand, use and shape the law. Namati's grassroots paralegals, known as *defensores de saúde* (health advocates), work to empower patients to understand their rights as citizens via educational sessions at health facility and community level, and to advocate for improvements to the system. The health advocates receive ongoing training and supervision and meet regularly as a team to discuss challenges and best practices.

Namati works closely with village health committees to transform what are often inactive groups into effective institutions for governance. Health advocates provide training and ongoing capacity-building, and support these committees to conduct participatory biannual health facility assessments. This process makes it possible to track progress on reducing barriers to the right to health over time, and ensures that the voices of those who are marginalised – the elderly, people with disabilities, women, people living with HIV or TB – are heard, and that they play a central role in the governance of health services. This approach has been formally approved by the Ministry of Health in Mozambique and incorporated into its new five-year National Strategy on Humanisation (respect for patient dignity/patient rights) and Quality of Health services.

Detailed feedback is gathered from patients, community members and health workers to assist them in identifying and prioritising challenges in healthcare providers' behaviour, infrastructure, equipment and supplies. Village health committee members then analyse the root cause of each problem, document the problem clearly, and formulate a potential solution. They aim for amicable resolutions with the local facility staff wherever possible, but, when necessary, seek redress from higher levels of authority.

Over a six-year period, Namati's health advocates and their clients took on a total of 4,864 grievances, of which 3,580 (73.6%) were resolved. Working with communities, village health committees and healthcare staff, Namati was able to address complaints around healthcare provider absenteeism; lack of privacy during HIV testing and medical consultations; lack of confidentiality; disrespectful treatment; bribery in the maternity ward and HIV services; lack of running water and functioning toilets at health facilities and lack of information regarding broken laboratory equipment or lost/delayed results. The majority of these grievances have been collective in nature – affecting from 10 to 20,000 people. Over the past two years, there has been an average reduction of 43% in these types of violations at facilities with health advocates.

Namati rigorously tracks data on every case the health advocates take on, and every community-facility dialogue they facilitate. In the aggregate, this data provides invaluable insight into how health policy is working in practice. They draw on this information to propose systemic changes that can affect the entire population, not just those living in catchments where health advocates are active. For example, Namati helped to draft a national policy on bribery in the health sector, and is supporting the Ministry of Health to develop a mandatory in-service right-to-health curriculum for healthcare workers, and to create patients'-rights offices at every health facility in Mozambique.

The organisation has also established a Centre for Training of Paralegals Focused on the Right to Health, offering coaching, tools and technical support to partner organisations both in Mozambique and beyond. Namati is committed to documenting and disseminating its methodology and the lessons that emerge from its work via in-person and virtual learning exchanges, and is currently working on a *Right to Health Practitioners' Guide*. Namati works in partnership with the Legal Aid Clinic (*Centro de Prática Jurídica*) at the Faculty of Law at Eduardo Mondlane University, which provides support in complex cases requiring legal counsel.<sup>126</sup>

126. Namati Mozambique (2019), 'The Impact of Legal Empowerment on Barriers to Health Care', Draft; Namati Mozambique (2018) Proposal to OSISA: Namati Mozambique Right to Health Program; Feinglass E., Gomez N. and Maru V. (2016), 'Transforming Policy into Justice:

The Role of Health Advocates in Mozambique', *Health and Human Rights Journal*, Vol 18(2). Available at: [www.hhrjournal.org/2016/09/transforming-policy-into-justice-the-role-of-health-advocates-in-mozambique/](http://www.hhrjournal.org/2016/09/transforming-policy-into-justice-the-role-of-health-advocates-in-mozambique/).

## 7 Programme Area 7: Monitoring and reforming laws, regulations and policies relating to HIV

### Getting started

Laws, regulations and policies can have a profound impact on the success of the national HIV response, including whether people take up and remain in HIV prevention and treatment services, or are driven away by punitive approaches. Most countries have good protective laws, such as laws against HIV-related discrimination, or laws to ensure that everyone has access to treatment. Unfortunately, many law enforcers do not have sufficient knowledge of protective laws, or they are not enforced for other reasons. Many criminal laws are enforced in harsh, punitive or overly-broad ways, undermining the HIV response by driving key populations underground and away from services. For example, using the condoms that sex workers carry as evidence of sex work, or clean syringes as evidence of drug possession, or arresting people who use drugs outside drop-in clinics that have been set up to provide them with services.

It has been recognised for some time that it is important to monitor and improve the legal environment (laws, law-enforcement and access to justice) in order to progress national AIDS strategies; mechanisms have been in place to monitor laws and policies related to HIV and their effects on access to services. These include the National Composite Policy Index (NCPI) under UNAIDS, LEAs using UNDP tools, and other efforts by local and regional actors to understand the laws, regulations and policies that either support or retard the national AIDS response.

### Activities for monitoring and reforming laws, regulations and policies include:

- Assessing policies/practices on testing, informed consent and confidentiality, and their impact on access to services
- Conducting LEAs or follow up to those already conducted
- Community-based monitoring of laws and policies and their implementation and impact on HIV and populations affected by HIV
- Advocacy and mobilisation for law and policy reform to increase access to HIV services.

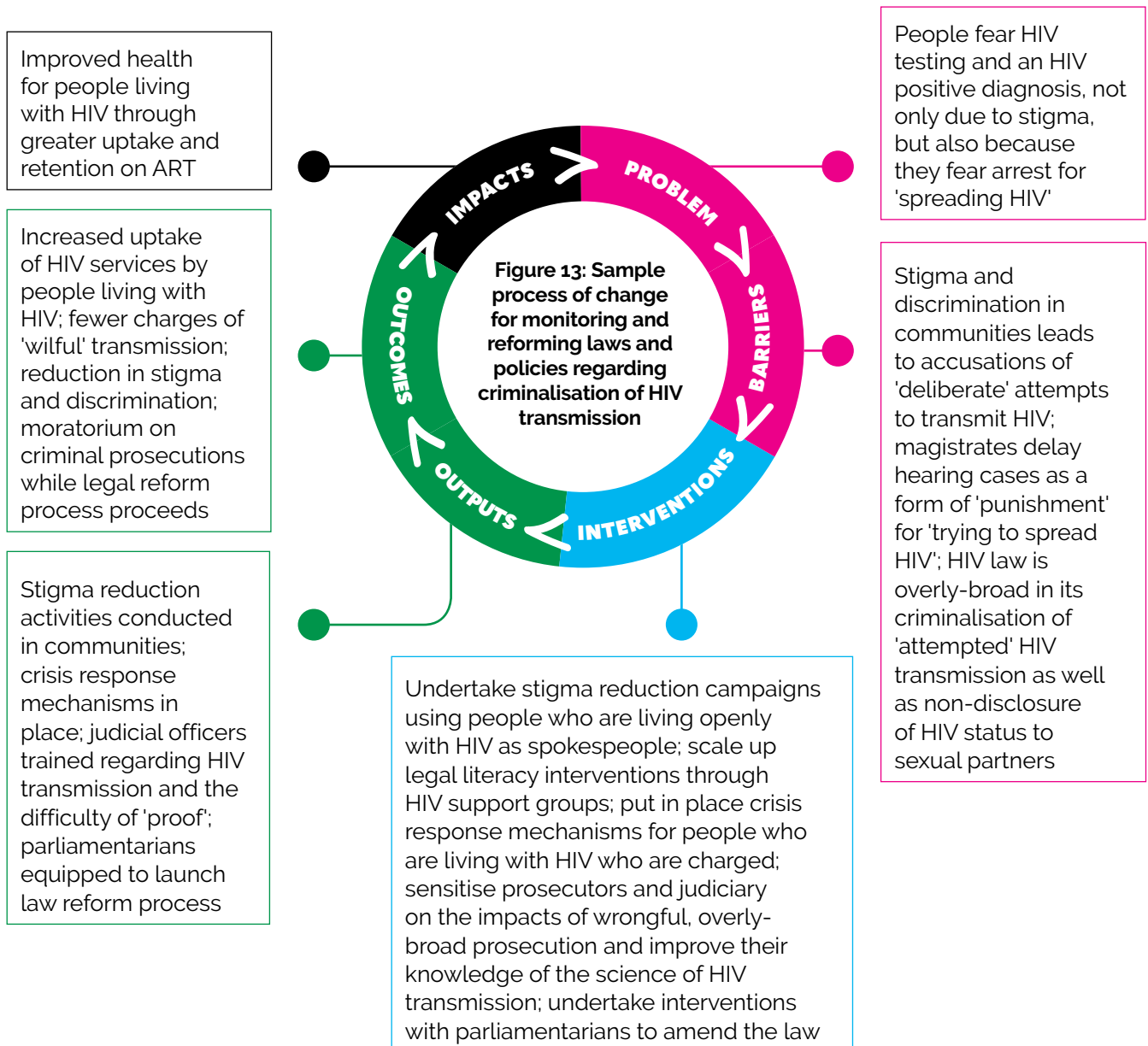


In efforts to reform laws, regulations and policies, it is important to assess which of these are problematic and can be changed relatively quickly to have a fairly immediate positive impact on the lives of those affected. Reforming laws is a long-term effort that requires extensive advocacy and sustained engagement with parliamentarians, among others. Policies and regulations can be easier to reform and may have more immediate effects on access to services. Consequently, it is important to assess priority areas for reform, and consider addressing policies and regulations to target for reform in the short or medium term, while planning and sustaining longer-term efforts.

### Step 1: Map the process of change

Figure 13 shows an example of a process of change linking law reform, in this case reform of overly-broad laws criminalising HIV transmission, to increasing uptake and retention in HIV services for people living with HIV.

In this example, the law contains overly-broad provisions criminalising 'attempted' transmission and non-disclosure of HIV status to sexual partners, and prosecutors have brought high-profile cases that have made people living with HIV, or those who think they have HIV, afraid to come forward for testing, diagnosis and enrolment on ART.



In addition to law reform, which may take some time to achieve, other actions are needed, including stigma and discrimination reduction in communities to prevent malicious accusations against people living with HIV; increased provision of legal literacy and legal services for people living with HIV; working with parliamentarians, prosecutors and judges to push for the adoption of evidence-based approaches regarding HIV transmission.

### Step 2: Combine interventions

Table 14 shows a combined programme for law and policy reform to address the range of effects punitive HIV laws have on the willingness of people living with HIV to access HIV services.

Repealing or amending laws, particularly controversial laws, such as those addressing key populations or those that legitimise public fears

regarding HIV transmission, may require extensive, but necessary efforts over time. While this work is underway, other interventions are needed that will have a more immediate protective effect, such as efforts to protect people living with HIV from malicious or stigma-driven accusations and criminal proceedings; ensuring that people living with HIV who are detained have their health and rights protected and respected, and building the case for law reform through advocacy and public education.

### Step 3: Coordinate implementation

For this programme area, parliamentarians, law reform experts, judicial officers, the police and networks of people living with HIV and their allies need to collaborate to achieve change in terms of removing legal barriers to HIV services. As with the other programme areas, putting in place a mechanism to facilitate this collaboration (or

**Table 14: Example of combined interventions for monitoring and reforming laws, regulations and policies relating to criminalisation of HIV transmission**

## ZERO STIGMA, DISCRIMINATION AND VIOLENCE IN THE CONTEXT OF HIV, TB AND MALARIA

Interventions	Activities
<b>Monitoring and reforming laws and policies</b>	<ul style="list-style-type: none"> <li>● Develop and implement an advocacy strategy for reforming HIV criminalisation law</li> <li>● Document and report on the public health harms of overly-broad criminalisation of HIV</li> </ul>
<b>Legal services</b>	<ul style="list-style-type: none"> <li>● Equip a cadre of lawyers to provide legal representation and mediation to people living with HIV who have been charged with HIV transmission</li> <li>● Put in place a 'crisis response' hotline to support people living with HIV who are charged</li> </ul>
<b>Legal literacy</b>	<ul style="list-style-type: none"> <li>● Equip people living with HIV to do legal literacy as peer human rights educators</li> <li>● Train and deploy people living with HIV as community paralegals</li> </ul>
<b>Sensitisation of law-makers and law-enforcement agencies</b>	<ul style="list-style-type: none"> <li>● Engage parliamentarians on the need for law reform</li> <li>● Sensitise prosecutors and magistrates on the science of HIV transmission</li> <li>● Train police officers and prison workers on respect for the health and rights of people living with HIV who are detained</li> </ul>

equipping an existing mechanism to perform this function) is an important step in programme design. Often there are already cross-party parliamentary committees on health or HIV that could serve as coordinating mechanisms. Some countries that undertook LEAs put in place national steering committees to guide the process and ensure ownership of the result. These too could serve as a mechanism for programme coordination.

#### Step 4: Select indicators and monitoring process

In this example, there are number of interlinked actions to monitor on a continuous basis, including the progress of law reform at the institutional level; the availability and effectiveness of legal representation and support services at the organisational or systems level, and the experiences of people living with HIV in communities at the individual level.

#### Key enablers

- ✓ **Strong partnerships involving civil society, community and key population-led organisations** are vital for pushing for policy reform and for ensuring implementation and/or monitoring government commitment.<sup>127</sup>
- ✓ **Understand the political environment.** Laws can usually only be changed through parliamentary processes, and it is important to assess whether efforts will result in positive change or will result in more repressive laws. If the latter, focus on ensuring existing protective laws are actually implemented and cover the violations that are occurring. Also try to put in place regulations that may result in protections at community level.
- ✓ **Support accountability mechanisms, including community-based monitoring.** Civil society monitoring – at local and national levels

Table 15: Example of indicators linked to a combined programme for reforming laws, regulations and policies

INDICATOR LEVEL	INDICATOR	DATA SOURCE
Coverage	Percentage of people living with HIV who know their HIV status	Programme data
Coverage	Percentage of people living with HIV currently receiving ART	Programme data
Outcome	Percentage of people living with HIV reporting their rights were violated who sought legal redress	Stigma studies and reports from community monitoring systems
Outcome	Percentage of members of parliament willing to champion HIV-related law reform	LEAs
Output	Prosecutorial guidelines in place regarding HIV-related prosecutions and the rights of people living with HIV (privacy, confidentiality, protection, access to treatment in detention, etc.)	Project data
Output	Percentage of judicial officers (judges, magistrates) trained on science of HIV transmission and HIV-related human rights	Project data

127. Htun and Weldon (2013), 'Feminist mobilisation and progressive policy change: why governments take action to combat violence against women', *Gender & Development*, Vol 21(2). Available at: <https://doi.org/10.1080/13552074.2013.802158>. Gaventa J. and Barrett G. (2010), 'So what difference does it make? Mapping the outcomes of citizen

engagement', Issue 347, pp. 1-72. Brighton: Institute for Development Studies, Development Research Centre, IDS. Available at: [https://doi.org/10.1111/j.2040-0209.2010.00347\\_2.x](https://doi.org/10.1111/j.2040-0209.2010.00347_2.x). Ainsworth M, Beyrer C, Soucat A (2003), 'AIDS and public policy: the lessons and challenges of "success" in Thailand', *Health Policy*, Vol 64 (0168-8510) pp. 13-37.

– of human rights violations, service quality, and the impact of the legal and policy landscapes, is key to gathering evidence to hold governments to account.<sup>128</sup>

✓ **Collaborative spaces for dialogue and action-planning** are critical for bringing together diverse stakeholders, such as organisations of people living with HIV and other key and vulnerable populations, human rights advocates, and legal and health experts, in order to strengthen efforts for policy or law reform.

✓ **Ensure that safety and security measures for human rights advocates are in place,**

particularly where human rights defenders and those from key and vulnerable populations may be threatened with violence. Safety is also important for allies in conservative institutions, such as governments, who may risk their professional reputations by taking up controversial issues, such as decriminalisation or other legal reforms affecting socially marginalised populations. (See *Unit 7, 7.2: Addressing safety and security across programme areas*).

✓ **Use and strengthen HIV capacity of existing institutions that provide monitoring of national laws and policies,** including human rights organisations and National Human Rights Institutions and Offices of Ombudsmen.

### ADDITIONAL RESOURCES

- **Rights–Evidence–ACTion (REAct)** – Frontline AIDS – A tool to record human rights violations that happen when accessing HIV and health services.<sup>129</sup>
- **The Practical Field Guide for Community Based Human Rights Documentation** – Asia Catalyst – provides helpful guidance on how to carry out an inclusive consultation. See Page 11 for a checklist for a human rights-based approach to documentation. Page 35 has data storage tips.<sup>130</sup>
- **HIV and the Law: Risks, Rights and Health** – UNDP Global Commission on HIV and the Law.<sup>131</sup>
- **Africa Regional Grant on HIV: Removing Legal Barriers** – UNDP web page has useful key resources and country policy scans.<sup>132</sup>
- **Legal environment assessment for HIV: An operational guide to conducting national legal, regulatory and policy assessments for HIV** – UNDP.<sup>133</sup>
- **Community-based monitoring and feedback accountability toolkit** – Women4GlobalFund.<sup>134</sup>
- **Self-care and prevention of burn out among activists – tools for everyday life** – Frontline AIDS.<sup>135</sup>

128. Gaventa J, Barrett G. (2010). *So what difference does it make? Mapping the outcomes of citizen engagement*. Brighton: Institute for Development Studies, Development Research Centre. IDS; 2010.

129. Frontline AIDS (2019). *'Rights–Evidence–ACTion (REAct)'*. Brighton: Frontline AIDS. Available at: <https://frontlineaids.org/our-work-includes/react/>.

130. Asia Catalyst (2016). *'Practical Field Guide for Community-based Human Rights Documentation'*. Available at: [https://asiacatalyst.org/wp-content/uploads/2014/09/Field-Guide-June\\_forWeb.pdf.pdf](https://asiacatalyst.org/wp-content/uploads/2014/09/Field-Guide-June_forWeb.pdf.pdf).

131. UNDP Global Commission on HIV and the Law (2018). *'HIV and the Law: Risks, Rights and Health'*. New York: UNDP. Available at: <https://hivlawcommission.org/>.

132. See UNDP website: [www.africa.undp.org/content/rba/en/home/democratic-governance-and-peacebuilding/africa-regional-grant-on-HIV.html](http://www.africa.undp.org/content/rba/en/home/democratic-governance-and-peacebuilding/africa-regional-grant-on-HIV.html)

133. UNDP (2014). *'Legal Environment Assessment for HIV – An operational guide to conducting national legal, regulatory and policy assessments for HIV'*. New York: UNDP. Available at: [www.undp.org/content/dam/undp/library/HIV-AIDS/Governance of HIV Responses/UNDP Practical Manual LEA FINAL web.pdf](http://www.undp.org/content/dam/undp/library/HIV-AIDS/Governance%20of%20HIV%20Responses/UNDP%20Practical%20Manual%20LEA%20FINAL%20web.pdf).

134. Women4GlobalFund (W4GF) (2019). *'A Toolkit to Sustain Global and National Advocacy'*. W4GF. Available at: <http://women4gf.org/2019/03/check-out-women4globalfunds-accountability-cbmf-toolkit-enabling-women-to-track-global-fund-investments-towards-gender-equality-across-hiv-tuberculosis-malaria/>.

135. Frontline AIDS (2018). *'Self care and prevention of burn out among activists'*. Brighton: Frontline AIDS. Available at: [https://frontlineaids.org/wp-content/uploads/old\\_site/self\\_care\\_workbook\\_\(webready\)\\_original.pdf?1532089391](https://frontlineaids.org/wp-content/uploads/old_site/self_care_workbook_(webready)_original.pdf?1532089391).

## CASE STUDY

### REMOVING LEGAL BARRIERS: A REGIONAL PROGRAMME TO REMOVE BARRIERS TO HIV AND OTHER HEALTH SERVICES FOR KEY POPULATIONS IN AFRICA

The Africa Regional Grant on HIV was funded by the Global Fund from 2016 to 2019 with UNDP as the Principal Recipient. It was implemented by ARASA, ENDA Santé, KELIN and SALC.

The grant covered ten countries – Botswana, Côte d'Ivoire, Kenya, Malawi, Nigeria, Senegal, Seychelles, Tanzania, Uganda and Zambia – and worked across regions to promote an alignment of national laws and policies with regional and international human rights commitments.

**Strategies** were implemented to strengthen the legal and policy environment and reduce the impact of HIV and TB on key populations, including:

- Capacity-strengthening of key stakeholders
- Strategic litigation
- Small grants
- LEAs and policy and engagement scans
- Advocacy campaigns
- Regional dialogues
- Engagement with the African Union Commission and regional economic communities.

**Emerging results** include:

- The African Key Populations Expert Group is sharing best practice and interventions to advance the engagement of key populations in the HIV response. The group also developed a model strategic framework on HIV for key populations.
- With 164 lawyers trained, 14 cases are being litigated in 6 countries, of which 3 have been successful. These cases help set precedents in the region.

- The Regional Judges Forum for Africa (129 judges from 16 countries) was formed and is sharing experiences, challenges, and developments in HIV jurisprudence to uphold the rights of people, including those from key and vulnerable populations. For example, in 2017, Malawian parliamentarians voted to reject coercive and criminalising provisions in a long-deliberated HIV Bill that endangered human rights and had the potential to negatively affect the HIV response in the country. This achievement was largely a result of coordinated advocacy efforts by national and regional CSOs, including ARASA and SALC.<sup>136</sup>
- National Human Rights Institutions are being leveraged to follow-up on regional commitments in-country and to lead national advocacy campaigns.
- The Africa Union Commission and Regional Economic Communities Partnership Forum was established to coordinate the efforts of regional and continental stakeholders in implementation of the catalytic framework to end AIDS, TB and malaria in Africa.
- Annual trainings for parliamentarians were held with 155 trained and a regional network of parliamentarians facilitated on HIV/TB and human rights to ensure continued engagement, cross fertilisation of ideas and learnings across countries. They have also advocated for reallocation of national budgets, established an AIDS trust fund, and integrated HIV into the ministerial policy statement.
- Trainings for 155 law-enforcement and healthcare workers were held, providing key knowledge on the challenges community members face accessing HIV and TB services.

Source: Africa Regional Grant on HIV: Removing Legal Barriers: [www.africa.undp.org/content/rba/en/home/democratic-governance-and-peacebuilding/africa-regional-grant-on-HIV.html](http://www.africa.undp.org/content/rba/en/home/democratic-governance-and-peacebuilding/africa-regional-grant-on-HIV.html). The website has links to reports, policy scans and key documents produced throughout the programme.

136. UNDP (2017), 'Malawi HIV law amended to remove rights-infringing provisions'. Available at: [www.mw.undp.org/content/malawi/en/home/presscenter/articles/2017/12/12/malawi-hiv-law-amended-to-remove-rights-infringing-provisions.html](http://www.mw.undp.org/content/malawi/en/home/presscenter/articles/2017/12/12/malawi-hiv-law-amended-to-remove-rights-infringing-provisions.html)

## UNIT 7: CROSS-CUTTING ISSUES

“ These [community] organisations have been driving this work for years, and will be doing so long after donors and international NGOs have shifted focus or left.”

Key informant interview, participant at *Breaking Down Barriers* meeting, Durban, 2019.

The issues in this section are cross-cutting and ongoing, and should be thought about and addressed throughout the 'understand', 'design' and 'deliver' stages.

### 7.1 Keeping communities at the centre of programmes

Effective programmes to reduce human rights-related barriers require the collaboration and commitment of all stakeholders. For example, civil society, government, the private sector and the faith-based sector, all have roles to play. Up until now, civil society has done the most to lead and implement programmes to remove human rights-related barriers to HIV, including defining and defending the rights of people living with and those most vulnerable to HIV. It has been civil society that has articulated, promoted and defended the key human rights principles that place affected communities, and those representing them, at the centre of all responses. However, this role has often been overlooked, under-valued and under-funded.<sup>137</sup>

As countries move forward to design, implement and scale up programmes to remove human rights-related barriers, communities must be at the centre, and where needed, sufficient investments made to build and sustain their capacity to achieve the necessary scale and impact.<sup>138</sup>

In 2020, there continues to be concerns around top-down, rapid, standardised and directive approaches, when what is needed are bottom-up, gradual, flexible and participatory approaches that enable communities to engage in critical reflection, build capacity and design responses.<sup>139</sup> In the context of removing human rights-related barriers to services, key and vulnerable populations have crucial roles in:

- identifying priority barriers to services and designing programmes to remove them
- receiving funding and implementing programmes to remove the barriers to services that they experience
- monitoring the situation and generating evidence of what works to respond to human rights-related challenges
- advocating for various human rights-based responses to HIV
- leading and participating in decision-making processes that affect the communities they represent.

Work on human rights should be guided by the priorities and experiences of those most affected.

137. Frontline AIDS and ARASA (2014), 'Good Practice Guide: HIV and Human Rights', Brighton: Frontline AIDS. Available at: <https://frontlineaids.org/resources/good-practice-guide-hiv-and-human-rights/>.

138. See Global Fund (2019), 'Community Systems and Responses': [www.theglobalfund.org/en/community-responses-systems/](http://www.theglobalfund.org/en/community-responses-systems/); see also Global Fund (2019), 'Technical Brief: Community Systems Strengthening': [www.theglobalfund.org/media/4790/core\\_communitysystems\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf); see also Global Fund (2019), 'Technical brief on

HIV and key populations: Programming at scale with sex workers, men who have sex with men, transgender people, people who inject drugs, and people in prison and other closed settings': [www.theglobalfund.org/media/4794/core\\_keypopulations\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/4794/core_keypopulations_technicalbrief_en.pdf).

139. Meeting on Implementation Support to Scale up of National Programs to Remove Human Rights-related Barriers to HIV, TB and Malaria Services, 10-11 June 2019, Durban, South Africa.



## What are community-led responses?

Community-led responses are actions and strategies that seek to improve the health and human rights of community members, and are specifically informed and implemented by and for communities themselves and the organisations, groups and networks that represent them. Such responses are determined by and respond to the needs and aspirations of their constituents, and include advocacy, campaigning and holding decision-makers to account; monitoring policies, practices, and service delivery; participatory research; education and information-sharing; service delivery; capacity-building, and funding of community-led organisations, groups and networks. Community-led responses can take place at global, regional, national, subnational, and grassroots levels, and can be implemented virtually or in person. Such responses are social enablers for the HIV response, shaping the social, economic, political and environmental factors that affect the performance of HIV and AIDS programmes and influence the outcomes.<sup>140</sup>

Where the objective is to remove human rights-related barriers to HIV services experienced by key and vulnerable populations, it is very important that the communities themselves are part of describing the barriers they experience and designing the programmes that would be most effective in removing these barriers. Furthermore, they will be crucial to help reach members of their communities with these interventions.

All of the programme areas and activities described in this guide can and should place affected communities at the centre. There should be funding for capacity-building and/or core management that enables community-led organisations to meaningfully engage in, design and lead programmes to remove human rights-related barriers to services. For example, if a peer paralegal programme is to be put into place, community-based organisations or networks of key

populations should design what is needed in terms of numbers of paralegals, recruitment, contractual arrangements and remuneration; description of activities; content of materials developed; and nature of supervision by lawyers. If the intervention involves selecting some community-based health workers who work under another programme to become peer paralegals, then the local CBOs should have input into the selection and/or training of the health workers and should have input in the design and implementation of rights materials.

### Key enablers in keeping communities at the centre of programmes:

- ✓ **Support the full participation of community-led organisations** – led and staffed by members of key and vulnerable groups.
- ✓ **Make sure budgets are allocated to core community-led responses** to remove human rights-related barriers to HIV services.
- ✓ **Champion a broad and inter-connected range of activities**, driven by community-led organisations, and understand the impact of this range of activities on their health outcomes.
- ✓ **Ensure that community-led organisations are meaningfully included in all coordinating mechanisms** in efforts to remove human rights-related barriers to services.
- ✓ **Consider carefully how to ensure data protection** when monitoring core community-led programmes, since the data involved is often highly sensitive.
- ✓ **Document and address technical and operational capacity needs** through adequate budget support, as well as through relevant capacity development interventions.
- ✓ **Build on the existing strengths, expertise and experience of CBOs** and their current efforts to address human rights-related barriers that impede their access to services.

140. Generated at 44th meeting, UNAIDS Programme Coordinating Board, 25–27 June 2019, Geneva.

## CASE STUDY

### **STRENGTHENING COMMUNITY-BASED MONITORING OF HUMAN RIGHTS VIOLATIONS IN THE SOUTHERN AFRICAN DEVELOPMENT COMMUNITY – IMPLEMENTING THE RIGHTS-EVIDENCE-ACTION (REACT) TOOL**

Effective advocacy and programming to end stigma, discrimination and violence towards key populations requires evidence. Documenting human rights violations against key populations is critical as a means of informing the development of local, national, and regional interventions. From 2015–2018, Positive Vibes implemented the REAct programme as part of the Global Fund KP REACH initiative in eight Southern African Development Community (SADC) countries. REAct is a secure, internet-based, human rights monitoring and response system owned and managed locally by 'REActors' – individuals directly responsible for implementing REAct by documenting and responding to human rights violations and analysing the data. The system was developed by Frontline AIDS and is used worldwide. REAct can be used to collect evidence to support the provision of individual emergency care, to extend organisations' human rights and legal services initiatives, and to support the engagement of healthcare workers and law-enforcement officers in responding to human rights violations.

The Global Fund KP REACH programme selected and trained 59 REActors from CBOs in the eight participating countries (Botswana, Lesotho, Malawi, Namibia, South Africa, Swaziland, Zambia and Zimbabwe) to document and report human rights violations against key populations (LGBT people and sex workers). REActors were also trained in providing practical, paralegal and psychosocial support to victims of human rights violations. Between 2016 and 2018, REActors reported 357 cases of human rights violations affecting 478 individuals. People in the local community were reported as the most frequent perpetrators of human rights violations, and violent assault was the most commonly experienced violation, comprising 27% of reported incidents. Sexual abuse (17%) and harassment and intimidation (14%) were the next most frequently reported violations.

REAct is much more than a monitoring tool and has multiple beneficial outcomes. Firstly, the REAct training strengthened the ability of REActors to understand and identify human rights violations. Secondly, community members who experienced human rights violations were provided with support in the form of crisis counselling, referrals to health or legal services, and access to emergency funds. Finally, documented incidents of human rights violations were consolidated and analysed for trends. This data could then be used for evidence-based advocacy, lobbying, programme design and planning. REAct committees were established in each of the eight countries, meeting quarterly to analyse trends and discuss courses of action.

For example, in Zambia, the REAct committee used REAct data when partnering with key stakeholders to facilitate dialogues with healthcare workers and lawyers; to engage with regional police commissioners, and to initiate rapid response initiatives to homophobic and transphobic media reports. In Zimbabwe, the REAct committee used WhatsApp to share information about human rights violations through sex workers' networks; mapped referral lists across the country to coordinate responses and increase the effectiveness of referrals of victims of human rights violations, and disseminated information and analysis from the REAct database to encourage more referrals and engagement with REAct.

*"REAct has helped. We now participate in the National Technical Working Group for key populations, and are sitting on the CCM (Global Fund Country Coordinating Mechanism). We have been presenting the REAct data, and they are starting to realise this is real."* Sex Worker REActor, Malawi

Source: Positive Vibes (2018). 'The end of othering: Positive Vibes and KP REACH: Accompaniment and the Enabling of Change' (for more information go to [www.positivevibes.org](http://www.positivevibes.org)); and African Sex Worker Alliance (2019). 'Violence against sex workers in Africa: "Every sex worker has got a story to tell about violence"'. Available at: [www.nswp.org/resource/member-publications/every-sex-worker-has-got-story-tell-about-violence-violence-against-sex](http://www.nswp.org/resource/member-publications/every-sex-worker-has-got-story-tell-about-violence-violence-against-sex)

## 7.2 Addressing safety and security across programme areas

Reducing human rights-related barriers to services can be complex in some settings and not welcomed by some stakeholders. For example, in countries where drug use, sex work or same-sex sexual activities are criminalised, government authorities may not welcome efforts to address and remove barriers. This can result in 'push

back', including threats to the safety and security of either the beneficiaries of the programmes or those implementing them. Therefore, any safety and security issues should be identified and addressed from the start and, where necessary, safety and security measures should be included across the programme life cycle. *Table 16* provides some examples of activities to prevent threats, respond to crises, and address longer-term prevention and protection of all those involved.

**Table 16: Suggested strategies to address safety and security risks<sup>141</sup>**

<b>PREVENTION AND PLANNING STRATEGIES TO PREVENT OR PLAN FOR SAFETY AND SECURITY CHALLENGES</b>	
<b>Prioritise safety and security as an organisation</b>	Prioritise safety and security in all strategies and decisions, such as where activities occur (e.g. location of drop-in centres), how services are delivered (e.g. outreach workers always in pairs), and how resources are allocated (e.g. contingency budget for crisis response).
<b>Develop safety and security plans</b>	Develop organisational plans/ToCs, supported by budgets, to prevent, mitigate, or respond to safety and security scenarios.
<b>Build security platforms/response teams</b>	Work with other stakeholders (e.g. CSOs, police, lawyers) to build platforms to prevent and/or urgently respond to safety and security challenges. This includes monitoring the media, coordinating a crisis response team, and creating a directory of organisations/resources that can be called upon when safety and security challenges arise.
<b>Develop safety and security protocols</b>	Develop organisational protocols and standard operating procedures to implement safety and security plans and platforms.
<b>Develop emergency-readiness tools and build individuals' capacity to use them</b>	Prepare tools (e.g. phone contact lists, know-your-rights cards, access to safe houses) to deploy during incidents, and build beneficiaries' and implementers' understanding of their rights and options when issues occur.
<b>Conduct risk and security assessments</b>	Implement risk/security assessments for activities, locations and partners. Implement preventive measures according to findings.
<b>Train personnel</b>	Train staff, volunteers and partners in knowledge and skills to prevent/respond to physical and virtual safety and security challenges (e.g. self-defence, first aid, emergency phone contacts, and safe passwords and locations).
<b>Take preventive measures</b>	Take practical, up-front measures to prevent or mitigate safety and security incidents (e.g. installing closed-circuit television, using encryption and other methods to secure communications and data, creating WhatsApp groups to immediately notify programme staff and community members if a location or event is no longer safe).
<b>Set up documentation systems</b>	Establish systems (e.g. databases) to record safety and security incidents.

141. Adapted from Frontline AIDS and LINKAGES (2018), 'Safety and Security Toolkit: Strengthening the Implementation of HIV Programs for and with Key Populations', Durham, NC: FHI 360. Available at: [www.fhi360.org/sites/default/files/media/documents/resource-linkages-safety-security-toolkit.pdf](http://www.fhi360.org/sites/default/files/media/documents/resource-linkages-safety-security-toolkit.pdf).

**IMMEDIATE RESPONSE****STRATEGIES TO MITIGATE OR STOP SAFETY AND SECURITY CHALLENGES THAT ARE ACTIVELY OCCURRING**

<b>Implement emergency plans, teams, and tools</b>	Deploy prepared strategies (e.g. emergency response teams, phone contact lists) to respond to safety and security incidents and coordinate with other stakeholders.
<b>Provide practical emergency support</b>	Provide or facilitate emergency support (e.g. medical care, safe spaces, legal advice, counselling) to the individuals or groups that are threatened.
<b>Provide emergency funds</b>	Provide or facilitate access to emergency funds to address safety and security incidents (e.g. to pay for medical or legal costs or relocation).
<b>Be able to make quick changes to security measures</b>	Urgently modify practical safety and security measures (e.g. hiring guards, changing locks, installing electric fencing).
<b>Be able to make quick changes to working practices</b>	Urgently modify individual, organisational, or programme practices (e.g. relocating offices, changing outreach sites).
<b>Document what happened</b>	Complete incident forms or databases to immediately capture the facts regarding safety and security incidents.

**LONGER-TERM RESPONSE****STRATEGIES TO DOCUMENT SAFETY AND SECURITY CHALLENGES AND BUILD AN ENABLING AND PROTECTIVE ENVIRONMENT**

<b>Compile evidence</b>	Systematically document safety and security incidents and use the data to inform advocacy, exchange experiences with other key population groups, and gather allies.
<b>Make strategic changes to how you work</b>	Use evidence, including documented cases, to make longer-term, strategic changes, such as service delivery methods, to respond to the safety and security context.
<b>Build coalitions</b>	Link with other national/regional/global key population organisations and other sectors (e.g. friendly police and politicians, human rights groups) to work collectively on safety and security issues.
<b>Advocate to decision-makers</b>	Advocate to decision-makers (e.g. government, donors, police) on the impact of safety and security challenges and the changes needed (e.g. to laws, law-enforcement, media output).
<b>Sensitise key stakeholders</b>	For example, police, health workers, religious leaders and the media, about safety and security challenges and their roles in creating safer environments.
<b>Take legal action</b>	Conduct strategic litigation or campaigns for legal redress on safety and security (including engaging with National Human Rights Institutions and Ombudsmen).

## 7.3 Sustaining programmes to achieve impact

Achieving sustainability can be complex and challenging. This section introduces some key elements in achieving sustainability. For further guidance see Hirschhorn, Talbot et al.<sup>142</sup>

### What is sustainability?

Sustainability is the ability of a health or human rights programme, or a country, to maintain and scale up services to a level that will provide the country or community with continuing control of a public health problem, even after the removal of external funding. It is an ongoing process rather than a single event. Piloting and adaptation are often critical to ensure the activities that are taken to scale are appropriate and likely to be effective over time. There are many dimensions to sustainability in the HIV response, such as financial, programmatic, systems-related, governance, human rights and political dimensions. *Box 9* provides a list of key elements that support effective and sustainable delivery at scale.

### Achieving sustainability

Throughout the process of implementation and scaling up, it is critical to consider how to sustain the delivery of programmes to remove human rights-related barriers at scale, and critical choices will need to be made. These include decisions regarding the potential transition of some activities or functions to larger organisations, or organisations in different places, or to government leadership, and/or forming or expanding partnerships. Any such transitions should be mutually agreed by stakeholders, ensure fidelity to original models, and support ongoing involvement of smaller and community-based organisations.

Decisions may also need to be made about whether it is best to retain the original effective model exactly as it was, or adapt it to resources and local contexts. For example, 'balancing flexibility/adaptability and standardisation' (see *Box 9*) captures the decisions and possible tensions around local-level innovation and standardisation. It is important to consider these issues in your context based on the consultation

### BOX 9: CHECKLIST FOR EFFECTIVE AND SUSTAINABLE DELIVERY AT SCALE

- Fiscal support
- Political support
- Community involvement, capacity, integration, buy-in and depth
- Partnerships
- Balancing flexibility/adaptability and standardisation
- Supportive policy, regulatory and legal environments
- Building and sustaining strong organisational capacity
- Transferring ownership
- Decentralisation
- Ongoing focus on sustainability
- Equity.

Source: Hirschhorn, Talbot et al (2013).

processes. There is no one formula, but your planning process will have helped to determine what makes sense and what is also most sustainable.

Also, think about how the programming to remove human rights-related barriers to services can promote community leadership and capacity-building, so that the learning, skills and experience gained through implementation remain in place after the specific activity or grant ends, creating capacity for future implementation.

As implementation and scale-up occur, implementers should consider the availability of domestic financing or other sources of ongoing funding, beyond the life of a particular grant cycle. This will be different in different countries. In countries transitioning out of Global Fund financing, domestic financing becomes critical. For effective national strategies, and to reach targets, programming to remove human rights-related barriers should be considered a core component of national strategies and plans, not a discretionary

142. Hirschhorn, Talbot et al. (2013), 'From scaling up to sustainability in HIV: potential lessons for moving forward'. *Global Health*, Vol 9 (57). Available at: <https://globalizationandhealth.biomedcentral.com/articles/10.1186/1744-8603-9-57>.

addition, and these programmes should be incorporated into all funding arrangements.

Think about what sources of funding are available now and will be in the near future, and how you could plan for sustainability in line with likely available resources. Build partnerships and relationships with key stakeholders and ensure community ownership and support. Integration into national plans, strategies and systems, and into existing programmes, can all support sustainability.

#### ADDITIONAL RESOURCES

- **Safety and Security Toolkit: Strengthening the Implementation of HIV Programs for and with Key Populations** – Frontline AIDS and the LINKAGES project.<sup>143</sup>
- **Technical Brief: Community Systems Strengthening** – Global Fund.<sup>144</sup>
- **Rights–Evidence–ACTion (REAct)** – Frontline AIDS – A tool to record human rights violations that happen when accessing HIV and health services.<sup>145</sup>
- **Good Practice Guide: HIV and Human Rights** – Frontline AIDS and ARASA.<sup>146</sup>
- **Technical Brief: HIV and key populations Programming at scale with sex workers, men who have sex with men, transgender people, people who inject drugs, and people in prison and other closed settings** – Global Fund.<sup>147</sup>



143. Frontline AIDS and the LINKAGES Project (2018), 'Safety and Security Toolkit: Strengthening the Implementation of HIV Programs for and with Key Populations', Durham, NC: FHI 360. Available at: [www.fhi360.org/sites/default/files/media/documents/resource-linkages-safety-security-toolkit.pdf](http://www.fhi360.org/sites/default/files/media/documents/resource-linkages-safety-security-toolkit.pdf).

144. Global Fund (2019), 'Technical Brief: Community Systems Strengthening', Geneva: Global Fund. Available at: [www.theglobalfund.org/media/4790/core\\_communitysystems\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf).

145. Frontline AIDS (2019), 'Rights–Evidence–ACTion (REAct)'. Brighton: Frontline AIDS. Available at: <https://frontlineaids.org/our-work-includes/react/>.

146. Frontline AIDS and ARASA (2014), 'Good Practice Guide: HIV and Human Rights', Brighton: IHAA. Available at: <https://frontlineaids.org/resources/good-practice-guide-hiv-and-human-rights/>.

147. Global Fund (2019), 'Technical brief on HIV and key populations Programming at scale with sex workers, men who have sex with men, transgender people, people who inject drugs, and people in prison and other closed settings'. Available at: [www.theglobalfund.org/media/4794/core\\_keypopulations\\_technicalbrief\\_en.pdf](http://www.theglobalfund.org/media/4794/core_keypopulations_technicalbrief_en.pdf)



**MODULE 3**

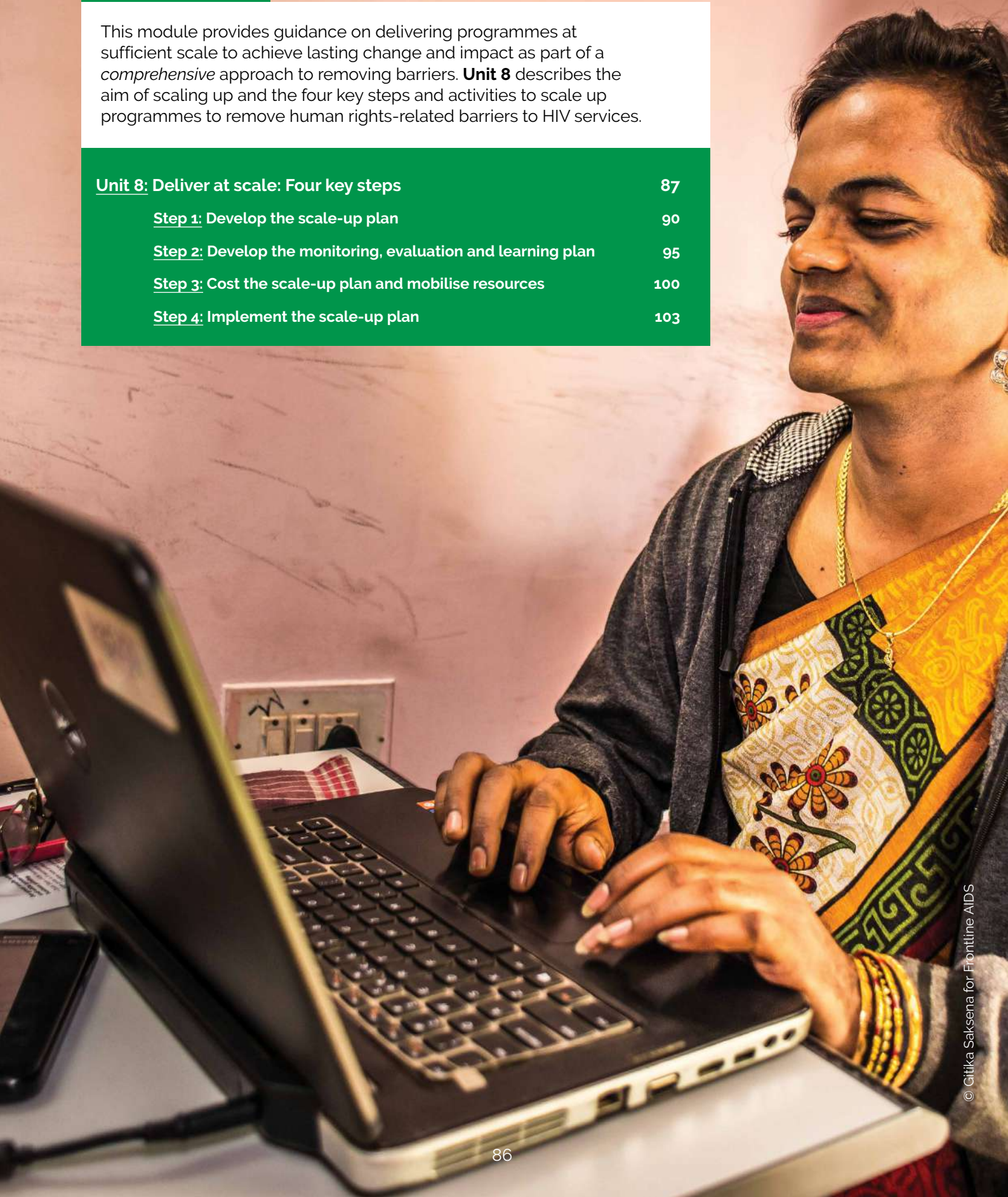
**DELIVER**

**PROGRAMMES AT SCALE  
TO REMOVE HUMAN  
RIGHTS-RELATED BARRIERS  
TO HIV SERVICES**

## ABOUT THIS MODULE

This module provides guidance on delivering programmes at sufficient scale to achieve lasting change and impact as part of a *comprehensive* approach to removing barriers. **Unit 8** describes the aim of scaling up and the four key steps and activities to scale up programmes to remove human rights-related barriers to HIV services.

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## UNIT 8: DELIVER AT SCALE: FOUR KEY STEPS

### Why scale-up?

In the past, as discussed in previous sections, programmes to remove human rights-related barriers to HIV services were often small, under-funded, *ad hoc* and ineffective. They frequently depended on the existence of an NGO with one-off funding to implement a programme in a particular location, for a particular group. Therefore, to date, programmes have not been implemented at scale, over time and in a strategic way. A comprehensive response to existing human rights-related barriers to HIV services has never been implemented at a national level in any country.

Now, for the first time in the history of the global response to HIV, there is the opportunity to plan, fund and implement programmes at the scale necessary to have a significant, positive and sustainable impact on access to services. The aim of scale-up is to achieve comprehensive responses that are effective in supporting key and vulnerable populations to access prevention, treatment and care services, and to realise their human rights in the context of HIV, including the rights to health, non-discrimination and freedom from violence.

Scaling up involves deliberate and planned efforts to increase the quality, quantity, reach,

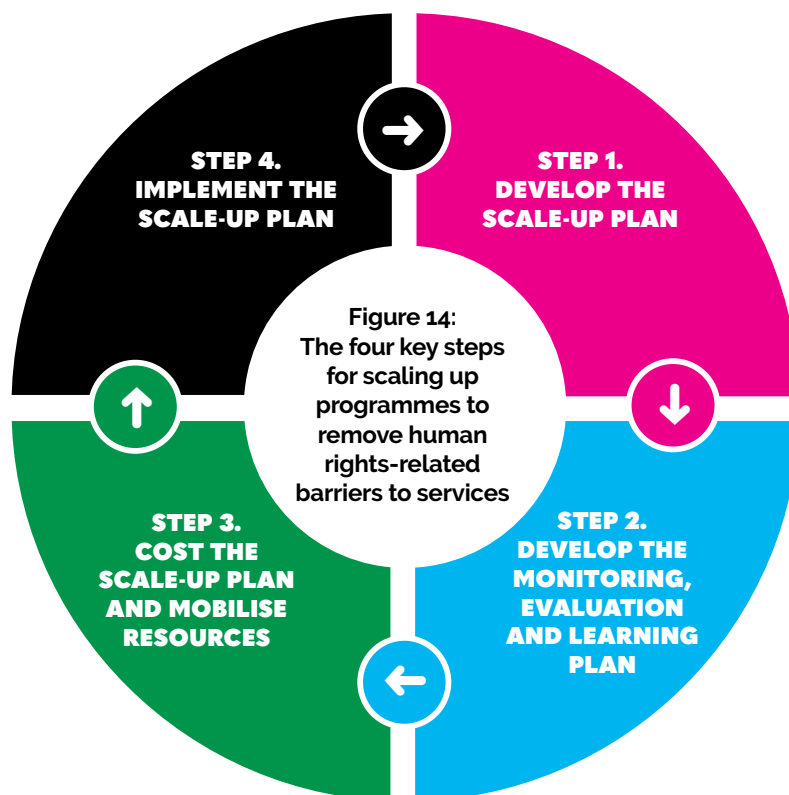
sustainability and impact of activities. It involves increased coverage of interventions as well as increased financial resources and human and organisational capacity. Scaling up does not mean scaling up all activities indiscriminately, or going for greater coverage in a non-strategic way. It should align with national priorities set out in HIV Investment Cases,<sup>148</sup> NSPs, health sector strategies and other efforts to scale up HIV prevention, treatment and key population programming. Scale-up should follow the Investment Case Approach, which seeks to maximise impact by prioritising interventions according to the prevailing epidemiology (incidence and prevalence) as well as equity and populations left behind – in this case – people experiencing many barriers and low levels of access to health services.

As in Investment Case analysis, scale-up strategies for programmes to remove human rights-related barriers to services should be designed to reach more people and different populations in a strategic manner, so as to have the greatest impact on the national epidemic and response. These might involve different combinations of programmes, different levels of coverage, moving outside urban areas, and/or engaging more and different stakeholders in areas hardest-hit by HIV in terms of incidence and prevalence.

148. The Investment Case is an approach developed by the Global Fund and describes the changes that a country wants to see with regard to ending AIDS, together with a prioritised set of investments required to achieve these results. It is not a comprehensive description of all of the activities underway, but instead, it presents a compelling case for how a *limited number of priorities* will put the country on the path to improve the HIV-related health outcomes for all over the long-term and thereby contribute to the achievement of the SDGs. See: [www.globalfinancingfacility.org/sites/gff\\_new/files/Investment\\_Case\\_Guidance\\_Note\\_EN.pdf](http://www.globalfinancingfacility.org/sites/gff_new/files/Investment_Case_Guidance_Note_EN.pdf)

## The four key steps for scaling up

This section describes the four key steps and activities to scale up programmes to remove human rights-related barriers to services. Each step and activity should be informed by evidence and the experience of implementers and programme beneficiaries, including from key informant interviews and pilot workshops (see *Module 2, Unit 7, 7.1: Keeping communities at the centre of programmes*). Table 17 provides an overview of the key steps.



**Table 17: Key steps and activities in scaling up programmes to remove human rights-related barriers to services**

STEP	ACTION	DESCRIPTION
<b>Step 1: Develop the scale-up plan</b>	1.1 Work through a scale-up planning checklist	See <i>Appendix 1: Scale-up planning checklist template</i>
	1.2 Define the scale-up strategy following the national strategy to scale up prevention, treatment, and key population programming	Decide which approaches to scale up  Consider an adaptation stage if implementing in a different setting or context to the original activity  Prioritise integration into scaled-up prevention, treatment, and key population programming
	1.3 Assess capacity	Estimate resources needed, including people and skills for implementation  Identify any available technical assistance needed and where it can be procured at what cost
	1.4 Write the scale-up plan	Write the plan and check for challenges, opportunities, priorities and possible bottlenecks

STEP	ACTION	DESCRIPTION
<b>Step 2: Develop the monitoring, evaluation and learning plan</b>	2.1 Decide what to measure and which type of indicators, baselines and targets to select	Study the process of change map and identify what needs to be measured or monitored
	2.2 Map existing data collection systems to identify opportunities for integration and scale-up	Identify existing mechanisms for monitoring and evaluating scaled-up prevention and treatment services and identify opportunities for integration into these
	2.3 Define indicators	Ensure indicators are aligned with global guidance and that it is feasible and practical to monitor them
	2.4 Collect and use data for monitoring and improvement	Decide who will be responsible for collecting, collating and analysing data; how it will be safely stored; and how it will be used
<b>Step 3: Cost the scale-up plan and mobilise technical, human and operational resources</b>	3.1 Determine costs and budget	<p>Develop a comprehensive budget linked to the scale-up plan</p> <p>Break down main interventions into sub-activities and inputs (staff, materials, travel, accommodation, technical support, etc.)</p>
	3.2 Map current investments and determine the resource gap	<p>Use existing sources, such as grant or project budgets. Estimate available resources from all sources and determine resource gaps</p> <p>The need for new investments should be minimised</p>
	3.3 Develop a resource mobilisation plan	Have a plan for addressing the resource gap and for how the programme can be sustained
<b>Step 4: Implement the scale-up plan</b>	4.1 Put in place implementation structures	Make sure that roles, responsibilities, reporting and accountability mechanisms are clear for all stakeholders
	4.2 Address technical and operational capacity needs	Technical support arrangements should be in place before implementation begins, if feasible
	4.3 Monitor, evaluate and learn	Learn from examples of scale-up in practice

## Step 1: Develop the scale-up plan

This first step is about planning to scale up the implementation of programmes to remove human rights-related barriers. Starting with a clear and comprehensive plan that has the buy-in of all relevant stakeholders is an important foundation for success. Ensuring this plan is fully costed and realistic in timeframe and budget, is also critical. At this stage, it is important to be aware of the available resources and develop the plan accordingly.

### 1.1 Work through a scale-up planning checklist

Using national plans and strategies to scale up prevention, treatment and key population programming, develop a scale-up plan that follows the national strategy and Investment Case. A planning checklist is a useful tool to help carefully think through each step (see *Appendix 1: Scale-up planning checklist template*). *Table 18* shows a completed checklist using an example of women who do sex work.

**Table 18: Example of a completed scale-up planning checklist**

QUESTION	ANSWER
<p><b>1. What is the barrier you want to address in scale up?</b> (Given the prevention and treatment programmes being implemented and scaled up in the specific location for the population in question.)</p>	<p><i>Female sex workers avoid HIV testing because they are treated poorly by clinic staff and they worry about police coming to the clinic.</i></p>
<p><b>2. What interventions are needed to address the barrier?</b></p>	<p><i>Peer support through community outreach and accompanying women to clinics; training for healthcare providers in delivering non-judgemental, supportive care to women who do sex work; development of clear clinic and police policies to prevent police officers from using healthcare facilities to target people for questioning or arrest; joint activities between sex workers and police.</i></p>
<p><b>3. Identify additional stakeholders who can address the barriers.</b> Who could be involved in removing them? Who is already an ally, and who might present an obstacle? Where are they? How can they be engaged?</p>	<p><i>Networks of women who do sex work in the new location, clinic management and staff, ministry of health officials, ministry of justice officials, police officials, including supervisors.</i></p>
<p><b>4. Which existing activities are addressing this barrier?</b></p>	<p><i>Small district-based sex worker-led project is training staff at a local clinic, with evaluations suggesting positive impact.</i></p>
<p><b>5. Which additional activities are needed?</b></p>	<p><i>Activities in other districts involving police and healthcare facilities; community support systems developed in those districts; reform and monitoring of workplace policies and practices of police and healthcare facilities in those districts.</i></p>
<p><b>6. Who are the best people, networks and organisations to involve in this additional activity?</b> What collaborations and partnerships are possible?</p>	<p><i>The network leading the existing project, healthcare staff at clinics, ministry of health, ministry of justice, police officials, sex worker networks in other districts, national key population network.</i></p>

QUESTION	ANSWER
<p><b>7. How can this be combined with activities to address other programme areas?</b></p>	<p><i>By ensuring training covers HIV-related human rights, stigma and discrimination and gender equality, this activity can address Programme Areas 1, 2, 3 and 4. Involving women who do sex work ensures that it is community-led. By expanding the cadre of peer human rights educators to train on 'know your rights' or linking to and expanding an existing activity offering this training, Programme Area 5 can also be included. Policy and practice reform in the police force and in healthcare facilities can be addressed by Programme Area 7 by collaborating with a national NGO to do advocacy work and a sex worker-led organisation to monitor community violations using REAct.</i></p>
<p><b>8. How can the additional activity be integrated into current programmes, plans or strategies?</b></p>	<p><i>Through advocacy and relationship-building, new activities could be integrated into national training programmes for police and the National Strategic Plan for HIV/AIDS.</i></p>
<p><b>9. How can this be delivered at scale?</b> Can it reach other geographical areas? Can it reach other key and vulnerable populations?</p>	<p><i>Learning from and adapting the original activity, with input and leadership from the original implementers, this activity can be adapted and piloted in other geographical areas. With further investment in adaptation, and the inclusion and engagement of other key and vulnerable population groups, it might be possible to also adapt the activity to reach other groups who experience stigma and discrimination in HIV testing clinics, for example, adolescents and young people or men who have sex with men.</i></p>
<p><b>10. What specific expertise is needed to implement this activity at scale?</b> Is more support needed to build the required expertise? For example, community-led organisations might have expertise in human rights, and with additional funding could develop the ability to work at larger scale. Large organisations might have the ability to work at scale but lack human rights and community expertise, so partnerships could help.</p>	<p><i>The sex worker-led organisation would benefit from institutional support to grow their systems and organise/mobilise sex workers in other districts. They will need greater support in their ability to manage funds, so their work can be properly resourced. There is a large, national NGO that can provide this assistance and has good relationships with national ministry and policing officials. However, they lack expertise in engaging with women who do sex work, and would benefit from capacity-building from the sex worker-led organisation to develop this. A collaboration can be developed to mutually benefit both organisations and deliver the activity together.</i></p>
<p><b>11. What technical assistance might be helpful? How can you access this?</b></p>	<p><i>Relevant technical assistance within the country or region might be useful, and the two partners should consider applying together.</i></p>

## 1.2 Define the scale-up strategy following the national strategy to scale up prevention, treatment and key population programming

### Decide which approaches to scale up, with which populations and in which locations

To be strategic and follow the Investment Approach to scale up so that the scaled-up programmes have the most impact, consider four 'pathways' or routes to scale up, as shown in *Figure 15*:

- **Horizontal:** reaching more people in the same place, or doing the same activity in a different place
- **Vertical:** informing political processes, influencing stakeholders, creating policy change or achieving legal reform
- **Organisational:** increasing capacity of an organisation or involving more organisations
- **Functional:** adding more activities or expanding the scope of an existing activity.

Your scale-up plan might include examples of all four pathways across different activities, and the same activity might be taken to scale through more than one route. It is important to reflect on the right pathway(s) for each activity. Again, this will be informed by the overall Investment Case, which identifies prevention/treatment priorities for epidemic impact; the barrier(s) you are aiming to remove; the populations that need to be supported; the activities on the ground and the changes/expansion you are trying to implement.

### Consider an adaptation stage

If you are taking an existing programme and replicating it in a different setting or for a different population, it is important to include an adaptation stage. It is not safe to assume that just because it worked in one place, it will work everywhere. It is also important to think about what made the original programme effective. Perhaps it was the involvement of peers who are trusted in that community, or extensive face-to-face training.

Figure 15: Four pathways to scale up



It might be tempting to skip these steps to save money, but doing so would mean you have implemented a different programme, without the ingredients that made the original one effective.

### Prioritise integration

Scale-up is not necessarily just 'doing more'. It is essential to think about how your scale-up plans can be integrated into existing prevention, treatment and key population programmes, in the context of national-level plans, strategies and policies. This approach also helps with achieving sustainability and cost-effectiveness. Creating a parallel programme that is not integrated with existing strategies and activities duplicates resources and does not make good use of available funds.

Sometimes, integration might not be possible. For example, the national strategies for scaling up prevention and treatment may leave out or exclude a population that is experiencing serious barriers and is key to the national epidemic. Or if your activity involves a criminalised and marginalised group, integrating into a larger programme might endanger the participants. In both cases, it might be necessary to develop, implement and scale up stand-alone programmes to remove human rights-related barriers. In this case, prioritise safety, inclusion and reach, and integrate only where you can still guarantee these.

### 1.3 Assess capacity

When thinking about the scale-up plan, *how* it is done is as important as *what* is done. For this activity, all the implementers who will be involved – from different organisations and stakeholders – need to come together, ensuring everyone is consulted. The scale-up plan should be an opportunity for everyone to grow and learn together, so think about what capacity is needed and how it can be developed. Technical assistance might be helpful to support specific activities, such as implementing a consultation process, or programme design and budgeting.

**Some other important considerations include:**

- ✓ **Think about the tools that will be needed for each scaled-up activity**, and whether these can

be adopted, adapted or need to be developed. Think carefully about the resource implications of this.

- ✓ **Consider all the human resources that will be needed.** What staff are required and where can they be found? Where can volunteers be involved? What training, skills and experience are needed? What perceptions and attitudes do staff and volunteers need to have to ensure the success of the activity? How will you recruit, train, supervise and support staff and volunteers? Will you need CBOs or other organisations that can provide support to staff and volunteers and, if so, how can they in turn be supported? How can this be coordinated and how can they be linked to a community of practice? Think about staff turnover – how can you ensure knowledge and commitment are institutionalised so programmes are not jeopardised by key staff moving on?
- ✓ **Think about capacity in relation to human rights and programming to remove human rights barriers to HIV services.** Some implementers and stakeholders will not understand or recognise the role and value of the key programmes. How can their knowledge be improved and their capacity built?
- ✓ **Ensure that any required specific knowledge or skill is recognised and included** in the capacity assessment and planning, for example, to provide specialist legal services.
- ✓ **Do not forget that capacity is not all about size or ability to absorb budgets.** Small organisations might need support to build institutional capacity but have significant capacity in terms of expertise and community involvement.
- ✓ **Consider sustainability** (see *Module 2, Unit 7, 7.3: Sustaining programmes to achieve impact*). Use your scale-up plan to build capacity so that existing organisations expand their remit and knowledge to be able to provide human rights-related services alongside existing services, such as HIV prevention or peer support.
- ✓ **Do not assume volunteers can deliver long-term projects, or that existing staff necessarily have capacity to do more.** The need for trained and supported implementers, including the involvement of communities and peers, together with realistic workloads and expectations, should be prioritised. Start from an honest appraisal of existing

skills, knowledge and time, and then assess the skills, knowledge and time required to deliver the scaled-up programme, costing in the increase in training or staff/volunteers needed to bridge any difference, and determining where remuneration is necessary.

### 1.4 Write the scale-up plan

When writing up the plan, consider that an effective plan should:

- Involve and be developed with all relevant stakeholders, and the leadership and full participation of people and organisations from key and vulnerable populations
- Build on a clear process of change
- Align with, and, where possible, integrate into national plans and strategies for scale-up of prevention, treatment and key population programming
- Consider scope, location, coverage
- Combine activities strategically across programme areas
- Involve activities that have evidence of effectiveness and have been adapted appropriately
- Consider all costs and ensure they are fully budgeted and sustainable
- Support implementation by government, civil society and communities.

The plan should also mitigate against the challenges and pitfalls in moving from small-scale or local implementation to national-level delivery, by ensuring:

- Replication is complete and vital elements of a programme have not been lost (e.g. a scaled-up programme that ends up prioritising service provision over community mobilisation)

### ADDITIONAL RESOURCES

- **Training of Trainers: Trainers Manual** – Aidsfonds – This workshop manual, developed with sex worker-led organisations, is one of seven training manuals. There are also manuals available on leadership skills, peer-based outreach, and counselling skills.<sup>149</sup>
- Tool for the Global Fund's **CRG Technical Assistance Program for Latin America and the Caribbean**, in **English** and **Spanish**.<sup>150</sup>

- There are sufficient implementers with sufficient capacity
- There is adequate preparation and resourcing of additional workload
- There are no disconnects between good practice on one hand and a country's laws and policies on the other (e.g. trying to scale up tailored services to men who have sex with men in a country where same-sex criminalisation laws are punitively enforced).

In developing your scale-up plan, it is important to consider whether barriers to implementation, such as safety of criminalised and key and vulnerable populations, would make stand-alone programming preferable. Some implementers involved in the piloting of this guide shared experiences of scaled-up programming that attracted attention from police, who then targeted their activities towards the scaled-up programmes to gather evidence or make arrests. In such contexts, it is critical to consider how the programme can be scaled up effectively while ensuring the safety of both staff and those accessing the services. (See *Module 2, Unit 7, 7.2: Addressing safety and security across programme areas*).

149. Aidsfonds (2018), 'Training of Trainers: Trainers Manual', Amsterdam: Aidsfonds. Available at: <https://aidsfonds.org/resource/training-manual-training-of-trainers>

150. <https://comunidad.plataformalac.org/en/tech-assistance-tool/>



## Step 2: Develop the monitoring, evaluation and learning plan

Knowledge about monitoring, evaluation and learning (MEL) regarding programmes to remove human rights-related barriers is growing as learning from the *Breaking Down Barriers* initiative emerges and other stakeholders prioritise this area. UNAIDS has developed guidance – *Rights-based monitoring and evaluation of national HIV responses* – that should be consulted as you develop your MEL plan.<sup>151</sup> In this guide, we offer a few key points to think about and a pathway through the process of developing an MEL plan. Think of this as a first step, and use the UNAIDS guidance to explore more detailed information.

Monitoring and evaluation are critically important to the successful implementation of programmes to remove human rights-related barriers to services generally, and also of implementing them at scale. An MEL plan ensures implementers collect the right data, evaluate it in a timely way, and learn from it so as to improve programming, address any issues and achieve greater impact. This in turn can help secure additional resources and funding. It can also help to identify where we may have made wrong

### BOX 10: WHAT IS A MONITORING AND EVALUATION FRAMEWORK?

'A monitoring and evaluation framework identifies and illustrates: a) the logic flow from programme inputs, activities, outputs, outcomes and impacts; b) the indicators that will be used to measure the performance and results of the programme outputs, outcomes and impacts; and c) how those indicators will be verified (i.e. the source of information for these measurements).'

Source: UNAIDS. *Rights-based monitoring and evaluation of national HIV responses*.

assumptions about how our interventions will effect change, and to revise our interventions accordingly.

### 2.1 Decide what to measure and which type of indicators, baselines and targets to select

The first step in creating an MEL plan is studying the process of change map and identifying what needs to be measured or monitored (See *Module 2* for examples). An MEL plan can typically include measurement or monitoring components in the following basic categories:<sup>152</sup>

- **Inputs:** Used to perform activities, an input is a resource used in a programme, such as financial and human resources from a variety of sources, and can also include curricula, materials and other resources.
- **Activities:** The actions taken or work performed through which inputs such as funds, technical assistance and other types of resources are mobilised to produce specific outputs.
- **Outputs:** The immediate results of programme activities. This relates to the direct products or deliverables of programme activities, such as the number of counselling sessions completed, the number of people reached, or the number of materials distributed.
- **Outcomes:** The intermediate changes that a programme effects on target audiences or populations, such as change in knowledge, attitudes, beliefs, skills, behaviours, service access, policies and environmental conditions.
- **Impacts:** The cumulative effect of programmes on what they ultimately aim to change over a longer period of time. Often, this effect will be a population-level health outcome, such as a change in HIV infection, morbidity and mortality. Impacts are rarely, if ever, attributable to a single programme, but a programme may, with other programmes, contribute to impacts on a population.

151. UNAIDS (2019), *Rights-Based Monitoring and Evaluation of National HIV Responses*. Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/JC2968\\_rights-based-monitoring-evaluation-national-HIV-responses\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/JC2968_rights-based-monitoring-evaluation-national-HIV-responses_en.pdf).

152. Definitions adapted from: UNAIDS (2019), *Rights-based monitoring and evaluation of national HIV responses*.

In combined programmes, it is important to have measures or indicators that can track progress across each of these levels of change, from outputs to impacts.

## 2.2 Map existing data collection systems to identify opportunities for integration and scale-up

As you develop your MEL plan, it is critically important to consider where human rights and health outcomes can be measured using **existing data collection and analysis**. Your plan should integrate with other local, subnational, national and regional-level data collection, utilising existing indicators and disaggregated data where possible, and adding questions to construct indicators to measure the outcomes of human rights interventions, where appropriate. Integration helps to prevent duplication, reduces resource implications and enables the use of validated indicators that are already being used for data collection in the prevention/treatment context.

In *Breaking Down Barriers* countries, baseline studies have been conducted and data is being collected again at mid-point (2020) and at end-point (2022). In other countries, consider how you can use existing data collection and evaluations to gather baseline data, and ensure that your MEL plan includes a plan to collect mid- and end-point data based on your timeline of implementation and/or scale-up of your programme(s). Collecting data at these three time points allows for analysis of whether human rights-related barriers are being reduced. It also provides a helpful framework for ongoing M&E for sustained implementation after the scale-up process has been completed.

### Some other important considerations include:

- ✓ **Get access to and benefit from technical assistance on MEL**, available from sources such as the Global Fund's *CRG Technical Assistance Program*<sup>153</sup> and the UNAIDS Technical Support Mechanism.
- ✓ **Align your MEL plan with national and global targets and indicators**, for example targets in your country's NSP and indicators in the UNAIDS GAM systems. Avoid, where possible, the development of new indicators.

✓ **Consider how you can align with existing data collection, analysis and reporting**, for example, IBBS, *HIV Stigma Index*, or general population surveys, as well as annual progress reporting to the UNAIDS GAM system.

✓ **Cost and budget for your MEL plan in line with the available budget and other resources**, to ensure it is realistic and deliverable.

✓ **Consider how programme data from health facilities, schools or other sources could be used to measure progress towards your outcomes**. Data is often already collected on, for example, number of HIV tests disaggregated by age and sex, number of early pregnancies, and rates of school dropouts among adolescent girls and young women. Reviewing this data in the geographical area of implementation can allow for proxy measurement of the baseline, and then the impact of your intervention. Short-term implementation is likely to require more programmatic data from other services, while long-term measurement can involve large-scale surveys and targeted data collection over longer timelines.

✓ **Do not forget that progress on the removal of human rights-related barriers can take time**.

Changing stigmatising attitudes, discriminatory behaviour, punitive policies and laws and harmful gender norms are all areas that require long-term investment and commitment to secure change. Use your process of change to determine and measure interim outcomes, while not losing sight of the long-term goals.

## 2.3 Define indicators

Indicators are used to measure change brought about by a programme or intervention. They include output indicators, such as number of people trained or with increased knowledge, and outcome indicators, such as reported attitudes and behaviours. It is important to choose indicators that together measure the changes an intervention has been designed to achieve, while also being realistic that you can collect, disaggregate and evaluate data against them.

The UNAIDS *Rights-based monitoring and evaluation of national HIV responses* includes information about different types of indicators; possible data sources; how indicators can be

153. See Global Fund Community Rights and Gender Technical Assistance Program: [www.theglobalfund.org/en/funding-model/throughout-the-cycle/community-rights-gender-technical-assistance-program/](http://www.theglobalfund.org/en/funding-model/throughout-the-cycle/community-rights-gender-technical-assistance-program/).

selected or developed; guidance to help ensure indicators include all the essential components to be effective; suggested indicators, and indicative data sources for measuring progress in each of the seven human rights programme areas.<sup>154</sup> (See also *Module 2, Unit 5* and *Appendix 2: Suggested indicators for monitoring progress*).

Consider other sources of indicators at the global, regional, national and local levels, such as PEPFAR and national epidemiological monitoring. Utilising existing indicators will allow you to also use existing data collection, and assess where the activities are contributing to national and global targets. This is important to help to avoid duplication.

#### Some other important considerations include:

✓ **Consider the following for each indicator:** What is the indicator definition? What is the baseline value (national or subnational)? What are the source(s) of baseline data and the source(s) of data to be collected, and how should data be disaggregated?

✓ **Wherever possible, include indicators that have been tested and validated with similar populations in similar settings.** Start with indicators that are already being used in the country and/or setting to support integration and to ensure that data can be easily aggregated and compared.

✓ **Include indicators not just about uptake/ access, but also quality of access** – for example, for data captured through service-user feedback mechanisms on health outcomes, collect data on attitudes and behaviours, systems and processes. Some health outcomes could be achieved by stigmatising and punitive approaches, so looking at health outcomes alone is not enough for MEL. Ensure that learning is also captured from community-based monitoring.

✓ **Ensure that indicators capture behaviour change in practice**, as well as changes in knowledge and attitudes.

✓ **Accountability is critical, and the MEL plan should include resources and support for independent civil society monitoring** of scaled-up programmes to remove human rights-related barriers to services. The success of scale-up should be measured in terms of reach, equity, realisation of rights and sustainability.

#### BOX 11: HOW TO ASSESS THE QUALITY OF THE INDICATOR AND THE DATA

Knowing that you can rely on an indicator, and the data that is collected to support it, to give accurate and reliable information is very important when designing an MEL plan. This means making sure that both the indicator and the data meet certain quality considerations. These questions, developed by UNAIDS, can help assess the quality of the indicator and the data:

- Does the indicator have a clearly stated title and definition?
- Does the indicator have a clearly stated purpose and rationale?
- Is the method of measurement for the indicator clearly defined, including the description of the numerator, denominator and calculation (where applicable)?
- Are the data collection methodology and data collection tools for the indicator data clearly stated?
- Is the data collection frequency clearly defined?
- Is any relevant data disaggregation clearly defined?
- Are there guidelines to interpret and use data from this indicator? For human rights indicators, this would include information on how the indicator measures compliance with human rights standards.
- What are the strengths and weaknesses of the indicator and the challenges in its use?
- Are relevant sources of additional information on the indicator cited?
- Has the indicator been field-tested and shown to perform as designed?

✓ **Use implementation outcomes to evaluate scale-up itself.** There is limited evidence on evaluation of scale-up processes, but proposed indicators include: acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability.<sup>155</sup>

154. UNAIDS (2019), 'Rights-Based Monitoring and Evaluation of National HIV Responses'. Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/JC2968\\_rights-based-monitoring-evaluation-national-HIV-responses\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/JC2968_rights-based-monitoring-evaluation-national-HIV-responses_en.pdf)

155. Proctor, E., Silmere, H., Raghavan, R. et al. (2011). 'Outcomes for Implementation Research: Conceptual distinctions, measurement challenges and research agenda', *Administration and Policy in Mental Health and Mental Health Services Research*, Vol 38 (2): pp. 65–76. Available at: <https://doi.org/10.1007/s10488-010-0319-7>

✓ **Do not forget about integration.** One of the benefits of a comprehensive approach is the opportunity to integrate MEL processes. How can data collection be shared safely across different outcomes or interventions to streamline processes and reduce costs? How can you utilise existing data collection and evaluation processes to also assess human rights indicators? Can you add indicators on human rights, quality and access, to existing data collection on uptake or retention? If data is already collected nationally, can you use or influence these processes so that they capture progress in removing human rights barriers? Can data already being collected be disaggregated to evaluate equity?

## 2.4 Collect and use data for monitoring and improvement

Once the indicators have been determined, you need to decide how the data will be collected and stored. What data will need to be collected in order to report against each indicator? If you are relying on data being collected under other processes, how will you access that data? Who will be responsible for collecting each different source of data? Ensure that this process has been appropriately resourced.

Data collection has to be done safely, accurately and thoroughly. That might involve training costs, staffing costs, and data storage costs, which should all be accounted for in the budget. Consider also where data should not be shared outside the organisation responsible for collecting it, for example, where data is sensitive and was shared based on a trusted relationship with the specific organisation collecting it. In such cases, data anonymisation and analysis should sit with the collecting organisation.

Confidentiality and data security must always be the first priority. There is a real risk that data collected in relation to human rights programming could expose people to danger. You have legal and ethical obligations to mitigate this risk. Key considerations include: informed consent for all data collection; upholding the right to self-identification or not in all data collection; ensuring the right to privacy; safeguarding for respondents and staff or volunteers during data collection; secure data storage; confidentiality and anonymity processes, including using unique identifier codes.

The MEL plan should include **quantitative** data (numbers of things such as percentages of people reached with interventions, for example, number of people living with HIV receiving legal services on property and inheritance, travel and employment rights). It should also include **qualitative** data collection and evaluation (text describing changes, for example, changes introduced in legislation regarding drug use), as well as multiple data sources, for example, programme data, community-based monitoring, key informants, surveys and surveillance.

Scale-up is not just about numbers reached, it is also important to measure the quality of services, the impact on individuals, and the perceptions and experiences of people from key and vulnerable populations. Include indicators to measure impact across HIV outcomes, service access, quality, equity, reach and implementation. Think about different ways to collect data. Video interviews with implementers can be effective in capturing diffuse, incremental progress. Peer-led surveys, such as the *HIV Stigma Index*, can reach more people.

Consider how data should be disaggregated to ensure that you measure progress for all groups. Equity is a core measure of success for programming to remove human rights-related barriers to services, so collect and disaggregate data by sex, gender, age, key and vulnerable population status, rural/urban divide, wealth quintile and education levels. In addition, it is important to recognise that people hold multiple identities, so data should be analysed recognising intersections and multiple discrimination.

Include community-based monitoring and documenting processes, such as REAct, in data collection plans. Large-scale surveys and mid- and end-point assessments are important, but so is programme monitoring and ongoing data collection that reveals progress and challenges in real-time. This allows you to make adjustments and improve activities and systems as implementation progresses.

The MEL plan should also be clear on who is responsible for collecting, collating and analysing data, thinking about how different stakeholders and organisations can collaborate effectively so as to

utilise their different strengths. These activities could be integrated within a national M&E system. Involving CBOs in collecting and storing data protects key and vulnerable populations in situations where there is a danger that data may be misused. You could consider using a larger NGO to take responsibility for data storage and anonymisation, or an academic partner could provide technical assistance on analysis.

**Some other important considerations include:**

✓ **Do not plan the MEL separately from the budget.** The MEL plan should be fully and realistically costed and included in the budget from the outset – not forgetting the cost involved in collecting data.

✓ **Allow for local innovation and leadership in the MEL plan.** Different community groups or networks may do things a little differently to best reach and engage the people they serve.

✓ **Ensure that the MEL processes include meaningful participation** of people from key and vulnerable populations, and promote transparency, accountability and non-discrimination. Every part of the scale-up plan should uphold human rights principles.

✓ **Consider using a case study approach to document scale-up.** There is a lot to learn from efforts to scale up programming to remove human rights-related barriers to services, and little evidence is currently documented. See the resource, *20 questions for developing a scaling up case study* for more guidance on how to do this.

**ADDITIONAL RESOURCES**

- **ALIV(H)E Framework** – Salamander Trust, Athena, UNAIDS et al. – See Part 3 on guidance for tracking progress using community-led accountability mechanisms.<sup>156</sup>
- **Rights-based monitoring and evaluation of national HIV responses** – UNAIDS.<sup>157</sup>
- **Global AIDS Monitoring 2019: Indicators for the monitoring of the 2016 United Declaration on Ending AIDS** – UNAIDS.<sup>158</sup>
- **Human Rights Indicators: A guide to measurement and implementation** – OHCHR.<sup>159</sup>
- **A human rights based approach to data – Leaving no one behind in the 2030 Agenda for Sustainable Development** – OHCHR.<sup>160</sup>
- **Defining rights-based indicators for HIV epidemic transition** – Amon et al.<sup>161</sup>
- **Guide for monitoring scale-up of health practices and interventions** – Measure Evaluation.<sup>162</sup>
- **Basic terminology and frameworks for monitoring and evaluation** – UNAIDS.<sup>163</sup>
- **Strengthening Monitoring and Evaluation: 13 Insights for Women's Organizations** – Association for Women's Rights in Development (AWID).<sup>164</sup>
- **Strengthening Monitoring and Evaluation for Women's Rights: 12 Insights for Donors** – AWID.<sup>165</sup>
- **20 questions for developing a scaling up case study** – MSI, ExpandNet and WHO.<sup>166</sup>

156. Salamander Trust, Athena, UNAIDS, AIDS Legal Network, Project Empower, HEARD and University of KwaZulu-Natal (2017), 'Action Linking Initiatives on Violence Against Women and HIV Everywhere, ALIV(H)E framework'. Available at: [www.unaids.org/en/resources/documents/2017/ALIVHE\\_Framework](http://www.unaids.org/en/resources/documents/2017/ALIVHE_Framework).

157. UNAIDS (2019), 'Rights-Based Monitoring and Evaluation of National HIV Responses'. Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/media\\_asset/JC2968\\_rights-based-monitoring-evaluation-national-hiv-responses\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/JC2968_rights-based-monitoring-evaluation-national-hiv-responses_en.pdf).

158. UNAIDS (2019), 'Global AIDS Monitoring 2020 – Indicators for monitoring the 2016 Political Declaration on Ending AIDS'. Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2019/Global-AIDS-Monitoring](http://www.unaids.org/en/resources/documents/2019/Global-AIDS-Monitoring).

159. OHCHR (2012), 'Human Rights Indicators: A Guide to Measurement and Implementation', New York: OHCHR. Available at: [www.ohchr.org/EN/Issues/Indicators/Pages/documents.aspx](http://www.ohchr.org/EN/Issues/Indicators/Pages/documents.aspx).

160. OHCHR (2018) 'A human rights based approach to data – Leaving no one behind in the 2030 Agenda for Sustainable Development'. Available at: [www.ohchr.org/EN/Issues/Indicators/Pages/documents.aspx](http://www.ohchr.org/EN/Issues/Indicators/Pages/documents.aspx).

161. Amon J.J., Eba P., Sprague L., Edwards O. and Beyrer C. (2018), 'Defining rights-based indicators for HIV epidemic transition'. *PLoS Med* 15 (12): e1002720. Available at: [www.ncbi.nlm.nih.gov/pmc/articles/PMC6303010/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC6303010/).

162. Adamou B., Curran J., Wilson L., Apenem Dagadu N., Jennings V., Lundgren R., Kiesel R. and Hardee K. (2013), 'Guide for Monitoring Scale-up of Health Practices and Interventions', MEASURE Evaluation. Available at: [www.measureevaluation.org/resources/publications/ms13-64](http://www.measureevaluation.org/resources/publications/ms13-64).

163. UNAIDS (2008), 'Basic terminology and frameworks for monitoring and evaluation', Geneva: UNAIDS. Available at: [www.unaids.org/sites/default/files/sub\\_landing/files/7\\_1-Basic-Terminology-and-Frameworks-MEF.pdf](http://www.unaids.org/sites/default/files/sub_landing/files/7_1-Basic-Terminology-and-Frameworks-MEF.pdf).

164. Srilatha Batliwala (2011), 'Strengthening Monitoring and Evaluation: 13 Insights for Women's Organizations'. Toronto: AWID. Available at: [www.awid.org/publications/strengthening-monitoring-and-evaluation-13-insights-womens-organizations](http://www.awid.org/publications/strengthening-monitoring-and-evaluation-13-insights-womens-organizations).

165. Srilatha Batliwala (2011), 'Strengthening Monitoring and Evaluation for Women's Rights: 12 Insights for Donors'. Toronto: AWID. Available at: [www.awid.org/publications/strengthening-monitoring-and-evaluation-womens-rights-12-insights-donors](http://www.awid.org/publications/strengthening-monitoring-and-evaluation-womens-rights-12-insights-donors).

166. MSI, ExpandNet and WHO (2007), '20 Questions for Developing a Scaling Up Case Study'. London: MSI, ExpandNet and Geneva: WHO. Available at: <https://expandnet.net/PDFs/MSI-ExpandNet-IBP Case Study 20 case study questions.pdf>.

## Step 3: Cost the scale-up plan and mobilise resources

As part of the planning and preparation for scale-up, it is important to think through costing and budgeting, and mobilising technical, human and operational resources.

### 3.1 Determine costs and budget

Costing and budgeting accurately and effectively is vital to the success of the scale-up plan. Costing human rights programmes can be challenging. Some initial guidance is given in this section. However, to ensure robust costing, it is strongly recommended to seek someone with sufficient technical expertise, for example in national health accounts. You need to assess the detailed costs of each intervention and activity to develop a comprehensive budget. It is also important to estimate the level of investment needed to implement comprehensive programmes to remove human rights-related barriers in order to advocate for increased funding and national budget allocations.

Sometimes, budgeting is done separately to the planning of activities, and led by consultants or staff with no role in developing the programme. This does not ensure effective linkages between the planned activities and the resources mobilised to implement them. Instead, include those involved in developing the scale-up plan in the costing and budgeting, alongside people with the specific expertise this activity requires. Programme, M&E and finance staff should all be involved. Specialist technical assistance may also be beneficial to support the process and provide additional expertise.

✓ **Align costing and budgeting** with the process of change and each step of developing the scale-up plan. It is critically important that inputs are linked to planned activities and interventions and desired outcomes. Distinguishing between unit costs and overall costs is important to ensure the accuracy of the budgeting process.

✓ **Evaluate all the resources** – human, material and other – involved in delivering a service, costing each element and developing a detailed budget that reflects the level and type of resources needed to deliver an effective service at scale.

✓ **Find efficiencies** through integration with existing programmes. Think about how the costs of activities can be integrated into existing prevention, treatment and key population programmes, for example, through sharing staff or premises.

✓ **Focus on developing budgets for specific programmes and grants.**<sup>167</sup> A national-level budget for programming to remove human rights-related barriers to services overall may eventually be developed, once scale-up is achieved and programmes to remove human rights-related barriers are recognised as integral parts of national plans.

If necessary, particularly where resources are very limited, go through a **prioritisation exercise** and identify critical areas of focus, or things that should be done immediately, and other activities that could be deferred while additional resource mobilisation takes place. **It is important in this situation to focus on implementing a set of focused interventions at scale, rather than a larger set of activities that do not have enough financial resources behind them to achieve scale and impact.**

### 3.2 Map current investments and determine the resource gap

Learning from the *Breaking Down Barriers* experience provides invaluable insights for the costing process and can be applied in other settings:

✓ **Estimate the total amount invested in relevant programmes** that address human rights-related barriers to accessing health services, a process also referred to as 'financial mapping'. This mapping is for the country as a whole and should include all major sources of funding.

167. UNAIDS (2012), 'Human Rights Costing Tool', Geneva: UNAIDS. Available at: [www.unaids.org/en/media/unaids/contentassets/documents/data-and-analysis/tools/The\\_Human\\_Rights\\_Costing\\_Tool\\_v\\_1\\_5\\_May-2012.xlsm](http://www.unaids.org/en/media/unaids/contentassets/documents/data-and-analysis/tools/The_Human_Rights_Costing_Tool_v_1_5_May-2012.xlsm). See pp. 7-8 on costing approaches.

✓ **Determine and calculate, where possible, the cost per unit of output** for effective interventions in order to facilitate and inform prospective resource estimation of a comprehensive package of services during this 'prospective costing'.

✓ **Collect input costs during interviews**, which may be useful for prospective costing, for example, the cost of a peer educator, accommodation, travel, *per diem* and salaries for NGO staff working on relevant activities, and venue hire.

Gathering information on the costs of programmes and interventions can be challenging, as sometimes governments, donors and implementing organisations may be reluctant to share it. It is therefore important to ensure that all parties understand how the costing data will be used, and reassure them that data will be anonymised before being shared. Ensure also that adequate time and resources are allocated for this process.

Based on this information, you can extract data on the total resources invested, input costs for selected activities, and cost per unit for effective interventions. Based on the scale-up plan, do the prospective costing using output unit costs (adapted where needed) developed from retrospective costing. Ensure that the costing accounts for inflation.

It is also important to budget for stakeholder consultations, including the meaningful participation of key and vulnerable groups in the planning, implementation, monitoring and evaluation of activities and programmes. This includes ensuring that you budget for meetings of representatives from community-led organisations, networks of key populations, women's rights organisations, and organisations specialising in HIV-related human rights. Associated costs might include staff and volunteer time, venue hire, transport and other expenses linked to community consultations.

#### Some other important considerations include:

- **Core costs of delivering the activity:** e.g. office rent, equipment, utilities, insurance, supplies, computer software and hardware, communication costs
- **Management or coordination costs:** e.g. managers, administrators, qualifications and experience needed of staff, recruitment costs, salary costs, training, governance, travel costs for governance or management, costs to support meaningful participation of key and vulnerable populations
- **Programme delivery staff costs:** e.g. staff needed, salary costs, training

#### ADDITIONAL RESOURCES

- **Human Rights Costing Tool (HRCT): Costing programmes to reduce stigma and discrimination and increase access to justice in the context of HIV** – UNAIDS – this tool is a system of live Excel spreadsheets (requires Microsoft Office). It is based on the seven programme areas and supports detailed activity-costing for related programmes. It focuses on costing at the service provider and district level, and can also support national-level costing and budgeting.<sup>168</sup>
- **User guide for the HIV-related human rights costing tool** – UNAIDS – This guide takes you through the process of using the HRCT.<sup>169</sup>
- **A guide to costing human rights** – Equal in Rights.<sup>170</sup>
- **Baseline assessments of human rights-related barriers to services** – Global Fund.<sup>171</sup>
- **Costing methods and results** – WHO website provides further useful resources.<sup>172</sup>

168. UNAIDS (2012), 'Human Rights Costing Tool', Geneva: UNAIDS. Available at: [www.unaids.org/en/media/unaids/contentassets/documents/data-and-analysis/tools/The\\_Human\\_Rights\\_Costing\\_Tool\\_v\\_1\\_5\\_May-2012.xlsm](http://www.unaids.org/en/media/unaids/contentassets/documents/data-and-analysis/tools/The_Human_Rights_Costing_Tool_v_1_5_May-2012.xlsm). See pp. 7-8 on costing approaches.

169. UNAIDS (2012) 'The user guide for the HIV-related human rights costing tool', Geneva: UNAIDS. Available at: [http://files.unaids.org/en/media/unaids/contentassets/documents/document/2012/The\\_HRCT\\_User\\_Guide\\_FINAL\\_2012-07-09.pdf](http://files.unaids.org/en/media/unaids/contentassets/documents/document/2012/The_HRCT_User_Guide_FINAL_2012-07-09.pdf).

170. Equal in Rights (2011), 'A guide to costing human rights', The Hague: Equal in Rights. Available at: <https://resourcecentre.savethechildren.net/library/guide-costing-human-rights>.

171. Global Fund Baseline Assessments. Available at: [www.theglobalfund.org/en/publications/](http://www.theglobalfund.org/en/publications/).

172. See WHO website: [www.who.int/choice/documents/costing\\_methods/en/](http://www.who.int/choice/documents/costing_methods/en/)

- **Direct costs of the service or activity:** e.g. costs for each element of the activity or service, how many people will be reached, volunteer costs, travel, outreach, communication, venue, refreshments, materials/supplies
- **Communication costs** for promotion of the service, advocacy, education or campaigning: e.g. design, printing, online distribution, physical distribution, research, website design/development/maintenance and advertising
- **Technical assistance:** e.g. what technical assistance might be beneficial for the activity, what is available, whether there are costs involved
- **Monitoring, evaluation and learning costs:** e.g. the costs involved in implementing the MEL plan, including ensuring meaningful participation.

### 3.3 Develop a resource mobilisation plan

It is very likely that even cost-efficient human rights programmes will have some resource gaps.

While country grant requests to the Global Fund have started to pay more attention to understanding the rights-related barriers impeding access to services, this often has not translated into greater funding.<sup>173</sup> Data from the UNAIDS *Global AIDS Response Progress Reporting* (GARPR) from 2015 shows that 0.13% of total AIDS spending reported to UNAIDS by low- and middle-income countries is allocated for human rights-related programming.<sup>174</sup>

The Global Fund's *Sustainability, Transition and Co-financing Policy* now requires all countries, regardless of income level, to include programmes to address

these barriers in their proposals. In addition, the *Breaking Down Barriers* initiative provides intensive investment to select countries and seeks to incentivise governments to commit larger portions of their grant allocations to human rights programmes.

Funding from the Global Fund and other donors goes a long way to supporting human rights programming. However, in the context of declining external funding and countries' increasing efforts to transition out of dependency on external funding, resource mobilisation plans need to target local investment, primarily through fiscal resources, and private sector funding.

Your resource mobilisation plan should involve communities most affected by rights-related barriers to services and the civil society efforts that serve them. They are a rich resource of information about best practices in human rights programming, and might have unpublished data that demonstrates both value for money and the public health impact of human rights programming

To increase domestic investment, both from government and private sectors, it is critical to meaningfully involve influential government and private sector stakeholders from the preliminary stages of programme design. It is important to demonstrate to them, not only best practices in human rights programming, but how this translates into improving HIV-related health outcomes and value-for-money. This will provide motivation for these stakeholders to invest and to prioritise support for human rights-related programming more systemically.

#### ADDITIONAL RESOURCE

**Raising Funds and Mobilising Resources for HIV/AIDS work: A Toolkit to Support NGOs and CBOs** – Frontline AIDS.<sup>175</sup>

173. The Global Fund, 'The Technical Review Panel's Observations on the 2017-2019 Allocation Cycle', October 2019, Geneva. Available at: [www.theglobalfund.org/media/8965/trp\\_2017-2019observations\\_report\\_en.pdf?u=637165999800000000](http://www.theglobalfund.org/media/8965/trp_2017-2019observations_report_en.pdf?u=637165999800000000)

174. Data for GARPR Indicator 6.1 on AIDS spending for countries who have submitted expenditure data at least once within the past five years, by last available year, UNAIDS.

175. Frontline AIDS (2003), 'Raising Funds and Mobilising Resources for HIV/AIDS work: A Toolkit to Support NGOs/CBOs', Brighton: IHAA. Available at: [www.who.int/hiv/topics/vct/sw\\_toolkit/raising\\_funds\\_mobilising\\_resources\\_work\\_full\\_version.pdf](http://www.who.int/hiv/topics/vct/sw_toolkit/raising_funds_mobilising_resources_work_full_version.pdf)



## Step 4: Implement the scale-up plan

You are now ready for the final step of this process – implementing the scale-up plan. Having assessed the potential for scale-up and developed the scale-up plan, including the MEL framework and budget, it is now time to put the plan into action.

Implementing at scale is a long-term activity, and should be informed by ongoing evaluation and learning, as well as accountability processes. Be ready to identify challenges or unexpected issues; to make adjustments as implementation moves forward, and to use the monitoring data to constantly improve. The results of scaling up can be unpredictable, especially in a relatively new area like programming to remove human rights-related barriers to HIV services. Learn, adapt and improve as the scale-up process moves forward.

### 4.1 Put in place implementation structures

Define clear roles and responsibilities for all stakeholders. The good practice checklist in *Table 19* can be used to assess your own contributions to scale-up efforts, and as an advocacy tool to influence key stakeholders to fulfil their roles effectively.

### 4.2 Address technical and operational capacity needs

*Step 1.3* of this unit described assessing the capacity-of potential implementers, including identifying needs and capacity-development strategies. These strategies now need to be implemented. It is good practice to include components on monitoring the results of the capacity development in the MEL plan. The MEL plan can also help to identify emerging capacity development needs as the scale-up plan moves forward.

### 4.3 Monitor, evaluate and learn

Throughout implementation of the scale-up plan, it is important to track and report progress, prioritising learning and making adjustments to improve implementation throughout. Evaluation should be ongoing – think about regular updates and reviews and scheduling these alongside budget reviews or mid-term reviews, for example. Do not wait until the end to evaluate and develop recommendations for others: evaluate throughout implementation, so you are able to implement those recommendations in your programming. Community-based monitoring systems provide important data to guide learning and implementation on an ongoing basis.

There are plenty of examples of scaled-up programmes to remove human rights-related barriers that offer insights. The lessons learned in the examples on page 105 will help you think through some potential questions or challenges. You can also draw on your national, regional and global networks to learn more from practical experience.

“ M&E of any of these interventions is not easy because there are very long causal pathways between any individual activity and ultimate decriminalisation, and a million other factors play into whether or not legal change ultimately occurs.”

Allan Maleche, Executive Director, KELIN<sup>176</sup>

<sup>176</sup> Presentation at UNAIDS consultation on target setting and estimation of impact and resource needs for social enablers, 20 June, 2019.

Table 19: Recommendations and good practice for stakeholder relationships in the scale-up process

STAKEHOLDER	RECOMMENDATION	GOOD PRACTICE CHECKLIST
<b>Implementing organisations</b>	Ensure integration and accountability for a comprehensive response	<ul style="list-style-type: none"> <li>Do these organisations ensure a transparent and accountable relationship with other stakeholders, especially those that are community-based?</li> <li>Does a clear MoU exist, outlining the role of the organisation and others in the partnership?</li> <li>Are there mechanisms through which other stakeholders can hold the organisation to account?</li> </ul>
<b>CBOs, groups and networks (also implementing)</b>	Build in full community engagement for transformation, sustainability and accountability	<ul style="list-style-type: none"> <li>Does financial, technical and institutional assistance reach these organisations – including those unable to formalise, or who do not want to?</li> <li>Are community responses balanced with the fund-management needs of donors?</li> </ul>
<b>Technical assistance providers</b>	Create multi-way relationships for learning and capacity-building	<ul style="list-style-type: none"> <li>Will larger or international organisations learn from and collaborate with smaller local ones?</li> <li>Will small organisations benefit from technical assistance that meets their priorities?</li> <li>Is this relationship flexible, inclusive, responsive and equal?</li> </ul>
<b>Donors</b>	Develop flexible and inclusive processes for impact and accountability	<ul style="list-style-type: none"> <li>Does the donor support initiatives that are driven by community agendas?</li> <li>Can communities hold the donor to account?</li> </ul>
<b>Government</b>	Encourage government buy-in, essential for protecting, promoting and fulfilling human rights, but also for integration, sustainability and domestic funding	<ul style="list-style-type: none"> <li>Is the government effectively engaged as a partner?</li> <li>Is there a strategy to manage this relationship when a government or members of it are against changes to legal or social norms?</li> </ul>
<b>Regional partnership</b>	Strategise in a safe place for strengthening scale-up and wider impact	<ul style="list-style-type: none"> <li>Are networks in place to support learning and sharing from other experiences in the region?</li> <li>Is this role clear in relation to national stakeholders?</li> </ul>
<b>National or district coordination</b>	Ensure inclusive and representative leadership for effective scale-up	<ul style="list-style-type: none"> <li>Does the steering group ensure accountability between stakeholders?</li> <li>Does the steering group ensure that all relevant stakeholders are linked and engaged?</li> <li>Is their role clearly defined?</li> <li>Is there a safe space to discuss and plan around sensitive issues?</li> </ul>
<b>Community of practice</b>	Promote peer learning and sharing of good practice for sustainability and reflective practice	<ul style="list-style-type: none"> <li>Are different stakeholders included?</li> <li>What mechanisms are in place to ensure learning can be shared effectively with all relevant stakeholders?</li> </ul>

## LESSONS FROM PRACTICE

**BONELA, BOTSWANA**

Implementing programmes to address human rights-related barriers to services at scale can be effective by working with a combined approach (across all programme areas) and inclusively (from the grassroots up) in a concentrated geographical area. BONELA works to integrate an ethical, legal and human rights approach to Botswana's HIV response. As part of its scale-up, BONELA has focused on four to five provinces, ensuring that it works comprehensively across programme areas in partnership with communities, CBOs, networks and authorities, and amplifying this work at national level – and this has worked well. BONELA warns against diluting impact by trying to cover every geographical area.

Community-based and grassroots organisations and networks of people from key and vulnerable

populations are vital to a successful response. Even if they are not formally registered or do not have strong financial budget monitoring, management, and organisational structures and capacity, they must be involved. Part of the process should be to support their development so that their systems and processes can better facilitate their human rights work. BONELA's experience (with funding from ARASA and the International Treatment Preparedness Coalition; long-term funding from the Global Fund's CRG Technical Assistance Program; and Frontline AIDS' Community Capacity Fund) shows this can work well and ultimately lead to such organisations developing the capacity to take on Global Fund Sub-recipient and Sub-sub-recipient status themselves. Specific and deliberate resources need to continue to be allocated for this.

For more information on BONELA, see: <https://bonela.org>

## LESSONS FROM PRACTICE

**AVAHAN, INDIA**

The *Avahan* initiative in India – funded by the Bill & Melinda Gates Foundation – aimed to reduce HIV transmission and the prevalence of sexually transmitted infections in vulnerable populations, notably female sex workers, men who have sex with men, and transgender people, through:

- Prevention education and services such as community mobilisation
- Legal literacy
- Condom promotion
- Management of sexually transmitted infections
- Behaviour change communication and advocacy.

*Avahan* was inspired by the work of the Durbar Mahila Samanwaya Committee sex workers' collective in the Sonagachi neighbourhood of

Kolkata, India. The programme was scaled up and transitioned to government-led status. In the process, some key elements of the intervention were neglected, in particular, the central importance of community mobilisation and support for community activities, which are crucial to ensure that community members are aware of their rights and get support for securing them.

An evaluation found that one year after transitioning to government leadership, changes in the programme were mostly perceived as positive; however, negative changes were also identified. These included funding delays, stock-outs of commodities, and community perceptions that the programme focus had narrowed too much. This highlights the importance, when scaling up, of both ensuring that programme funding and delivery are maintained through scale-up, as well as maintaining and prioritising the elements of a programme that have been key to its effectiveness and community acceptance.

## CONCLUSION

This guide has sought to provide practical guidance to all those involved in the planning and implementation of a comprehensive response to human rights-related barriers to HIV-related services. It comes at a crucial time when new opportunities are available through unprecedented funding and political commitment.

The guide has taken implementers through the stages of **understanding**, **designing** and **delivering** programmes **at scale** to most impact the aspects of the HIV epidemic that have so far eluded the response – reaching those most vulnerable and marginalised with critical HIV prevention and treatment services.

The programmes described in this guide are essential to the success of any national AIDS response, and will go a long way towards achieving global and national targets, as well as the Sustainable Development Goals and universal health coverage. States have committed to implementing these programmes, and members of key and vulnerable populations remain in need of them.

Now is the time to establish comprehensive and strategic programmes at scale that will ensure maximum value and impact in national, regional and global responses to HIV. Only by doing so will we ensure no one is left behind, as we work towards ending AIDS.



## APPENDIX 1: SCALE-UP PLANNING CHECKLIST TEMPLATE

QUESTIONS	ANSWERS	DONE
1. What is the barrier to be addressed?		<input type="checkbox"/>
2. What interventions are needed to address the barrier?		<input type="checkbox"/>
3. Who can help to remove the barrier? Who could be involved in removing it? Who is already an ally, and who might present an obstacle?		<input type="checkbox"/>
4. Which existing activities are addressing this barrier? Which organisations are delivering these activities?		<input type="checkbox"/>
5. Which additional activities are needed?		<input type="checkbox"/>
6. Who are the best people, networks and organisations to involve in this additional activity? What collaborations and partnerships are possible?		<input type="checkbox"/>
7. How can this activity be combined with activities to address other programme areas?		<input type="checkbox"/>
8. How can the additional activity be integrated into current programmes, plans or strategies?		<input type="checkbox"/>
9. How can this be delivered at scale? Can it reach other geographical areas? Can it reach other key and vulnerable populations?		<input type="checkbox"/>
10. What specific expertise is needed to implement this activity at scale? Is more support needed to build the required expertise?		<input type="checkbox"/>
11. What technical assistance might be helpful? How can this be accessed?		<input type="checkbox"/>

## APPENDIX 2: SUGGESTED INDICATORS FOR MONITORING PROGRESS IN REMOVING HUMAN RIGHTS-RELATED BARRIERS TO HIV SERVICES

PROGRAMME AREA	EXAMPLE OUTPUT INDICATORS	EXAMPLE OUTCOME INDICATORS
<b>1. Reduction of HIV-related stigma and discrimination</b>	<ul style="list-style-type: none"> <li>● Number and coverage of campaigns (TV, radio, newspaper) at the national and community levels to reduce HIV-related stigma and discrimination among the general population</li> <li>● Number of times stigma is measured among people living with HIV (<i>HIV Stigma Index</i>) and in communities</li> <li>● Number of community dialogues held on stigma and discrimination</li> <li>● Number of anti-discrimination policies developed in education, workplace sector</li> </ul>	<ul style="list-style-type: none"> <li>● Percentage of people with correct knowledge of how HIV is transmitted, disaggregated by age and sex (<i>population-based surveys and IBBS surveys</i>)</li> <li>● Percentage of people reporting fear of HIV transmission through casual contact with people living with HIV (<i>population-based surveys</i>)</li> <li>● Percentage of people reporting discriminatory attitudes towards people living with HIV, disaggregated by age and sex (<i>population-based surveys</i>)</li> <li>● Percentage of people who report negative individual-level and population-level manifestations of HIV-related stigma (<i>population-based surveys</i>)</li> <li>● Percentage of people living with HIV reporting discrimination in community settings, disaggregated by age and sex (<i>HIV Stigma Index</i>)</li> <li>● Percentage of key populations reporting discriminatory attitudes, disaggregated by age and sex (<i>IBBS surveys</i>)</li> <li>● Percentage of key populations who reported physical violence in the last 12 months because someone believed they were members of a key population group (<i>IBBS surveys</i>)</li> </ul>

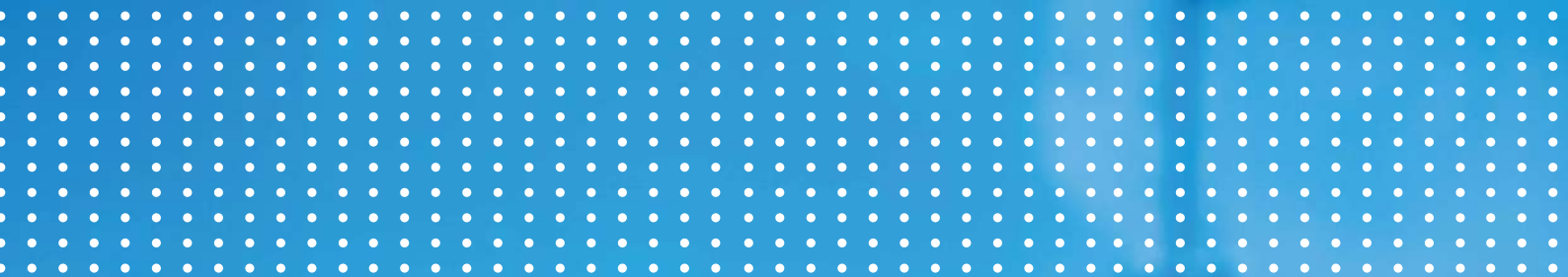
PROGRAMME AREA	EXAMPLE OUTPUT INDICATORS	EXAMPLE OUTCOME INDICATORS
<b>2. Training healthcare providers on human rights and medical ethics</b>	<ul style="list-style-type: none"> <li>● Number and coverage of programmes to train and sensitise healthcare providers on non-discrimination, confidentiality and informed consent</li> <li>● Whether curriculum for healthcare worker training has been revised</li> <li>● Number of medical training facilities where training on human rights and medical ethics has been incorporated into pre-service curriculum</li> <li>● Whether a Patients'-Rights Charter has been developed nationally and/or regionally</li> </ul>	<ul style="list-style-type: none"> <li>● Mechanisms in place to record and address cases of HIV-related discrimination (<i>NCPi</i>)</li> <li>● Percentage of healthcare facilities with policies that protect the health and safety of healthcare workers (<i>surveys among healthcare staff</i>)</li> <li>● Percentage of healthcare facilities with policies to prevent discrimination against people living with and vulnerable to HIV (<i>surveys among healthcare staff</i>)</li> <li>● Percentage of people living with HIV reporting discrimination in healthcare settings, disaggregated by age and sex (<i>HIV Stigma Index</i>)</li> <li>● Percentage of key populations citing fear of stigma as a reason to avoid seeking healthcare (<i>IBBS surveys</i>)</li> <li>● Percentage of healthcare staff reporting observed unjust treatment of patients living with HIV in their facility in the past 12 months (<i>surveys among healthcare staff</i>)</li> </ul>
<b>3. Sensitisation of law-makers and law-enforcement agents</b>	<ul style="list-style-type: none"> <li>● Number and coverage of programmes to sensitise law-makers and law-enforcement officers on the human rights of people living with or affected by HIV, sex workers, gay men and other men who have sex with men, transgender people, and people who inject drugs in the context of HIV</li> <li>● Number of sensitisation sessions held on HIV and human rights in the past 12 months (disaggregated by target audience)</li> <li>● Number of joint activities funded and implemented between police and CBOs/ networks of key and vulnerable populations</li> </ul>	<ul style="list-style-type: none"> <li>● Percentage of key populations reporting having experienced physical violence who identified police as the perpetrator(s) (<i>IBBS surveys, community-based monitoring</i>)</li> </ul>

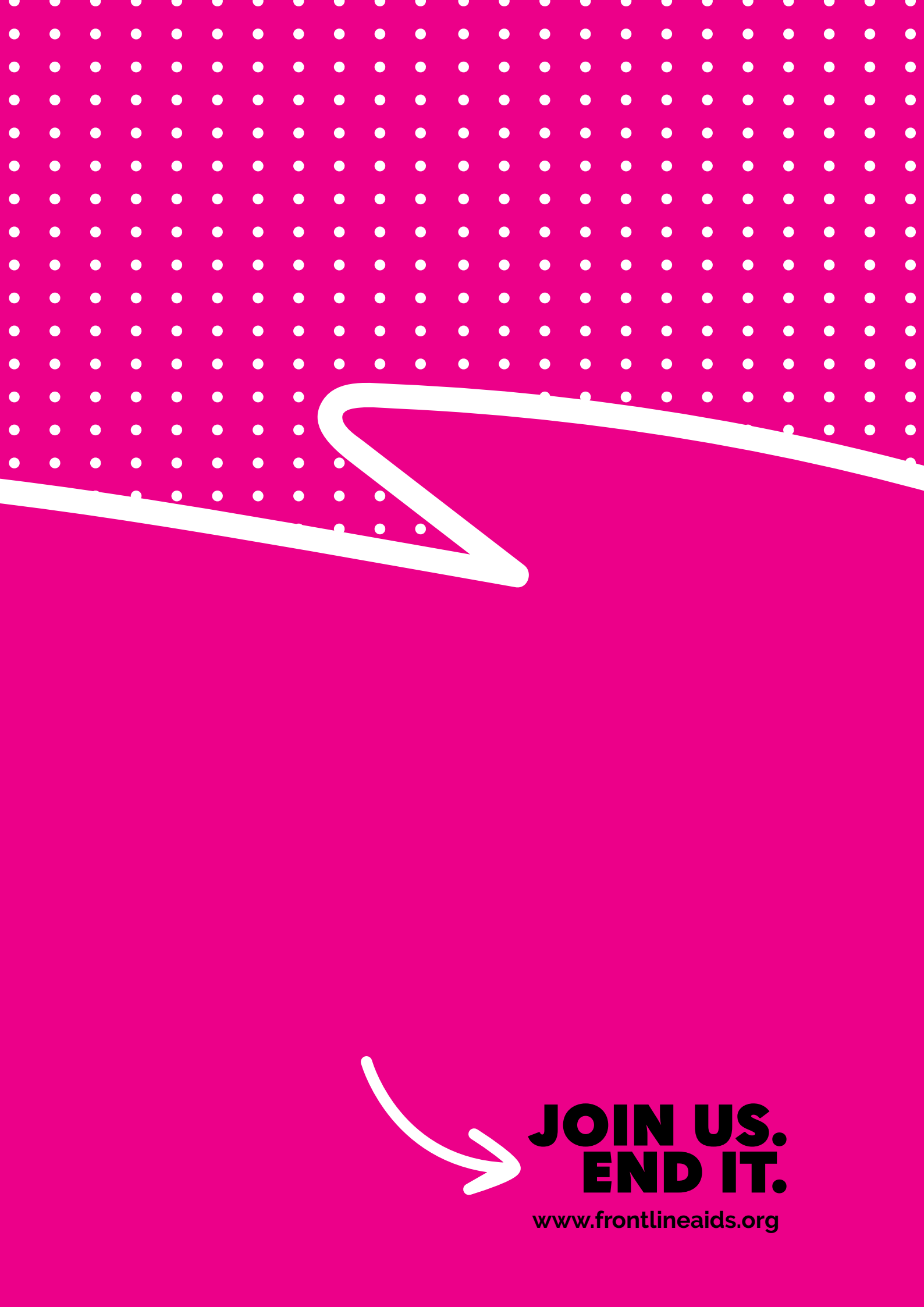
PROGRAMME AREA	EXAMPLE OUTPUT INDICATORS	EXAMPLE OUTCOME INDICATORS
<b>4. Reducing discrimination against women and girls in the context of HIV</b>	<ul style="list-style-type: none"> <li>● Number of women and adolescent peer human rights educators trained and deployed</li> <li>● Number of education sessions about women's rights and gender equality in the context of HIV</li> <li>● Number of women and adolescent girls reached by education sessions about women's rights and gender equality</li> <li>● Number of primary healthcare facilities with functioning referral systems for survivors of GBV</li> <li>● Number of capacity-building sessions held with traditional and religious leaders on the issue of women's rights and gender equality in the context of HIV</li> </ul>	<ul style="list-style-type: none"> <li>● Existence of policies and laws relating to gender inequality and violence that impact HIV vulnerability for women and girls (policies and laws on early marriage, age of consent, girls' education, property and custody rights, marital rape, intimate partner violence, female genital mutilation and protection from forced sterilisation) (<i>LEA and/or gender assessments</i>)</li> <li>● Percentage of ever-married or partnered women (aged 15–49 years) who experienced physical and/or sexual violence by a current or former intimate partner in the last 12 months (<i>population-based surveys</i>)</li> <li>● Percentage of women (aged 15–49 years) who experienced sexual violence by persons other than an intimate partner since age 15 (<i>population-based surveys</i>)</li> <li>● Percentage of girls (aged 15–19 years) who report experiencing forced sexual intercourse or any other forced sexual acts, by age at first incident of violence (<i>population-based surveys</i>)</li> </ul>
<b>5. Legal literacy ('know your rights')</b>	<ul style="list-style-type: none"> <li>● Number and coverage of programmes to inform and educate individuals about their rights within the context of HIV</li> <li>● Amount of materials on rights and legal literacy distributed</li> <li>● Number of peer outreach sessions conducted</li> <li>● Number of peer human rights educators trained and deployed</li> <li>● Number of hotline calls received and number of referrals made to legal services</li> <li>● Number of cases of HIV-related discrimination received</li> </ul>	<ul style="list-style-type: none"> <li>● Knowledge of HIV-related rights among people living with HIV and key populations (<i>programme data</i>)</li> <li>● Percentage of people living with HIV who sought redress when their rights were violated (<i>HIV Stigma Index</i>).</li> </ul>



PROGRAMME AREA	EXAMPLE OUTPUT INDICATORS	EXAMPLE OUTCOME INDICATORS
<b>6. HIV-related legal services</b>	<ul style="list-style-type: none"> <li>● Number of training sessions held to incorporate HIV into existing general legal aid services</li> <li>● Number of individuals provided with training</li> <li>● Number of community paralegals recruited, trained and deployed</li> <li>● Number of referrals for legal support or advice services for people living with HIV and other affected populations</li> <li>● Number of cases taken to judicial process</li> <li>● Number of people using legal support services</li> </ul>	<ul style="list-style-type: none"> <li>● Knowledge among key populations of their rights and available redress (<i>programme data</i>)</li> <li>● Number and percentage of referred cases satisfactorily resolved (<i>programme data</i>)</li> <li>● Percentage of people living with HIV who sought redress when their rights were violated in the past 12 months (<i>HIV Stigma Index</i>)</li> </ul>
<b>7. Monitoring and reforming laws, regulations and policies relating to HIV</b>	<ul style="list-style-type: none"> <li>● LEAs or legal audits and desk reviews completed and disseminated to key stakeholders</li> <li>● Number of engagements on relevant issues with parliamentarians and ministers of government departments</li> </ul>	<ul style="list-style-type: none"> <li>● Existence of non-discrimination laws that specify protections for key populations and people living with and affected by HIV (<i>legal and policy documents, LEAs</i>).</li> <li>● Existence of laws and/or policies that present barriers to the delivery of HIV prevention, testing and treatment services or the accessibility of these services (<i>legal and policy documents, LEAs</i>).</li> <li>● Awareness of human rights standards and international guidelines among law-makers, law-enforcement agents and members of the judiciary (<i>programme data</i>)</li> </ul>







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