

# PANCAP Stigma Reduction Framework for HIV and AIDS: National Actions to Reduce HIV-Related Stigma & Discrimination and Improve Health Outcomes

## Understanding Stigma and Discrimination

Stigma and discrimination (S&D) are neither new, nor specific to HIV. Throughout history, prejudice and intolerance have been present in many forms, including racism, sexism, and social economic privilege or social rejection. Stigma refers to the categorizing and labeling as undesirable and is a process of discrediting other human beings. This process leads to discrimination: actions of unfair or inequitable treatment. In many cases, discrimination is a process of denying basic human rights—from rights to health, care, and information to protection from harm. Unjust treatment and social disdain, moreover, can lead to internalized stigma and destroyed self-confidence, as well as further negative self-perception and isolation, avoidance, and denial. This can be especially true among marginalized groups and individuals.

All of these consequences can and often do lead to higher vulnerability to HIV infection and lower uptake of health services, including testing and treatment. The effects of stigma and discrimination on HIV prevention, care, and treatment are clear. For example, given recent advances in HIV treatment, many thought that the prevention of mother-to-child transmission would be a relatively easy success story; but, while great progress has been made, persistent S&D has contributed to many mothers not testing or accessing early treatment, thereby resulting in avoidable infections among children. In another example, stigma and discrimination prevents sexually active youth from testing for HIV and many groups from exercising their right to access stigma-free health services.

Social change does not always come easy, but it is possible. Building an enabling environment that supports people to adopt healthy sexual lives, safeguard family life, access health and other public services, and participate fully in community activities is key to achieving change and effectively responding to HIV.



## Lessons Learned

After 30 years of combating HIV, we have learned a few key lessons:

**Reducing stigma and discrimination requires responding to HIV at various levels and from various angles.** Simultaneous and sustained efforts in education and understanding, processes and procedures, and laws and policies can make a difference. The discovery of HIV, the virus that causes AIDS, meant that the world had to change its health priorities. Unprecedented levels of action were undertaken; but, over time, we came to see the collective need for a more sustainable means of (1) ensuring access to health for marginalized populations, (2) integrating HIV into existing mechanisms and systems for sexual and reproductive health programs, (3) finding synergies with non-communicable diseases, and (4) linking responses to development efforts, particularly in education, gender equality, and poverty reduction.

**Acceptance and tolerance comes more easily with familiarity.** When people hide from society, avoid testing, or do not disclose status in fear of lack of confidentiality or rejection, we cannot learn about the experiences of those living with or affected by HIV. Helping individuals and groups feel confident in speaking about sex, sexuality, and health is integral to an effective HIV response, particularly in reducing S&D and promoting higher uptake of prevention services. Similarly, helping the socially disenfranchised work together to identify common challenges and solutions and to increase trust and confidence in themselves and their communities is key to moving forward as a society.

**Positive change stems from positive action and should be based on knowledge of a specific situation and best available evidence.** Years of working in public health has taught us that saying no or enacting prohibition are not always particularly effective responses. Helping people adopt healthy options and positive attitudes can however be a successful strategy. Smoking campaigns helped to decrease smoking but not to eliminate it. Banning alcohol did not lead to people stopping drinking but did increase crime. The war on drugs did not eliminate drugs but increased violence. Ending sexual violence will not come with simply telling people it is bad. The fundamental message here is that positive legal and social change can help foster an enabling environment and benefit all citizens, not only those who are stigmatized.

## Action for a Sustained Response

Social change is about moving from increased understanding to collective action—taken at various levels and within multiple arenas. This PANCAP Stigma Framework is built around three key components—Health and Development, Collective Empowerment, and Social Justice and Gender Equality—which represent crucial areas to address in the Caribbean response to HIV-related stigma and discrimination.

**Health and development** refers to the access and use of health and prevention services. To create an effective HIV response, existing systems should be strengthened to ensure access to stigma-free services, especially for persons living with and affected by HIV. Today more than ever, it is important to make S&D a central part of a successful national HIV strategy. New developments in treatment are making it possible to both prolong healthy lives and prevent new infections, but stigma continues to impede access to testing and treatment as well as adherence to medication. Secondly, it is important to integrate HIV services into a broader framework that addresses related issues such as sexual and reproductive health, sexual violence, gender equality, and non-communicable diseases.

**Collective empowerment** is the essential combination of building capacities and confidence. People need to understand HIV as well as stigma and discrimination and their effect on health and health service use. This process includes social mobilization and community development of youth, encouragement of community and religious leadership, and involvement of cultural practitioners. Vital to these efforts are finding more effective

ways of involving marginalized populations affected by HIV. Good governance and transparent decision making helps to build effective coordinated responses with efficient communication and reference systems.

**Social justice and gender equality** encompass laws and policies, enforcement mechanisms, and access to justice, as well as social action on issues such as gender-based violence. Social justice refers to the idea of creating a society that is based on the principles of equality and solidarity, one which understands and values human rights, and recognizes human dignity for all. It grew out of religious notions of acceptance, forgiveness, and ethical fairness. In the context of HIV in the Caribbean, where underprivileged and marginalized sectors of society are often most affected by HIV, social justice is considered vital to the creation of an enabling environment—where social and political conditions encourage positive social and personal change. Adopting this framework should help countries address their national and local needs and provide an opportunity to address the challenges posed by HIV and take a comprehensive look at national policies and programs while encouraging country ownership. Above all, it should help countries build their own template for action.

## PANCAP Stigma Framework

### What is the PANCAP Stigma Framework?

The framework represents a guide for collective national action in the reduction of HIV-related stigma and discrimination and is to be applied within a broader context of sexual and reproductive health and social development. It outlines a process to help countries identify the focus of their S&D response. It is also a diagnostic tool that can be tailored to guide development, implementation, and evaluation of specific national responses in Caribbean countries. For example, the key questions included for policymakers and social change champions can be adapted to reflect national contexts and capacities.

### What is PANCAP?

The Pan Caribbean Partnership Against HIV and AIDS (PANCAP) was formed by a decision of the CARICOM Heads of Government in 2001. The Heads recognizing the imminent threat to the development of the region that HIV posed, committed to work together to respond to the challenges HIV would pose on developing nations. PANCAP operates under the roadmap of the Caribbean Regional Strategic Framework (CRSF) 2008–2012, The CRSF embraces all CARICOM (Caribbean Community) Member States and Associated Members, as well as Cuba, the Dominican Republic, the Dutch Overseas Territories, the French Overseas Departments of the Americas, and the United States Territories in the Caribbean. It calls on these nations to accelerate their individual efforts against HIV and AIDS, while enhancing their regional collaboration. PANCAP which has multiple partners including Governments NGO and development partners, focuses on six key thematic areas of work:

- An enabling environment that fosters universal access to HIV prevention, treatment, care, and support services
- An expanded and coordinated multisectoral response to HIV
- Prevention of HIV transmission
- Treatment, care, and support
- Capacity development for HIV and AIDS services
- Monitoring, evaluation, and research

### Who should use this framework?

The framework focuses on country-level responses and is primarily aimed at agencies that coordinate national responses to HIV, sexual and reproductive health, and other related health issues. The framework is designed to help facilitate a national process of reflection and social mobilization to ensure that S&D reduction is part of a comprehensive national response to HIV. It also offers ways to help affected communities, community leaders, academia, and social advocates fully participate in collective action as well as in monitoring national responses.

## Why do we need a new framework for reducing S&D in the Caribbean?

In the past 10 years, national and regional strategic plans have indicated that S&D remain the biggest barriers to effective responses to health issues such as HIV. Stigma and discrimination have a broad impact on health and development in many ways, including weakening productive members of society, weighing heavily on already overburdened health systems, affecting tourism, and exacerbating existing social injustices related to gender, economic independence, etc.

According to the United Nations General Assembly Special Session's (UNGASS) country reports in 2010, almost all Caribbean countries reported the existence of programs designed to change societal attitudes of HIV-related S&D, but only half of those countries reported using performance indicators or benchmarks for reducing it.

While many tools and processes have been developed for addressing stigma and discrimination, few guides exist for national responses, especially in small countries, emerging nations, and island states. A framework provides a tool that countries can use to diagnose and collectively act. It should be used to build national capacity for long-term sustainable responses to HIV and related issues such as sexual and reproductive health.

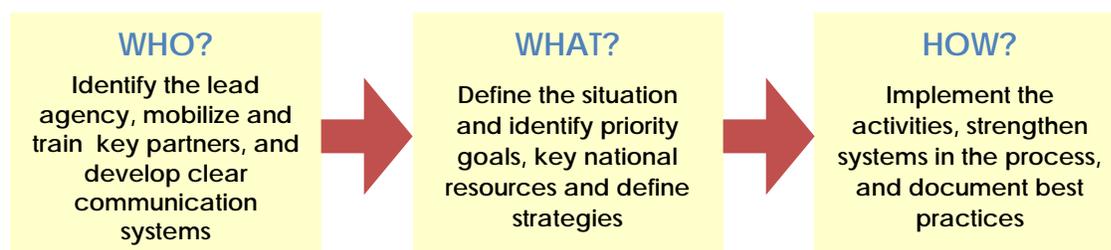
## How was it developed?

In response to national requests for direction on stigma and discrimination, PANCAP asked a group of implementing and development partners to jointly develop a simple, yet comprehensive approach to responding effectively to stigma and discrimination. A team of 10 representatives from key PANCAP implementing partners with experience in reducing S&D reviewed the existing frameworks and Caribbean tools and sketched out broad strokes of the approach. Subsequently, a small group of technical experts drafted an initial framework for the team to review, revise, and circulate for broader input from actors regionwide. PANCAP partners presented a working draft at the 2011 Caribbean HIV Conference as well as at the 2011 PANCAP AGM for input and discussion. Since that time, PANCAP national partners have been "piloting" the framework in a few countries which subsequently led to this current draft of the framework.

## Creating a Roadmap for National Action on Reducing Stigma and Discrimination

### How do countries appropriate this process?

The Caribbean region has the second highest HIV prevalence rate worldwide, and international development resources for HIV are dwindling. As a consequence, strengthening country ownership and leadership are paramount for achieving change and sustaining an effective response to HIV. Although developed as a regional tool, this framework is meant to be adopted by national and local partners and used in integrating stigma reduction into existing programming, wherever possible. It is a guide, not a magic bullet. The following provides a template for country action and is meant as a short step-by-step guide for a more effective response to HIV-related stigma and discrimination, while ensuring greater country ownership, social development, and sustainability. There are three simple steps to using the framework:



## How will PANCAP support the process?

PANCAP comprises many players and actors who come together for a regional response. PANCAP, through implementing partners, will introduce the framework to national partners; help identify, support, and reinvigorate national champions; guide a process of reflection and action; and provide technical assistance and tools to assist countries in answering and addressing emerging questions. PANCAP implementing partners can also use the framework process to guide development partners' action in a specific country.

### Step 1: WHO?

#### 1. Involve participants who can influence and foster change

- a. Each country will have a slightly different process, but existing mechanisms for national coordination constitute natural entry points (e.g., the National AIDS Program (NAP), the National AIDS Commissions, or Country Coordinating Mechanism). Although in many countries the NAP will help drive the process, the framework may be a useful tool for other stakeholders as well.
- b. Early on, each country should identify who has a vested interest in the tool and who could serve as national champions to mobilize actors and action and use the tool to facilitate multisectoral dialogue and define national strategies.
- c. Ensure that a number of key individuals representing different sectors are trained and able to facilitate community dialogue processes or to train others in addressing stigma and discrimination.

#### 2. Build understanding and an evidence base for decisionmaking and action

- a. Evidence to support effective responses exists, but we have not always used that evidence in designing stigma reduction programs. Although an evidence base is vital for guiding an effective response to HIV, a response should not be hindered by being too ambitious. How do we make the best use of existing assessments and data? How can we complement this information with rapid assessments? Where national evidence is not available, can proxy information, for example from neighboring countries, be accessed?
- b. Over time, clear mechanisms for evaluating programs and defining gaps in information and research should be developed with local academic, implementing, and policymaking partners.

#### 3. Ask questions, share information, and build opportunities for dialogue

- a. Good communication systems and opportunities for informed dialogue are vital elements of a successful comprehensive response.
- b. Provide opportunities for communities to come together to discuss difficult issues related to equality, social justice or strategies for reducing stigma, discrimination and violence.

### Step 2: WHAT?

#### 1. Conduct a rapid analysis of existing evidence

- a. While this framework provides the broad brush strokes for mobilizing actors across sectors, it is important to ask the right questions of the right people, and, in the process, tailor information, action, and capacity building to national needs and defined strategies.
- b. To begin with, it is important to determine the most appropriate key questions for a particular country; then, information can be gathered to answer those questions. Consultation is also important in getting input and commitment from many social sectors. See Table 1 for some key questions with which to begin: Who is affected by stigma and discrimination, and how does this affect health outcomes?

- c. It is sometimes necessary to undertake simple surveys to establish a baseline and then to measure change over time. Sometimes analysis of existing data sets such as Demographic Health Surveys can help. Focus groups with affected populations can also help to gauge change over time.

## **2. Identify financial and human resources**

- a. What financial resources do we have? Who can we mobilize to help achieve a sustainable response?
- b. What human resources do we currently have? Do they have particular needs in capacity building? Are there other human resources or services to consider?

## **3. Identify the priority actions (e.g, over 5 years) and where to start**

- a. Priority actions should help achieve the following broad goals:
  - i. Ensure effective high-quality, stigma-free health services for all
  - ii. Ensure justice and equality in our services and communities
  - iii. Work toward sustainable development at the individual/community, institutional, and socio-political levels
- b. A framework is only just that—a frame that needs to be put to work; this framework is meant to mobilize actors to decide on a few key actions—at least one in each component outlined. Choosing priority actions and aligning them with resources (human and financial) is paramount—as is effectively utilizing what we already have.

### **Step 3: HOW?**

#### **1. Define strategies for selected priorities**

- a. See Table 2 for some strategies that have shown positive results in the Caribbean and worldwide and some sources for further tools and information.

#### **2. Identify or strengthen social mobilization, coordination, and governance systems**

- a. What coordination systems do we need in place or to be strengthened?
- b. What health and social systems need to be reinforced to achieve priority objectives?
- c. How do we document, disseminate, and expand best practices for S&D reduction?

#### **3. Focus on health services to social empowerment to policy reform**

- a. Begin with a focus on health and social services, including functional referral services.
- b. Include clear objectives related to building capacity and reinforcing emerging organisations and developing networking mechanisms.
- c. Ensure that an overall approach to creating an enabling environment puts social justice and gender equality front and centre.
- d. Look at other sectors to see how we might best get and keep them involved. How, for example, do we get the education sector more involved in sexual health; how to get workplace policies adopted and implemented; how do we get youth or women's organisations involved and active in reduction of stigma and discrimination?
- e. Policy reform takes time and is best placed in the hands of informed and trained people.

**Table 1** outlines some guiding considerations for exploration: What do we know? What do we want to change? What can we realistically undertake? To this end, some key questions are outlined for reflection and action planning. Information should be gathered to help answer these and other country-appropriate questions, based on existing evidence.

<b>Finding Answers</b>	<b>Goals</b>	<b>Questions to guide information gathering and social dialogue</b>	<b>Sectoral-specific questions</b>
<b>Health and development</b>	Improved access and use of high-quality HIV, health, and social services	<ul style="list-style-type: none"> <li>• What does HIV-related stigma and discrimination mean for access and use of health and social services?</li> <li>• What are the key issues and challenges for discussing sex and sexuality in your country?</li> <li>• What affect does discrimination and gender inequality have on a person and their behavior? Health seeking behaviour? Risk behaviour?</li> </ul>	<ul style="list-style-type: none"> <li>• Health: How do we provide stigma-free services to encourage the marginalized and the poor to seek and use services?</li> <li>• How can a response to S&amp;D be better integrated into existing services to be less dependent on external financing?</li> <li>• How might an institutional response to HIV-related S&amp;D assist with responses to other health issues?</li> </ul>
<b>Social justice and gender equality</b>	An improved social debate, an enabling environment, and supportive laws	<ul style="list-style-type: none"> <li>• How are stigma and discrimination manifested in our country?</li> <li>• How does your country respond to discrimination?</li> <li>• What is the effect of prejudice on social health and development? On productivity? On tourism?</li> <li>• What obligations does your country have according to signed international treaties? Are they consistent with national laws and policies?</li> </ul>	<ul style="list-style-type: none"> <li>• Justice: What policies and laws exist in relation to discrimination? How are infringements reported? Regulated?</li> <li>• Who (and what) are key influencers on attitudes? <ul style="list-style-type: none"> <li>◦ In terms of stigma and discrimination?</li> <li>◦ In terms of sexuality and gender?</li> </ul> </li> <li>• Culture: What opportunities exist for exchange and informed social dialogue?</li> </ul>
<b>Collective empowerment</b>	A strong and sustainable response with capacity building, accountability, and monitoring mechanisms	<ul style="list-style-type: none"> <li>• In what areas do we need to build capacity to have a more effective response to HIV?</li> <li>• How can capacity building affect other health outcomes?</li> <li>• What are the needs of the specific actors or groups to help them become more engaged or more effective?</li> <li>• How do we help citizens (especially the socially marginalized) become more visible and participate in policy dialogue?</li> </ul>	<ul style="list-style-type: none"> <li>• In what areas do we need to build capacity for teachers, policymakers, and advocates? How do we improve networking, policy dialogue, strategic data use, etc?</li> <li>• Education: Is stigma and discrimination and gender addressed in education? In sexual health education?</li> <li>• How can non-health sectors contribute to the response to HIV? What does HIV contribute to collective development in your sector?</li> </ul>

**Table 2** focuses on tools and information sources. Once we know what we want to change, how do we go about it? What strategies work? What tools and resources are needed? This table outlines example strategic interventions, resources, and considerations for monitoring and evaluating the process. One size does not fit all

Using Resources	Key sources of evidence at the national level	Strategic interventions	Existing regional and international resources
<b>Health and development</b>	<ul style="list-style-type: none"> <li>National HIV Strategic Plan</li> <li>National Strategic Plan for Health</li> <li>National Development Plan</li> <li><i>Epidemiological</i> information from country (or from neighboring countries) such as key DHS indicators</li> <li>Reports and information from PLHIV groups, key populations, networks, and service organizations</li> </ul>	<ul style="list-style-type: none"> <li>Stigma-free services where key populations feel at ease accessing services</li> <li>Guarantees related to confidentiality</li> <li>Outreach mechanisms with organizations and key leaders of populations affected by HIV</li> <li>Development of services based on needs of specific populations (PLHIV, persons w/ other health issues, persons highly vulnerable to HIV)</li> </ul>	<ul style="list-style-type: none"> <li>PANCAP model codes of practice<sup>1</sup></li> <li>PANCAP model condom policy<sup>2</sup></li> <li>Workplace policies</li> <li>Other: UNAIDS, Pan American Health Organization, Stigma Action Network (SAN)</li> <li>CARICOM development plan</li> </ul>
<b>Social justice and gender equality</b>	<ul style="list-style-type: none"> <li>National laws</li> <li>Municipal regulations</li> <li>Policies and guidelines to health, justice, and equality</li> <li>Legal assessments and information from mechanisms for identifying S&amp;D (stigma index, key DHS indicators, service delivery surveys)</li> <li>International treaties</li> <li>Women’s organizations</li> <li>MSM, SW and transgender organizations</li> </ul>	<ul style="list-style-type: none"> <li>Stigma-reduction programs with lawmakers and opinion leaders who shape norms and policies</li> <li>Creation of an enabling environment (moving from prohibitive to protective) <ul style="list-style-type: none"> <li>Law reviews and advocacy campaigns to change harmful laws</li> <li>Confidentiality policies</li> <li>Anti-discrimination workplace policies, training, and enforcement</li> </ul> </li> <li>Knowledge of rights and suggested services for PLHIV</li> </ul>	<ul style="list-style-type: none"> <li>PANCAP Model Policy<sup>3</sup></li> <li>PANCAP Model Legislation on stigma and discrimination<sup>4</sup></li> <li>Other: UNAIDS, International Development Law Organisation (IDLO), United Nations Development Program (UNDP) and Stigma Action Network (SAN)</li> </ul>
<b>Collective Empowerment</b>	<ul style="list-style-type: none"> <li>Capacity assessments of health providers, associations of health and other professionals, and nongovernmental organizations</li> <li>Monitoring systems (service use: who is accessing and who is not; service quality: prevention, uptake in testing, service satisfaction)</li> <li>Education, Labour and Tourism sector involvement</li> </ul>	<ul style="list-style-type: none"> <li>Capacity building in various areas depending on need</li> <li>Alliance building and strengthening of networking mechanisms (nurses association, etc.)</li> <li>Citizen monitoring and evidence-based advocacy</li> <li>Social capital of marginalized, including opportunities for participation in policy dialogue</li> </ul>	<ul style="list-style-type: none"> <li>PANCAP HIV Anti-stigma tool kits<sup>5</sup></li> <li>Jamaica Reporting and Redress System</li> <li>CRN+ Human Rights Desks</li> <li><i>Understanding &amp; Challenging HIV &amp; Key Population Stigma &amp; Discrimination: Caribbean Facilitators Guide</i></li> <li>Others: UNAIDS and Stigma Action Network (SAN)</li> </ul>

<sup>1</sup> [http://www.pancap.org/docs/Psycho\\_Social\\_Model\\_Code\\_for\\_Practitioners.pdf](http://www.pancap.org/docs/Psycho_Social_Model_Code_for_Practitioners.pdf)

<sup>2</sup> [http://www.pancap.org/docs/World\\_Bank\\_Studies/REGIONAL\\_MODEL\\_CONDOM\\_POLICY%20-%20FINAL.pdf](http://www.pancap.org/docs/World_Bank_Studies/REGIONAL_MODEL_CONDOM_POLICY%20-%20FINAL.pdf)

<sup>3</sup> <http://www.pancap.org/docs/Final%20Policy%20on%20Stigma%20and%20Discrimination.pdf>

<sup>4</sup> [http://www.pancap.org/docs/Final\\_Anti-Discrimination\\_Bill\[1\].pdf](http://www.pancap.org/docs/Final_Anti-Discrimination_Bill[1].pdf)

<sup>5</sup> [http://www.pancap.org/index.php?option=com\\_content&view=article&id=334&Itemid=87](http://www.pancap.org/index.php?option=com_content&view=article&id=334&Itemid=87)