



**NGO Delegation Annual Report  
to the  
UNAIDS Board**

**Stigma and Discrimination: Hindering Effective HIV Responses**

**Presented at the  
26<sup>th</sup> UNAIDS Board Meeting  
Geneva, Switzerland  
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The PCB NGO Delegation

## EXECUTIVE SUMMARY

This year's annual report to the board builds on last year's NGO report, which identified stigma and discrimination as the most widespread barrier to universal access. This year's report informs the agenda on non-discrimination in HIV responses and delineates the need to better identify, support, collect data about, target resources, and ensure universal access for, people living with HIV and key affected populations.

The report is based on and an extensive consultation among civil society that included an on-line survey in ten languages of more than 1000 respondents; and more than 50 one-on-one interviews and focus groups; Delegates' experience within their own networks and constituencies; and a review of recent literature on stigma and discrimination. Respondents were from all regions and represented every key population group.

The respondents in the consultation experienced a high degree of stigma and discrimination. Sixty-three percent of respondents experienced negative attitudes or behaviors because of their HIV status and more than fifty percent experienced negative attitudes and behaviors because of their associations with marginalized populations.

Between fifty-six and sixty-one percent of all respondents report experiences of stigma and/or discrimination when accessing prevention services, sexual and reproductive health services, treatment, care and support services. Between thirty-five and forty-one percent report being afraid to access or being denied these services. When respondents were asked to elaborate on why they were afraid to or denied access services, the most common response (62%) was that confidentiality was not ensured. The second most popular reason was identifying with a group that is marginalized. And the third most common reason (more than 50% of all respondents) was the attitude of health care workers.

Respondents were greatly concerned by the criminalization of behavior, transmission and non-disclosure of HIV status. These prevented access to services, increased marginalization, and undermined the public health response to HIV and AIDS. The majority of respondents knew of services or protective laws. However, the majority who knew of these laws also said that those laws were not used effectively.

When asked specifically about the work of UNAIDS, more than forty percent of respondents knew of technical assistance and financial support. The majority of respondents from Africa, Asia and the Pacific, Latin America and the Caribbean indicated that they thought that UNAIDS and its Cosponsors were at least somewhat effective in their in-country programming to contribute to the elimination of HIV-related stigma and/or discrimination.

When asked about global priorities aimed at tackling stigma and discrimination, respondents rated raising general awareness and knowledge about HIV as the first priority, followed by pressuring governments to change harmful policies and laws, and funding for civil society organizations as the third priority.

The report concludes that stigma and discrimination continue to seriously hinder an effective HIV response, and requests the board to take action to:

- Work toward the removal of punitive laws, including via regular dialogue with law enforcement, judiciary, health ministries, parliaments and civil society.

- Scale up comprehensive packages of programs to combat stigma and discrimination.
- Raise public awareness of HIV as a global priority.
- Acknowledge and fight structural-level discrimination, including criminal laws and ineffective HIV policies and barriers such as poverty, sexism and racism.
- Reaffirm commitments to universal access to HIV prevention, treatment, care and support, and focus on reducing stigma and discrimination at the 2011 High Level Meeting.
- Equip health service providers with training in non-discrimination, informed consent, confidentiality, duty to treat, sexuality, and specific needs of key populations so as to ensure that staff within health care settings provide care to all populations in a manner that is non-discriminatory and protective of their human rights.
- Recognize that key populations are doubly impacted by stigma and discriminated against because of both their HIV status, and their association with a marginalized group.
- Ensure that people living with HIV and key populations are at the heart of programmes to tackle stigma and discrimination and participate directly in local, national and global programmes.
- Improve our ability to monitor and evaluate stigma, and build capacity of national governments and civil society to make use of existing stigma-measurement tools.
- Support the application of global and national level indicators specific to key populations and build the capacity of governments and civil society in collecting and reporting accurate information specific to key populations.

*I think it's when we enter into the human reality of this disease that we understand, and that we understand why it's important not to discriminate and stigmatize...We have to do better than we've ever done before. It's a matter of simple equity; of justice.* – Dr. Jonathan Mann

## **INTRODUCTION**

1. Each year, the NGO Delegation presents a report to the board. The report has varied over the years in its structure, but has always aimed to bring the perspectives of people living with HIV (PLHIV) and key affected populations to the Programme Coordinating Board (PCB). Although this year's report relies on a survey of more than 1000 civil society participants, it can never do justice to the richness of their voices, or to the urgency of the need to achieve universal access to HIV prevention, treatment, care and support.
2. Last year's NGO report carried out a consultation to learn about key barriers to achieving universal access. The most frequent barriers related to stigma and discrimination. Following the report of 2009, the Board agreed to examine the issue in more depth, via an agenda item in the 26<sup>th</sup> Programme Coordinating Board (PCB) meeting titled "Non-Discrimination in AIDS Responses." This year's report informs this agenda item and builds on the findings and recommendations laid out last year. Specifically we argue the need to better identify, support, collect data about, target resources, and ensure universal access for, people living with HIV and key affected populations, including women and girls, men who have sex with men (MSM), transgender persons (TGs), people who use drugs, sex workers, migrants and mobile populations, indigenous populations, youth, prisoners, and others. The NGO Delegation strongly believes that we must urgently address stigma and discrimination as a fundamental pillar in our response to HIV and AIDS.

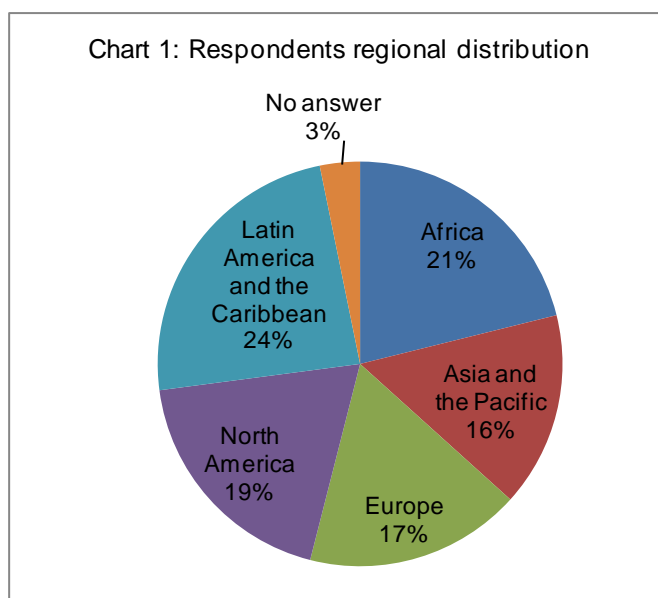
## **METHODOLOGY**

3. The report is based on the experience of delegates within their own networks and constituencies; a review of recent literature on stigma and discrimination; and an extensive consultation among civil society that included:
  - An anonymous on-line survey in ten languages (Arabic, Burmese, Chinese, English, French, Portuguese, Russian, Spanish, Swahili, and Thai). More than 1500 respondents started the survey and 1021 respondents completed all of the questions.
  - One-on-one interviews with more than 50 persons. Some of the interviews were selected regionally by delegates; some were selected from among those taking the questionnaire online.
  - Eight focus group consultations carried out by delegates.
4. Invitations to participate in the on-line survey went out by email through general list-serves, the NGO Delegation's mailing list, and the networks of NGO Delegates and partner NGOs. A post was also placed on the NGO Delegation's website. The survey was available in ten languages and allowed respondents to submit in a voluntary and anonymous manner. One-on-one interviews and focus groups were conducted by Delegates in their regions among their networks and by the Communications Facility. Some, but not all, of the interviewees also took part in the on-line survey. The regional interviews and focus groups formed regional reports by each Delegate, which formed part of the basis for this summary paper. Quotations used in the report come from direct interviews or from anonymous comments provided in the online survey.

5. The on-line survey, and individual and focus group discussion interview guide, were divided into three sections. The first section gathered general information about the respondent. The second section asked about how stigma and/or discrimination are impeding access to HIV prevention, treatment, care and support, as well as sexual and reproductive health (SRH) services. The third section asked about the programming of UNAIDS (including the ten Cosponsors) in addressing stigma and/or discrimination. All survey questions were multiple choice with the additional option of adding comments to a multiple choice response. Details about interview and focus group discussion respondents are provided in Annex A.
6. The findings of the report are summarized here, but a more detailed breakdown and analysis of the survey results will be available in a separate report on our website at: [www.unaidspcbngo.org](http://www.unaidspcbngo.org). The Communications Facility of the NGO Delegation worked with a university-based researcher, to rigorously analyze the data. All results are public.
7. Despite all efforts, we cannot know how truly representative our respondents were of persons living with HIV and key affected populations. On the one hand they had to have access to computers to complete the survey, which may select for respondents with better access to HIV prevention, treatment, care and support services; but on the other hand respondents could answer for themselves or for the people they represent or work with, which should increase the representativeness of the sample.

## RESPONDENTS

8. Sixty percent of survey respondents were male, 36% female and 4% transgender. The distribution amongst regions was fairly even, with a range from 16% in Asia and the Pacific to 24% in Latin America and the Caribbean (see regional breakdown in Chart 1 below<sup>1</sup>). The majority of respondents identified as being from community based organizations, closely followed by national organizations.
9. When asked to affiliate with a particular community, 65% of respondents self-identified as being or serving persons living with HIV. The consultation reached persons coming from or working with all key affected populations, as broken down globally in Table 1.



<sup>1</sup> Please note that because MENA is not one of the five UNAIDS regions represented by the NGO Delegation, MENA respondents were divided between Africa and Asia.

<b>Population groups</b>	<b>Population group(s) identified with or served</b>	<b>Population group(s) respondents were responding to the survey on behalf of</b>
People living with HIV	65%	57%
Youth	44%	32%
Men who have sex with men	41%	22%
Gay or lesbian	40%	26%
Women and girls	39%	33%
Sex workers	29%	35%
People who use drugs	26%	21%
Transgendered people	24%	37%
Children	20%	17%
Older persons	16%	13%
People with disabilities	16%	6%
Indigenous communities and ethnic minorities	14%	5%
Migrant	14%	12%
Prisoners	14%	6%
Former prisoners	11%	10%
Faith based	10%	12%
Labour	8%	12%
Refugee or asylum seeker	8%	8%
Mobile communities (temporary movement or permanent resettlement)	8%	6%
Other (please specify)	8%	8%
Private sector	7%	6%
Internally displaced person	6%	12%
No answer	2%	7%

\*Multiple answers possible

## **STIGMA AND DISCRIMINATION AS BARRIERS TO UNIVERSAL ACCESS**

10. In general, our respondents experienced a high degree of stigma and discrimination in various forms. Around two thirds of respondents had experienced negative attitudes or behaviors because of their HIV status and more than half had experienced negative attitudes and behaviors because of their associations (eg. sex work, drug use, sex between men, incarceration, etc.). Just under half experienced negative attitudes or exclusion from family members. Other experiences in at least one third of the sample included loss of employment, health care workers refusing care, social or vocational exclusion, and/or involuntary disclosure. A full one third experienced criminalization of behavior and discriminatory laws. North American respondents were more likely to report the criminalization of transmission and/or non-disclosure.
11. Manifestations of stigma and discrimination as reported in the survey are shown in Table 2 below. One quarter of online survey participants identified physical violence as a threat; regional interviewees expounded on that threat. As one example, Asian sex workers talked

about the 100% condom programming<sup>2</sup> continuing to be used as a justification for the state to police sex workers and also for compulsory testing and arrests.

<b>Table 2: Experiences of HIV-related stigma or discrimination*</b>	
Negative attitudes and behaviors because of HIV status	63%
Negative attitudes and behaviors because of association with certain groups	56%
Negative attitudes or exclusion from family activities	47%
Loss of employment	43%
Health professionals are not helpful or willing to provide care	42%
Exclusion in the workplace	38%
Exclusion from social gatherings or activities	34%
Involuntary disclosure of HIV status by health staff, government officials, or press	32%
Criminalization of behavior (i.e. laws against sodomy; sex work, drug use)	31%
Exclusion at school	28%
Laws that are discriminatory	26%
Criminalization of transmission	26%
Physical threats (violence or fear of violence)	25%
Exclusion from religious activities or places of worship	23%
Forced disclosure of HIV status to enter another country	22%
Forced disclosure for employment	18%
Forced disclosure for another reason	16%
Detention or isolation	12%
Forced disclosure of HIV status to remain in current country	9%
Deportation	9%
None of the above	5%
Other, please explain below	4%
Don't know	4%
* Multiple answers possible	

12. Stigma can lead to violations of human rights,<sup>3</sup> including unlawful discrimination in housing, employment and health and social services. Unfortunately, the survey results showed that discrimination in the workplace remains a key barrier. More than 40% of online survey respondents report loss of employment as a form of HIV-related discrimination and 37% report exclusion in the workplace. Workplace discrimination was noted even in places where laws are on-record to prohibit such discrimination, such as in Cameroon, Kenya, Lesotho, South Africa, United States and Zambia.<sup>4</sup>

*"My boss acted as HR rep when we got health insurance and was there to 'peruse' our forms to ensure they were completed correctly; I did not list my HIV out of fear for my job."*

- Survey, North America

<sup>2</sup> 100% Condom Use Programme (100% CUP), a public health program implemented in South East and East Asia that aims to prevent HIV/AIDS among the general population through the promotion of condom use in the commercial sex industry. The program has the aspect of helping sex workers insist on condom use and refuse a customer if he does not agree to use a condom, but is seen as a simplified solution to a complex issue. More discussion can be found in SANGRAM, *Rights-Based Sex Worker Empowerment Guidelines: An Alternative HIV/AIDS Intervention Approach to the 100% Condom Use Programme*, July 2008.

<sup>3</sup> Discrimination as violations of human rights are outlined in the UNAIDS paper to the 26<sup>th</sup> PCB, *Ensuring non-discrimination in responses to HIV*, 2010. Therefore, this report does not repeat known findings but seeks to compliment that report with survey findings.

<sup>4</sup> Survey comments on legal protections

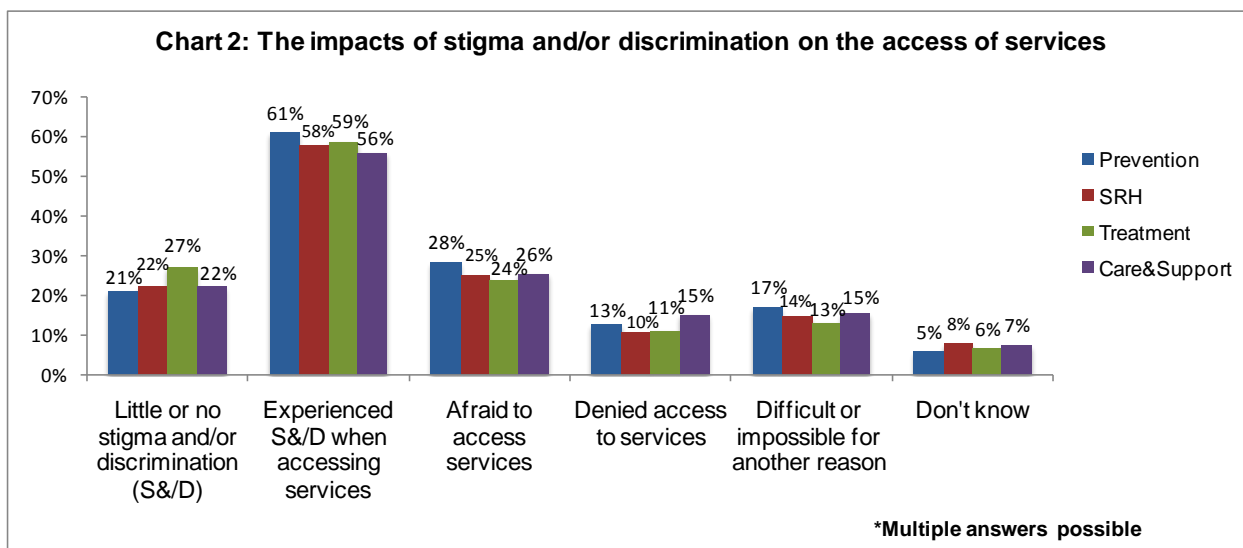


13. Despite endorsement at the 24<sup>th</sup> Programme Coordinating Board (PCB) to *support governments in harmonizing all laws and policies on HIV testing to ensure adherence to internationally accepted standards that include: informed consent, confidentiality, pre and post-test counseling, and proper referral to treatment, care and support services*<sup>5</sup>, mandatory testing is still widespread and was mentioned by many respondents as a barrier to employment, health insurance and residence.

## HOW STIGMA AND DISCRIMINATION IMPEDE ACCESS TO HIV PREVENTION, TREATMENT, CARE AND SUPPORT

14. The survey data supports the already well-documented fact that stigma and discrimination are barriers to universal access.<sup>6 7 8 9 10 11</sup>

15. The survey asked for information about how stigma and/or discrimination affect access to HIV prevention, treatment, care and support services, as well as sexual and reproductive health services. The chart below gives a visual representation of the global responses to each question. More than half of all respondents reported that stigma and/or discrimination is present when accessing services. More than one-third of participants reported being afraid to access services or denied access to services. Forty percent of respondents were afraid to access or denied access to prevention services and care and support services. Thirty-five percent were afraid to access or denied access to sexual and reproductive health services and to treatment. Only about one quarter of respondents was able to access treatment without stigma or discrimination.



16. In the one-fifth of respondents who said that access was difficult or impossible due to reasons other than stigma and discrimination, gave the following reasons: services do not exist; transport to the clinics is unavailable or unaffordable; information is scarce; and

<sup>5</sup> Programme Coordinating Board 24 Final Decisions, Conclusions and Recommendations, June 2009.

<sup>6</sup> UNAIDS, *Reducing HIV Stigma and Discrimination: a critical part of AIDS programmes*, December 2007.

<sup>7</sup> International Center for Research on Women, *HIV-related Stigma and Discrimination: A Summary of Recent Literature*, August 2009, available at: [http://data.unaids.org/pub/Report/2009/20091130\\_stigmasummary\\_en.pdf](http://data.unaids.org/pub/Report/2009/20091130_stigmasummary_en.pdf)

<sup>8</sup> NGO Delegation report to the Programme Coordinating Board, 2009.

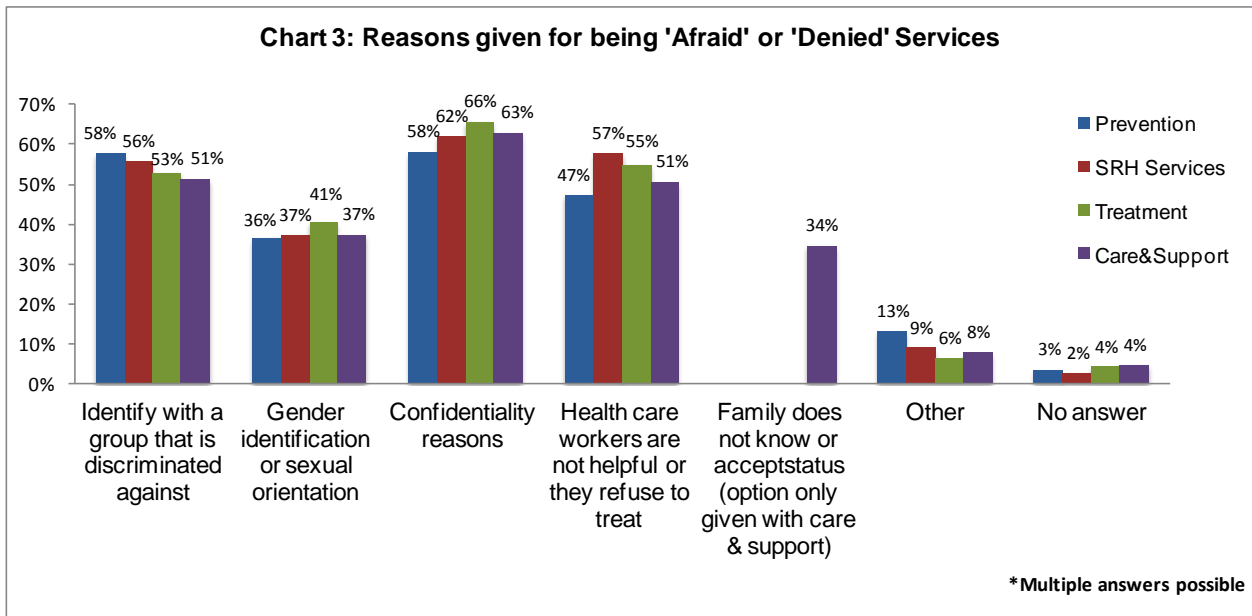
<sup>9</sup> UNAIDS Board paper on non-discrimination lays out clearly the relationships in more detail.

<sup>10</sup> 2001 Declaration of Commitment on HIV/AIDS, notably paragraphs 13 and 17.

<sup>11</sup> 2006 Political Declaration, paragraph 11

workplace discrimination remains a real concern. Respondents from Africa were more likely to say that access was impossible or difficult due to these reasons.

17. Respondents who answered 'afraid or denied access' were given the opportunity to explain why. The key reasons cited for being afraid to access services included *confidentiality* (on average 62% of the sample), *identification with a discriminated group* (55%), *health care workers who were unhelpful or refusing service* (53%) and *gender identification or sexual orientation* (38%). Chart 3 details this broken down by HIV prevention, treatment, care and support and for sexual and reproductive health services.



## CONFIDENTIALITY

18. Across all regions, comments came back about the lack of confidentiality especially from health care professionals and within systems of care. Respondents report being afraid to access testing or medications for fear of being identified as a person living with HIV. One respondent talked about it in terms of the “bush telegraph” working too well. While confidentiality was mentioned across regions and languages, comments in this area were especially noted by or on behalf of the gay, bisexual and transgender community in the Russian language survey comments.

*“Stigma and discrimination within migrant communities can be terrible. HIV infection is quickly summarized as a result of sexual immorality, punishment from God, witchcraft, being cursed, and such other negative connotations. One who is infected will therefore be isolated due to fear of association. There is also fear that, such as often happens in the countries of origin, the health care providers will reveal the patient's status to one's community or to others.”*

*Survey, Africa*

19. People with disabilities are often afraid to access services due to lack of confidentiality. One participant pointed out that this is especially true among the deaf - where the service

providers do not have skills to communicate with them in private, and the blind – as their private medical information is shared with their guides and/or helpers.<sup>12</sup>

## **IDENTIFICATION WITH A MARGINALIZED GROUP**

*“Commit ourselves to intensifying efforts to enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and developing strategies to combat stigma and social exclusion connected with the epidemic”*

*- From the 2006 Political Declaration (paragraph 29)*

20. While the impacts of stigma and discrimination were limiting factors, respondents in this research made clear that social and structural barriers impede access. Stigma was often discussed in relation to one’s difference from mainstream society – be it race, ethnicity, income, drug use, sex work, sexual orientation, incarceration, immigration status, disability or age. The survey asked about stigma and discrimination and gave examples of experienced discrimination; however, participants emphasized that multiple layers of stigma and discrimination impede individuals from even attempting to access services.

21. More than half of all respondents said they were afraid to access or denied access to services because of the fact that they work with or belong to a group that faces stigma and/or discrimination. Comments and examples arose from each region and population with a similar message of exclusion from society, multiple layers of stigma, and frustration leading to self-stigma. Individuals commented on being less willing to keep trying to interact with the health care system that seems continually dismissive, unwilling or unable to provide appropriate services.

*“Maybe you got HIV because God wants you to die.”*

*- Interview, Asia*

22. The clinical director of St. Ann’s Corner of Harm Reduction (HIV/drug treatment center) in the Bronx talked about the “institutional racism” of imprisonment amongst black and Hispanic populations in the United States. He described the cycle of increased risk experienced by minorities who are imprisoned for non-violent drug-related crimes. A criminal record impedes access to jobs and to loans, so there is an increase in stress, anger, and hopelessness which can fuel increased substance abuse and increased risk taking. This cycle also pushes people out of mainstream society, maintains poverty and further drives stigma.<sup>13</sup>

*“If HIV infection happened among the elite groups then the stigma would be very different, but as HIV occurs mainly among the poor people, or key affected populations (also the criminalized groups), the HIV stigma is very strong.”*

*- Interview, Asia*

23. Similarly, the discussion of HIV in black African communities in Europe and North America has focused on individual-level actions, especially sexual behavior (and transmission) and ignored the broad-scale, high-level determinants, such as the social, structural aspects like racism and poverty, that can drive the transmission of HIV. The focus on disease

<sup>12</sup> Survey comment, East Africa

<sup>13</sup> Interview, North America

transmission, ignoring other social determinants, has stigmatized this population as sexually promiscuous and hyper-masculine. Adding HIV status to this mixture marginalizes these communities even further.<sup>14</sup>

24. Respondents from a focus group discussion in Swaziland mentioned that generally, HIV services are difficult to access because health service providers shun those groups they see as 'immoral' such as MSM and sex workers. Lesbian, gay, bisexual transgender and intersex communities (LGBTI) were mentioned as facing particular difficulties in accessing HIV and SRH-related services as they are criminalized and therefore often have to pretend to be heterosexual to access services.<sup>15</sup> "Also many sex workers are uninsured and can only access limited services in some countries. Migrant sex workers may be afraid to access services if they are undocumented."<sup>16</sup>
25. Namibian respondents mentioned cultural traditions that inhibit young people from talking openly to elders (both parents and services providers) about their sexual health and HIV status. "Young people are often afraid to disclose their status to family because they are afraid to talk to elders about being infected."<sup>17</sup>
26. Focus group and interview respondents discussing drug use report cases of doctors refusing to treat people who use drugs for HIV, or insisting that they seek treatment for drug use before starting ART. In Indonesia, people who use drugs wanting to access harm reduction services are forced to disclose a lot of personal information, for example, the name and address of their parents. Many are concerned that this information could be provided to the police by the public health center. In Pakistan, one interviewee talked about the refusal of doctors to treat a female drug user with ART.<sup>18</sup>
27. People who use drugs report not accessing opiate substitution therapies and other treatment services due to fear of judgment from doctors in particular. One respondent from Russia noted that "substitution therapy for IDUs is prohibited. Formally, people can get ARV in Provincial AIDS Center only, and a person who has no local permission for residence has no access to medicines (it is regulated by provincial laws)."<sup>19</sup> In this case, stigma and criminalization of behavior may interfere with access to services. In many places, needle exchange, which is proven effective in reducing HIV transmission, is not promoted due to the stigma, discrimination and punitive laws surrounding drug use.<sup>20</sup> In some cases, laws prohibiting and punishing possession of injection equipment create disincentives to obtain and carry clean equipment, and to carry used equipment for purposes of safe disposal. Additionally, distribution point or some policing practices also interfere with the ability and willingness of people who use drugs to use other harm reduction services.
28. Undocumented, migrant populations are denied access to treatment and care in some countries. This interview response from the Netherlands rings true for other countries as well: "Many migrants, especially when illegal, do not understand the health care infrastructure of the Netherlands (as it differs greatly with that of their countries of origin, eg. not understand that confidentiality by health care providers is guaranteed by law); are afraid they will be deported if they seek help; are afraid of discrimination from their social communities if their

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<sup>14</sup> European NGO Delegates report

<sup>15</sup> African NGO Delegates report

<sup>16</sup> Survey comment, Western and Central Europe

<sup>17</sup> African NGO Delegates report

<sup>18</sup> Asian NGO Delegates report

<sup>19</sup> Survey comment, Eastern Europe

<sup>20</sup> Interview, North America

HIV status is revealed (so do not make use of support groups); are distrusting towards the white Dutch health care providers (fears include those of deliberate infection, being given ineffective/low quality/expired medication, etc on the grounds of their being ethnic minorities).<sup>21</sup>

29. A Liberian interviewee talked about the particular challenges that internally displaced persons (IDPs), refugees and returnees face in his country in accessing HIV-related services. Returnees may be unsure of where to get help; persons testing positive in camps may be denied entry to relocate to a new country.<sup>22</sup>
30. Prisoners and detainees are not able to access services, notably condoms and ART, on a regular basis. One respondent pointed out that “It was difficult in prison to access care. Prisons are not good at confidentiality (speaking in low voices or caring to hide your condition), and other prisoners do not look fondly upon other offenders with HIV (to say the least).”<sup>23</sup> As well, several respondents talked about legislation prohibiting access to HIV prevention services (e.g., sterile injection equipment) for prisoners.

### **HEALTH CARE WORKER ATTITUDES, ESPECIALLY WITH REGARDS TO SEXUAL ORIENTATION AND WOMEN AND GIRLS**

31. Beyond the stigmatizing behaviors and lack of confidentiality, many health care workers are ill-equipped to handle specific issues faced by different populations.<sup>24</sup> Training of health workers around stigma and HIV must include sensitization and understanding of the specific needs of people who are homosexual, transgender, sex workers, youth and people who use drugs.

32. Health care workers were reported to be either not receptive to transgender, sex workers, or MSM or not able to provide appropriate services. One respondent from Libya commented that “The stigma against MSM is tremendous. Thus the persons who should benefit from the prevention programs addressed to most vulnerable populations (MSM, sex workers (male & female), IDUs) refuse to visit public centers because we fear the lack of confidentiality among the health care providers themselves.”<sup>25</sup>

*“Services focusing on female sex workers may not be seen as appropriate by transwomen not involved in sex work.”*  
- Interview, Asia

33. Health workers may also not be receptive to specific needs of individuals. A female sex worker, for example, has sexual and reproductive health issues that must be addressed as any woman, but also has special sexual health needs, such as more frequent Pap screening for cervical cancer. In Malaysia, there is “rising evidence of anal STIs, Chlamydia, genital warts from human papillomavirus (HPV) infections in male and female transgender sex workers. Yet there are no services available for us.”<sup>26</sup>

<sup>21</sup> Survey comment, Western and Central Europe

<sup>22</sup> Interview, West Africa

<sup>23</sup> Survey comment, North America

<sup>24</sup> Latin America and Caribbean NGO Delegates report

<sup>25</sup> Survey comment, North Africa

<sup>26</sup> Asian NGO Delegates report

34. According to a recent literature review on HIV-related stigma and discrimination, more evidence is needed to understand the relationship among gender, stigma and the use of services. Studies to date

*“The issues faced by us as transgender persons have not even begun to be accepted in public spaces, let alone supported in legislation and practices. We have a long way to go.”*

- *Mia Quetzal, President of Trans in Action, (Caribbean group of transgender persons)*

imply that men and women experience stigma differently.<sup>27</sup> The results of the 2010 NGO Delegation consultation, in which transgender persons in focus groups reported greater discrimination than PLHIV, imply that we need to add transgender persons to future research needed on the relationships between stigma and gender.

35. In Latin America, respondents talked about the fact that gay and bisexual men, especially those who “look it,” are almost always guaranteed stigma and discrimination, and frequently victims of violence that in some cases resulted in death.<sup>28</sup> A recent study of HIV epidemics among MSM in Central and Eastern Europe shows high levels of discrimination and violence towards gay people: “Physical violence as a result of sexual orientation ranged from being reported by 10% of MSM in Georgia to 23% in Turkey,... In some instances, the utilization of healthcare and psychological services by MSM is hindered by a lack of healthcare professionals’ knowledge of the sexual health needs of MSM.”<sup>29</sup> In many countries, stigma, discrimination, and violence have marginalized MSM and made it difficult for them to access HIV prevention and treatment services. A recent report by Asia Pacific Network of PLHIV (APN+) on treatment research attests to the fact that MSM face physical abuse from the health care providers.<sup>30</sup>

*“Social interaction between gay people in Iraq is becoming less and less because people are scared. For example, there was newspaper coverage about the assassination of a man who was the coordinator of small LGBTI program in Bagdad. He was killed in a barber shop.”*

- *Interview, Asia*

36. The homophobia that drives criminalization laws against same-sex acts is also present in the health system. HIV prevalence is higher amongst MSM in Eastern Europe than among the general population. Yet in Eastern Europe and Central Asia, LGBT populations are largely ignored in HIV policy, surveillance and programs. This is reflected in the fact that there are no services to address their needs, especially MSM. When MSM attempt to access services, they face discrimination by service providers and cannot talk openly about their sexuality. This in turn results in examinations that are inappropriate or not targeted (“no anal check, just tests for STIs”) and as such MSM do not feel “reached.”<sup>31</sup> Moreover, these results are reflected in studies among MSM worldwide: MSM in developing countries are 19 times more likely to be HIV positive than the general population.<sup>32</sup>

<sup>27</sup> International Center for Research on Women, HIV-related Stigma and Discrimination: A Summary of Recent Literature, August 2009, available at: [http://data.unaids.org/pub/Report/2009/20091130\\_stigmasummary\\_en.pdf](http://data.unaids.org/pub/Report/2009/20091130_stigmasummary_en.pdf)

<sup>28</sup> Latin America and Caribbean NGO Delegates report

<sup>29</sup> I Bozicevic, et al, “HIV epidemics among men who have sex with men in central and eastern Europe,” Sexually Transmitted Infections 2009;85:336–342.

<sup>30</sup> APN+, Access to HIV-related Health Services in HIV Positive Women, Men who have sex with Men, Transgender and Injecting Drug Users, August 2009. Available at: [http://www.apnplus.org/document/APN\\_Report2009.pdf](http://www.apnplus.org/document/APN_Report2009.pdf)

<sup>31</sup> European NGO Delegates report

<sup>32</sup> Baral S, Sifakis F, Cleghorn F, et al. Elevated risk for HIV infection among men who have sex with men in low- and middle-income countries 2000-2006, a systematic review. *PLoS Med* 2007; 4:e339

37. Women and girls face specific challenges, especially around sexual and reproductive health care. In Indonesia, one interviewee talked about a doctor suggesting that HIV positive women should not have sex at all.<sup>33</sup> Several female respondents commented on their inability to plan families and the complete disregard of doctors of the idea that a woman living with HIV might have the same desires of motherhood and be entitled to the same discussions regarding family planning as women who are not living with HIV.

*“By 2005, ensure development and accelerated implementation of national strategies for women’s empowerment, promotion and protection of women’s full enjoyment of all human rights and reduction of their vulnerability to HIV/AIDS through the elimination of all forms of discrimination, as well as all forms of violence against women and girls, including harmful traditional and customary practices, abuse, rape and other forms of sexual violence, battering and trafficking in women and girls”*

- From the 2001 Declaration of Commitment on HIV/AIDS (paragraph 61)

38. Forced sterilization is unfortunately a real threat for women in many parts of the world. Women living with HIV in Namibia mentioned a fear of seeking SRH services in the public and even private health care sector, due to reports of (and on-going campaigning and litigation against the Namibian government for) sterilization of women living with HIV without their informed consent.<sup>34</sup> The respondents mentioned a distrust of the health care service providers when accessing SRH services compounded by a fear that they too, may be consenting to being sterilized without a thorough understanding of what they were being coerced into agreeing to, as happened to their peers. An interviewee in Indonesia cited the case of the forced sterilization of a woman living with HIV without her knowledge after delivering her baby.<sup>35</sup>

*“Commit ourselves to strengthening legal, policy, administrative and other measures for the promotion and protection of women’s full enjoyment of all human rights and the reduction of their vulnerability to HIV/AIDS through the elimination of all forms of discrimination, as well as all types of sexual exploitation of women, girls and boys, including for commercial reasons, and all forms of violence against women and girls, including harmful traditional and customary practices, abuse, rape and other forms of sexual violence, battering and trafficking in women and girls”*

- From the 2006 Political Declaration (paragraph 31)

39. Social disapproval is greater for women who are associated with marginalized groups. For example, stigma associated with women who use drugs is amplified further for mothers who use drugs. This leads to women accessing services by proxy or not at all. In Latin America, focus group participants highlighted the absence of facilities for women who are drug and alcohol users as a major problem.<sup>36</sup>

*“Sexual and reproductive health services are difficult or impossible for Lesbian, Gay, Bisexual, Transgender and Intersexual as well as Commercial Sex workers, some cannot afford it and there are legal and policy barriers.”*

- Survey, Africa

## **CRIMINALIZATION**

<sup>33</sup> Asian NGO Delegates report

<sup>34</sup> African NGO Delegates report

<sup>35</sup> Asian NGO Delegates report

<sup>36</sup> Latin America and Caribbean NGO Delegates report

40. All respondents were concerned by the increase in criminalization of behaviors such as homosexuality, drug use and sex work; as well as of HIV transmission; and of non-disclosure. Criminalization of PLHIV for either transmission of HIV or non-disclosure of HIV status in sexual situations is especially relevant in some developed countries. In Canada, there have been close to 100 criminal charges laid since the 1980s in cases of non-disclosure of HIV, even in the face of no evidence of HIV transmission, with over 70 of these resulting in convictions. Respondents felt that HIV had a double stigma in Western Europe where sex workers can be locked up, transmission or non transmission can be criminalized, and people accessing HIV treatment with undetermined immigration status can be deported to countries where they cannot access the same treatment.<sup>37</sup>
41. Respondents said that criminalization of HIV nondisclosure contributes to a reduction in willingness to get tested for HIV, as well as a reduction in willingness to access HIV services including other sexual and reproductive health services. Sex workers cited criminalization as a factor negatively affecting the provision of health care services, including HIV testing and other forms of health screening. In Canada, African, Caribbean and black communities carry a disproportionate burden of this form of stigma and discrimination as close to half of the criminalization cases in Canada are in black heterosexual men.<sup>38</sup> The same trend has been identified in Western Europe.<sup>39</sup>

#### **Effects of criminalization** talked about by respondents:

- Criminalization contributes to and perpetuates stigma and discrimination which further marginalizes populations that are affected by HIV and AIDS.
- Criminalization undermines the public health response to HIV and AIDS.
- Criminalization does not support evidence-based approaches to the challenges of the HIV epidemic.
- Criminalization discourages HIV testing.
- Criminalization encourages denial and with it unsafe behavior.
- Criminalization unfairly targets ethno-racial communities.
- Criminalization affects AIDS service organizations and impedes provision of services. Fears of legal liability negatively affect provision of education, treatment and other health-related services.
- Criminalization of non-disclosure of HIV-positive status increases stigmatizing attitudes in the general public, often presenting persons living with HIV as “potential criminals,” which adds an additional layer of stigma and discrimination that these groups face.
- Biases and lack of awareness about HIV and AIDS within the justice system makes the system unprepared to handle these cases.

## **PROTECTIONS AGAINST STIGMA AND DISCRIMINATION**

*“By 2003, enact, strengthen or enforce as appropriate legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups”*

*- From the 2001 Declaration of Commitment on HIV/AIDS (paragraph 58)*

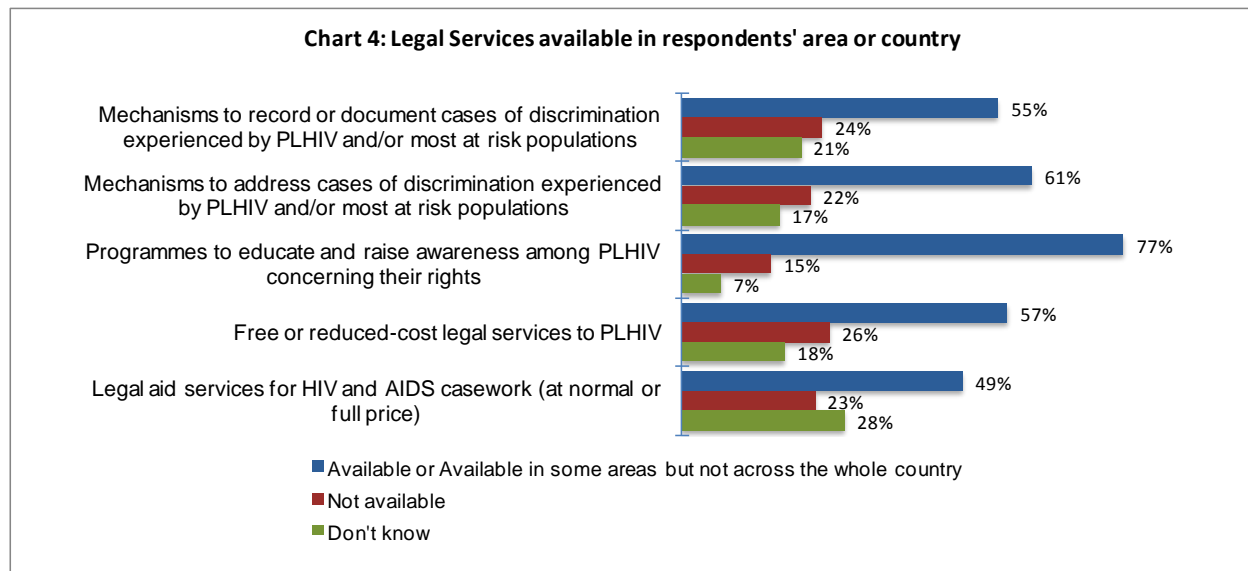
<sup>37</sup> European NGO Delegates report

<sup>38</sup> North American NGO Delegates report

<sup>39</sup> Global Network of People Living with HIV/AIDS Europe (GNP+ Europe) and Terrence Higgins Trust (THT), Criminalisation of HIV transmission in Europe: A rapid scan of the laws and rates of prosecution for HIV transmission within signatory States of the European Convention of Human Rights, 2005. Available at: [www.gnpplus.net/criminalisation/rapidscan.pdf](http://www.gnpplus.net/criminalisation/rapidscan.pdf)



42. The majority of respondents knew of services available in at least part of their country that provided protection against stigma and discrimination. This is detailed in Chart 4.



43. When asked about the kinds of services available to respond to stigma and discrimination, more than three-fourths of all respondents knew of the availability of programs to educate and raise awareness among PLHIV concerning their rights in at least some part of their country. On the face of it, this would imply that such services are widespread; however, survey respondents would be more likely to know of or need these services. More research is needed to find out if and how most people are able to access such services. This was not a question in the survey, but the overall survey results imply that people are not yet able to fully use such services to their advantage.

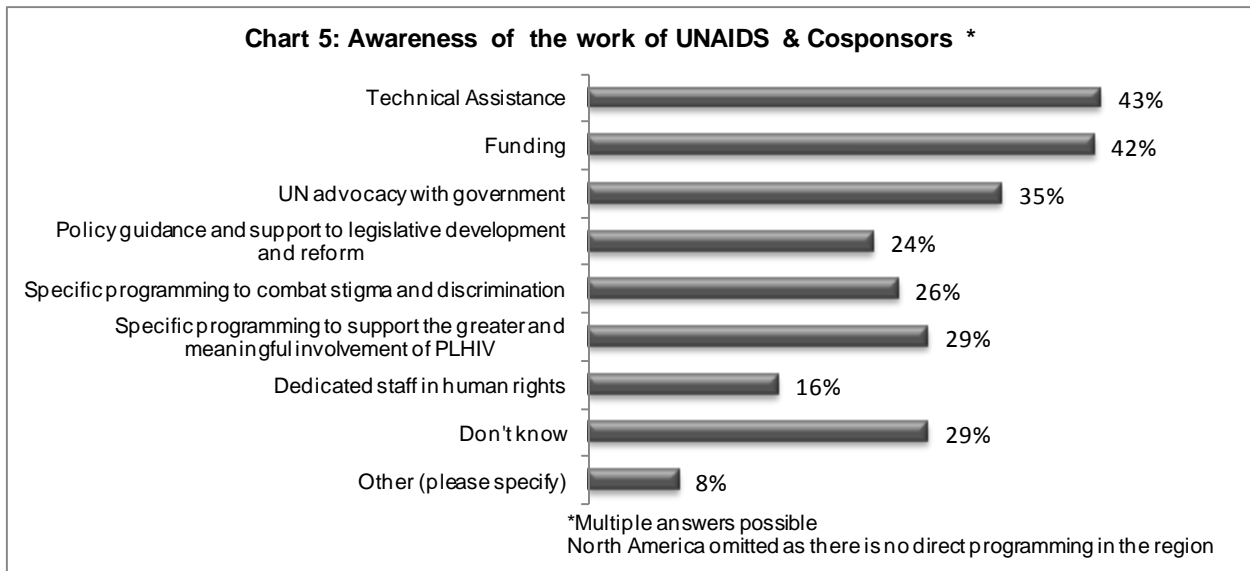
## **PROTECTIVE LAWS**

44. While most respondents (77%) were aware of laws to protect against stigma and discrimination, 59% said the laws were not well-known; and 78% said the laws are either not enforced or not followed. More awareness-raising is needed around protective laws, including human rights, and how to use them in relation to HIV-related discrimination. In contrast, 44% of 1115 respondents were aware of laws making it more difficult to access prevention, treatment care and support. Most comments mentioned laws prohibiting same sex behavior and sodomy; needle exchange; and criminalization of HIV transmission and non-disclosure. Of the 478 respondents who knew of such laws, at least 30% reported effects on: persons living with HIV (PLHIV), people who use drugs (PUD), sex workers, migrants, gays and lesbians, men who have sex with men, transgender persons and prisoners.

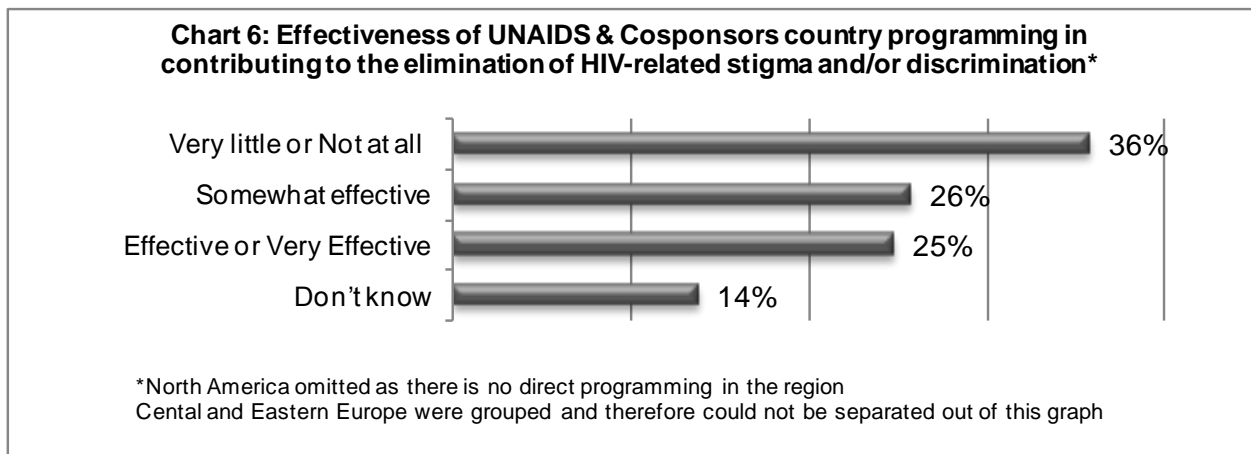
## **UNAIDS PROGRAMMING**

45. When asked about their familiarity with the work of UNAIDS to combat stigma and discrimination, more than forty percent of respondents in every region reported that UNAIDS and its Cosponsors were engaged in technical assistance and funding. But of the more than

1000 persons responding, almost thirty percent outside of North America were not familiar with what kinds of work UNAIDS is carrying out in the region or community.



46. When asked about the effectiveness of UNAIDS in combating stigma and discrimination, about one third of respondents reported that UNAIDS was not at all effective or had very little effectiveness. The majority of respondents from Africa, Asia, Latin America, and the Caribbean indicated that they thought that UNAIDS and its Cosponsors were somewhat effective, effective, or very effective in their in-country programming to contribute to the elimination of HIV-related stigma and/or discrimination. In regions where there is not a strong UNAIDS presence, such as North America and Western Europe, the majority of respondents did not know the answer to the question, or found UNAIDS to have little or no effectiveness.



47. Almost 35% of global respondents know of UN advocacy with governments, but only 16% know of dedicated staff in human rights. This survey result supports findings in the Second Independent Evaluation of UNAIDS that more needs to be done to address human rights at the country level, and should be considered in the staffing review as UNAIDS addresses the need to increase a country-level response in the area of human rights.

48. When asked what limits the response to stigma and discrimination, 75% of respondents cited lack of funding. More than half of all respondents named lack of government support or lack of dedicated staff to work on stigma and discrimination. This may be linked to the previous finding that only 16% of respondents knew of dedicated UNAIDS staff working in human rights.
49. In order to adequately program and respond to stigma and discrimination, we need a way to measure progress. There are now tools to measure HIV-related stigma and discrimination, one of which is the PLHIV Stigma Index,<sup>40</sup> whose findings in Myanmar, Rwanda, China and the United Kingdom as explained in the non-discrimination paper mirror results of our NGO consultation. These tools, as pointed out in the non-discrimination paper, are not used widely enough at national level and are not yet used in conjunction with formal UNGASS indicators. The current UNGASS indicators are not sufficient in assessing a reduction in stigma and discrimination. One place that UNAIDS promotes reporting is in the National Composite Policy Index (NCPI). This indicator, also an UNGASS indicator and therefore part of country reports to measure progress toward universal access, assesses the development of national-level HIV/AIDS policies and strategies and covers four broad areas: strategic planning, prevention, human rights, care and support. Part A is to be filled in by governments and part B by civil society, although the government must sign off on the report (see annex B for the stigma and discrimination related questions in the NCPI).
50. The NCPI touches on human rights, yet these qualitative indicators are not sufficient to establish a baseline, ensure broad civil society participation, measure progress or impact of programming, or be used to inform programming to confront barriers at country level. In the NGO survey, only 245 respondents of 1021 were familiar with the NCPI and 118 of those persons had provided data for part B in the past. We can conclude that civil society awareness of the NCPI is limited at best. If we are going to use the NCPI to measure progress in stigma and discrimination reduction and to improve programming, then not only do the indicators need to be appropriate and more detailed, but civil society will need to be engaged to fully participate in data gathering.

## **PRIORITIES**

51. Sadly, almost 30 years into the AIDS pandemic and there is still the critical need to raise awareness and knowledge about HIV; this was the first priority for more than a third of participants (38%). As one survey respondent commented, *“Providing information and education about HIV/AIDS to general people is very important at this moment to reduce stigma and discrimination. More awareness about HIV/AIDS is required.”*<sup>41</sup> In the regional breakdown of priorities, all regions with the exception of Africa included raising awareness among the public on HIV in their top three priorities.
52. The second global priority selected was pressuring governments to change harmful policies and laws. This was the number one priority among European respondents and the second

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<sup>40</sup> The PLHIV Stigma Index is a tool for and by PLHIV. The goal of the initiative is to improve programmes and policies to achieve universal access to prevention, treatment, care and support. The tool aims to evaluate efforts to address stigma and collect evidence and is most effective when implemented as part of a comprehensive research and advocacy initiative. The People Living with HIV Stigma Index founding partners are: The Global Network of People Living with HIV/AIDS (GNP+); The International Community of Women Living with HIV/AIDS (ICW); The International Planned Parenthood Federation (IPPF); and The Joint United Nations Programme on HIV/AIDS (UNAIDS).

<sup>41</sup> Survey comment, Southern Africa

highest priority overall. Respondents also recognized the need to address criminal laws that exacerbate stigma against marginalized groups and PLHIV, and the fact that many potentially protective laws – those that can be used to respect, protect and fulfill the rights of marginalized groups and PLHIV were not well-known or enforced. *“We must try and remove the HIV criminal transmission laws... they are outdated and harmful, and do nothing to reduce transmission and continue to stigmatize HIV....”*<sup>42</sup>

53. Respondents identified funding for civil society organizations as the third global priority. This was the number one priority for both African and Latin American and Caribbean respondents to the survey. One respondent commented on the effects of mobilizing civil society: “My organization has been responsible to work with other civil society organizations to address cases of discrimination experienced by people living with HIV. The efforts were successful because we were able to mobilize [the] support of various civil society organizations in putting pressure on the authorities concerned to get redress.”<sup>43</sup>

*“By 2003, ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS that: address the epidemic in forthright terms; confront stigma, silence and denial; address gender and age-based dimensions of the epidemic; eliminate discrimination and marginalization; involve partnerships with civil society and the business sector and the full participation of people living with HIV/AIDS, those in vulnerable groups and people mostly at risk, particularly women and young people”*

- From the 2001 Declaration of Commitment on HIV/AIDS (paragraph 37)

54. Comments in the survey reflected that some civil society view UNAIDS as too closely aligned to governments to effectively challenge them on human rights. Civil society in some countries may be better placed to carry out local advocacy, and we should build the subsequent capacity to make this effective. One respondent explained: “If funding is available, civil society organizations will be able to reach areas that are landlocked. If capacities of civil societies are built the more, work on HIV/AIDS will be done effectively and government will also pass bills in Parliament for organizations to have policies and this will reduce stigma and discrimination.”<sup>44</sup>

## **REGIONAL DISCUSSION POINTS**

55. In each regional set of interviews, participants expressed concern regarding the insufficient attention to key populations in achieving universal access:
56. European interviewees were particularly critical of how UNAIDS seemed to back away from universal access and expressed concern that the language regarding key populations will disappear once universal access deadlines end in 2010.<sup>45</sup> They also commented on the lack of human rights staff at country level that is critical to supporting national stakeholders in implementing access to justice programs, such as HIV-related legal services.
57. North American interviewees felt that UNAIDS could do more in North America regarding policy, identification of best practices, and influencing national governments. More work is needed to combat the problem of stigma and discrimination, universal access and

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<sup>42</sup> Survey comment, North America

<sup>43</sup> Survey comment, Western and Central Africa

<sup>44</sup> Survey comment, Western and Central Africa

<sup>45</sup> European NGO Delegates report

criminalization. The work in HIV Travel Restrictions was cited as a positive example of UNAIDS leadership and partnership with concrete results.<sup>46</sup>

58. Asian interviewees strongly echoed the urgent need to work with governments and increase support to key affected populations. UNAIDS could increase work with populations by providing them greater opportunities to manage funds directly. More support was requested to build the capacity of key populations to manage their own funds, design, implement, and evaluate their own programs.
59. African interviewees echoed the need to increase funding and capacity of civil society organizations. It is the non-governmental organizations and networks of people living with HIV that are the most active in addressing stigma and discrimination (through awareness campaigns to address HIV-related fear), more so than UNAIDS and other UN agencies. The implementation of effective anti-stigma programmes by civil society is hampered by poor technical capacity of staff to implement effective programming and a lack of resources.
60. Respondents added the need for UNAIDS to again engage communities directly in fighting stigma and discrimination (get GIPA principle back on the agenda), as the current focus has shifted away from addressing stigma and discrimination, empowering PLHIV and involving them to help address stigma. In Namibia specifically, civil society called on UNAIDS to be more vocal in its public denunciation of forced sterilization.<sup>47</sup>
61. In Latin America, UNAIDS must work to increase involvement with the communities, and not only be seen as working with governments. Respondents view the role of UNAIDS as formal, and not always resonating with the real, daily issues of the people affected.<sup>48</sup>

## Key Conclusions and Recommendations for Action

Several key themes have emerged from this consultation with civil society to examine stigma and discrimination. They are summarized here with accompanying points for action.

1. Stigma and discrimination continue to seriously hinder an effective HIV response, and efforts to address them must be urgently scaled up. It is difficult to convey the urgency with which we must tackle stigma and discrimination. Programs to combat stigma and discrimination are available and can be effective, but they are too limited and need immediate scale-up. In places where services and care are potentially available, stigma and discrimination are preventing access to and use of those services. In other cases, stigma associated with certain groups of people and practices can affect the program design itself and limit access to those who are not stigmatized or most in need.<sup>49</sup>

Governments and civil society must work toward the removal of punitive laws, policies and practices that block effective responses to HIV, including by documenting and evaluating the impact of such laws, and by facilitating regular dialogue among law enforcement, health ministries, parliaments, judiciaries, AIDS Committees and civil society with the support of UNAIDS in order to create an enabling environment.

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<sup>46</sup> North American NGO Delegates report

<sup>47</sup> African NGO Delegates report

<sup>48</sup> Latin America and Caribbean NGO Delegates report

<sup>49</sup> Such as the example of needle exchange and opiate substitution therapy discussed previously

2. HIV-related stigma and discrimination decrease the quality of life of individuals and seriously limit universal access to HIV prevention, treatment, care and support. This is all too easy to forget for those of us living our sexuality openly and who have freedom of choice in our professions and lifestyles. Individuals, especially those identified with key populations, such as MSM, transgender, sex workers, people who use drugs, migrants, immigrants, and prisoners, are mentally and physically threatened in all parts of the world. Stigma and discrimination increase their invisibility by pushing them out of mainstream society and therefore reducing their access to HIV and other health services, as well as economic and social opportunities. Therefore, each person involved in the HIV response must re-prioritize tackling stigma and discrimination against PLHIV and other marginalized communities as an urgent, priority – at international, regional, national, and local levels.
3. Raising public awareness of HIV was a global priority from the survey. Breaking barriers of stigma will not happen overnight but requires constant discussion, awareness raising and education in order to demystify and bring normalcy to the taboos of HIV and sexuality. UNAIDS and partners must raise awareness of and promote leadership in fighting stigma and discrimination among policy-makers, elected officials, bureaucrats, healthcare workers, civil society and the general public.
4. Structural-level discrimination, including criminal laws and ineffective HIV policies, often driven by morality at the expense of evidence-based public health research, undermine the ability of PLHIV and other marginalized groups to fulfill their right to health. Barriers to universal access extend beyond the health sector and will require legal support, sustainable livelihoods, education opportunities for all and increased and accessible information and communications, in addition to accessible health interventions.<sup>50</sup> As discussed in the report and highlighted in the survey and interviews, barriers such as poverty, sexism and racism compound stigma and further limit access to HIV-related services. UNAIDS has been, and must continue to be, a leader in championing a multi-sectoral approach.
5. UNAIDS must ensure that global and country-level action frameworks are in place to meet and sustain efforts to achieve universal access to HIV prevention, treatment, care and support. Concrete steps must be put in place for a grounded plan toward realizing the specific commitments of universal access, as we will not have achieved them by the end of this year. The deadlines of 2010 and 2015 are needed to demonstrate the urgency of our task and maintain accountability, but they cannot be seen as limits. Instead, 2010 offers a critical moment to assess our progress to date, rethink our strategy, and renew the commitment and political will that are needed to make HIV prevention, treatment, care and support accessible for all and to achieve the MDGs.<sup>51</sup>

Commitments to universal access to HIV prevention, treatment, care and support must be strongly reaffirmed. UNAIDS and governments can show their support for tackling stigma and discrimination by making the reduction of stigma and discrimination one of the main priorities in

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<sup>50</sup> Respondents who said that access was difficult or impossible gave the following reasons: services do not exist; transport to the clinics is unavailable or unaffordable; infrastructure was weak or non-existence; information is scarce or not communicated in vernacular or explained for low-literacy people. Key HIV messaging and information about the availability of services are still not being communicated on a wide enough scale, nor are they reaching those who are illiterate or do not speak the local language. As well, the use of media, such as radio and internet, is not widespread enough. Interestingly, more respondents from Africa said that access was impossible or difficult. One comment: "NGOs, local organizations have the ability to do the work, but lack the funding. They have no materials, no means of communication to carry out their work. There are very few treatment centers and people have to travel a long way to get to them. Sometimes people die on the way to the centers."

<sup>51</sup> "In particular, high levels of discrimination against people living with HIV, gender inequality and violence against women and girls, marginalization of men who have sex with men, people who use drugs and sex workers combined with punitive laws, policies and practices continue to hold back effective national responses" Accounting for Universal Access, Note 1, 15 April 2010.

the 2011 High Level Meeting to review progress to date and determine a clear, costed way forward to fulfilling outstanding commitments.

6. UNAIDS is well-placed to work with countries and support civil society partners in stopping and reversing the spread of criminalizing laws against PLHIV and behaviors related to risk in relation to HIV. UNAIDS and partners must lead in recording, evaluating and carrying out advocacy around the detrimental effects of the criminalization of behaviors, transmission and non-disclosure.

UNAIDS should continue to support countries in tackling stigma and discrimination by urgently scaling up a comprehensive package of programmes and initiatives that are proven to combat HIV-related stigma and discrimination, and mainstreaming stigma reduction into all HIV services. This includes conducting more evaluations of stigma and discrimination reduction programs, and using evidence and results to inform design, implementation, scale up and allocation of resources.

7. Individual-level stigma and discrimination persists, with especially detrimental effects when enacted by frontline healthcare providers. HIV-related discrimination occurs most visibly in health care settings. The focus of survey respondents on discriminatory health care practices supports the literature documenting extensive health care stigma.<sup>52</sup> Sexual and reproductive health services must be extended to men, women and transgender persons, including sex workers of all genders. Health service providers must be equipped with the knowledge and products necessary to allow for a comprehensive, safe, healthcare environment for all people to access, regardless of sex, age, sexual orientation or gender identity.

Governments, with support from UNAIDS, should engage with professional health care associations and civil society to intensify efforts to train health care workers on non-discrimination, informed consent, confidentiality, duty to treat, sexuality, and specific needs of key populations so as to ensure that staff within health care settings provide care to all populations in a manner that is non-discriminatory and protective of their human rights.

8. Key populations are *doubly* impacted by stigma and discriminated against because of both their HIV status, and their association with a marginalized group and must be at the heart of programmes to tackle stigma and discrimination. This means engagement in the design, implementation and monitoring of programs. While community members from all cross-sections of society – youth, faith-based communities and leaders; elected officials; families; teachers; police and law enforcement officials; healthcare providers; people living with HIV; people not living with HIV; – should be engaged in understanding, identifying and addressing stigma, members of key affected communities, such as people who use drugs, MSM, transgender, sex workers, prisoners, migrants and mobile populations, and youth, must be involved in the development, design, implementation and evaluation of programs to decrease stigma and discrimination in their own communities.
9. We must vastly improve our ability to monitor and evaluate stigma, and build capacity of national governments and civil society to make use of existing stigma-measurement tools.

UNAIDS should continue to develop and consolidate HIV-related stigma measurement tools. UNAIDS should work with partners to ensure that tools are consolidated, strengthened, and

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<sup>52</sup> International Center for Research on Women, HIV-related Stigma and Discrimination: A Summary of Recent Literature, August 2009, available at: [http://data.unaids.org/pub/Report/2009/20091130\\_stigmasummary\\_en.pdf](http://data.unaids.org/pub/Report/2009/20091130_stigmasummary_en.pdf)

resourced and build the capacity of governments and civil society to use these tools to measure the quality of life of individuals as well as the reach and impact of stigma and discrimination reduction programs. Civil society, especially people living with HIV, must be empowered to be active participants in the development and monitoring of HIV-related stigma and discrimination, such as with the PLHIV Stigma Index, and subsequent programming to reduce HIV-related stigma and discrimination.

10. Specific indicators are needed to document and measure stigma and discrimination against key affected populations, including women and girls, MSM, sex workers, transgender, youth, prisoners, and persons who use drugs. Beyond a broad measure of stigma and discrimination, UNAIDS must support attention to potential and concentrated epidemics by accurately collecting data and developing tailored responses. This is especially vital for key populations, as they are not always recognized by their governments and will not be identified for support unless there is pressure from the international community and donors.

UNAIDS and all partners must intensify and harmonize efforts to address the barriers which inhibit effective responses to the needs of key affected populations, and to enhance their direct participation in global and national programs. UNAIDS and all partners, in reviewing UNGASS indicators, including the NCPI, and in strengthening data collection to “know your epidemic,” should support the further improvement and application of global and national level indicators specific to key populations and build the capacity of governments and civil society in collecting and reporting accurate information specific to key populations. This will provide a baseline, progress and analysis of how key populations are reached.



## Annex A: Information on participants of individual and joint interviews and focus groups

Interview type	Name	Affiliation	Location	Constituency
<b>Africa</b>				
Individual Interview	Anonymous	Leticia Ponien		Youth living with HIV
Individual Interview	Anonymous	UNICEF	Uganda	PLWHA'S
Individual Interview	Anonymous	Regional Doctor	Nairobi	CSO's
Individual Interview	Anonymous	UNFPA	Uganda	Women, Children and people with disabilities.
Individual Interview	Anonymous	Religious Council	Uganda	Youth, PLHIV.
Individual Interview	Chenyuende Delphine Nyikwe	DELIMAR Gourmets HOME GROUP	Cameroon	PLHIV; Women; Youth; Children; People with disabilities
Individual Interview	Rahab Mwaniki	National Empowerment Network of People Living with HIV & AIDS in Kenya (NEPHAK)	Kenya	PLHIV
Individual Interview	Slimen Zougari	Tunisian Organization against AIDS and STIs	Tunisia	PLHIV, MSM, Youth
Individual Interview	Stephen k. McGILL	Stop AIDS in Liberia (SAIL)	Liberia	PLHIV, key populations, migrants, people with disabilities, prisoners, youth and children, older persons
Focus group	Individuals not named	Swaziland Positive Living (SWAPOL) Treatment Literacy Trainers	Swaziland	PLHIV; people affected by HIV; NGO supporting PLHIV
Focus group	Individuals not named	ICW Namibia / Namibia Women's Health Network	Namibia	Women living with HIV
<b>Asia and the Pacific</b>				
Individual Interview	Shiba	Asia Pacific Network of People Living with HIV/AIDS (APN+)	India but based in Thailand	PLHIV
Individual Interview	Andrew Tan	Executive Committee, Malaysian AIDS Council/APN+ and APCOM	Malaysia	MSM, PLHIV
Individual Interview	Thissadee Sawangying	Population Services International	Thailand	MSM, PLHIV
Individual Interview	Joy	Swing	Thailand	Sex workers; Youth
Individual Interview	Edward Low	Positive Malaysian Treatment Access & Advocacy Group (MTAAG+)	Malaysia	PLHIV, key populations, migrants, people with disabilities, prisoners, labour
Joint Interview	Selvi Kay Thi Win	Anonymous	Malaysia Myanmar	Sex workers
Joint Interview	Uffe Gartner Individuals not named (2)	International NGO Anonymous MSM (Doctor) Anonymous MSM (Bartender)	Iraq	MSM, Refugees
Focus group	Noel Quinto	Pinoy Plus Association	Philippines	PLHIV
	Omar Syarif	JOTHI	Indonesia	
	Basanta Chettri	NAP+N	Nepal	
	Masood Fareed Malih	The Association Of People Living with HIV & AIDS	Pakistan	
	Bounyang Siththinarangsy	LNP+	Laos	
<b>Europe</b>				
Individual Interview	Ibi Fakoya	UCL Centre for Sexual Health & HIV Research	United Kingdom	Migrants black and ethnic minorities
Individual Interview	Jonathan Elford	City University London	United Kingdom	MSM and Ethnic Minorities and migrants
Individual Interview	Richard Walker	UK Consortium on HIV and International Development	United Kingdom	International Development Organization's that have HIV as a part of

				their work
Individual Interview	Roman Dudnik	AIDS Foundation East-West (AFEW)	central Asian Republics	MSM Eastern Europe
Individual Interview	Anke van Dam	AIDS Foundation East-West (AFEW)	Netherlands	MSM Eastern Europe
Joint Interview	Moono Nyambe and Julian Hows	Global Network of People living with HIV (GNP+)	Netherlands	PLHIV
Joint Interview	Fabrice Olive	l'Auto Support des Usagers de Drogues (ASUD) (French Drug Users Movement)	France	European Network of People who Use Drugs
	Berne Stålenkrantz	Swedish Drug Users Union	Sweden	
	Eliot Albert	Gold Standard Team / Respect (UK drug user activist)	UK	
Joint Interview	Shona Schonning	Eurasian Harm Reduction Network	Lithuania	European AIDS Treatment Group - Policy working Group Treatment-related interests of people living with HIV and AIDS
	Raminta Stuikyte	Independent consultant working for EHRN, ICASO and OSI	Lithuania	
	Gus Cairns	NAM	UK	
Focus group	Yuri de Boer	AIDS Foundation East-West (AFEW)	Netherlands (NGOs based in the Netherlands)	Domestic and international NGO focused on policy development and research with a strong interest in SRHR, MSM and research
	Marieke Ridder-Wiskerke	STI AIDS Netherlands (SOAIDS)		
	Moniek A. van der Kroef	StopAIDSNow		
	Joost van der Meer	Centre for Culture and Leisure (COC)		
	Mark Vermeulen	StopAIDSNow		
Focus group	Christoforos Mallouris	Global Network of of People living with HIV (GNP+)	Free Space Programme – Global HIV Networks	PLHIV, faith, women, sex workers, civil society
	Marcel van Soest	World AIDS Campaign		
	David Barr	International Treatment Preparedness Coalition (ITPC)		
	Peter Prove	World Lutheran Federation and soon Ecumenical Advocacy Alliance		
	Kieran Daly	International Council of AIDS Service Organizations' (ICASO)		
	Beri Hull	International Community of Women living with HIV/AIDS (ICW)		
	Ruth Morgan Thomas	Global Network of Sex Worker Projects		
	Raoul Fransen	International Civil Society Support (ICSS)		
<b>Latin America and the Caribbean</b>				
Individual Interview	Joan Didier	AIDS Action Foundation	St. Lucia	PLHIV
Individual Interview	Marcela Romero	Secretariat Red Lac Trans	Argentina	Trasgender
Individual Interview	Elena Reynaga	Secretaria RedLac Trab Sex	Argentina	Sex Workers
Individual Interview	Jason McFarlene	the Jamaica Forum of Lesbians, All Sexual and Gays (JFLAG)	Jamaica	GLBT
Individual Interview	Joel Simpson	SASOD Guyana	Guyana	GLBT
Individual Interview	Leo Arenas	Secretario COASCE	Chile	NGOs and BCOs working with prisoners in the Americas
Individual Interview	Robinson Cabello	Director, Vía Libre Perú	Peru	Peruvian NGO

Individual Interview	Ionie Whorms	The Ionie Whorms Inncercity Counselling Centre	Jamaica	Substance Users
Individual Interview	Mia Quetzal	Caribbean Trans in Action	Caribbean Regional	Transgender
Individual Interview	Juan Jacobo Hernandez	Director, Colectivo Sol Mexico	Mexico	MSM
Individual Interview	Steeve Laguerre	SERovie	Haiti	PLHIV, GLBT
Individual Interview	Princess Brown	Sex Work Association of Jamaica (SWAJ)	Jamaica	Sex Workers
Individual Interview	Rachell Erazo	Redtrans	Ecuador	Transgender
Individual Interview	Marcus Day	The Caribbean Harm Reduction Coalition	Caribbean Regional	Substance Users
Individual Interview	Santiago Jaramillo	Coalición de personas viviendo VIH Ecuador	Ecuador	PLHIV
Individual Interview	Ethel Pengel	President of Double Positive	Suriname	Women living with HIV
Individual Interview	Miriam Edwards	Caribbean Sex Work Coalition (CSWC)	Caribbean Regional	Sex Workers
Focus group	Individuals not named (8)	CEEPVS	Ecuador	PLHIV
Focus group	Individuals not named (15)	Trans	Ecuador	Transgender
Focus group	Individuals not named (12)	NGOs	Ecuador	NGOs
<b>North America</b>				
Individual Interview	Valerie Pierre Pierre	African and Caribbean Council on HIV/AIDS Services	Canada	Black, African and Caribbean North Americans; Immigrants, Refugees and Migrants
Individual Interview	Shannon Ryan	Black Coalition for AIDS Prevention	United States of America	Black, African, Caribbean; Immigrants, Refugees and Migrants
Individual Interview	Richard Elliott	Canadian HIV/AIDS Legal Network	Canada	Legal Reform and Human Rights. Key work among Prisoners, people who use drugs and PLHIV
Individual Interview	Ken Clement	Canadian Aboriginal AIDS Network	Canada	Indigenous
Individual Interview	Art Zocole	Two Spirits of the First Nation	Canada	Indigenous
Individual Interview	Emily Carson	Global Youth Coalition for HIV/AIDS	United States of America	Youth
Individual Interview	Reshma Pattni	Global Youth Coalition for HIV/AIDS	United States of America	Youth
Individual Interview	Bart Major	St. Ann's Corner of Harm Reduction	United States of America	People who use drugs

## Annex B: NCPI questions relating to Stigma and Discrimination

Does the multisectoral strategy/action framework address the following target populations, settings and cross-cutting issues? (one yes or no choice: Addressing stigma and discrimination)

Does the country have laws and regulations that protect people living with HIV against discrimination? (such as general non-discrimination provisions or provisions that specifically mention HIV, focus on schooling, housing, employment, health care etc.)

- IF YES, for which sub-populations?
- IF YES, Briefly explain what mechanisms are in place to ensure these laws are implemented

Does the country have laws, regulations or policies that present obstacles to effective HIV prevention, treatment, care and support for vulnerable sub-populations?

- IF YES, for which sub-populations?
- IF YES, briefly describe the content of these laws, regulations or policies and how they pose barriers

Is the promotion and protection of human rights explicitly mentioned in any HIV policy or strategy?

Is there a mechanism to record, document and address cases of discrimination experienced by people living with HIV and/or most-at-risk populations? IF YES, briefly describe this mechanism

Does the country have the following human rights monitoring and enforcement mechanisms?

- Existence of independent national institutions for the promotion and protection of human rights, including human rights commissions, law reform commissions, watchdogs, and ombudspersons which consider HIV-related issues within their work:
- Focal points within governmental health and other departments to monitor HIV-related human rights abuses and HIV-related discrimination in areas such as housing and employment
- Performance indicators or benchmarks for compliance with human rights standards in the context of HIV efforts
- Performance indicators or benchmarks for reduction of HIV related stigma and discrimination

Have members of the judiciary (including labour courts/employment tribunals) been trained/sensitized to HIV and AIDS and human rights issues that may come up in the context of their work?

Are the following legal support services available in the country?

- Legal aid systems for HIV and AIDS Casework
- Private sector law firms or university based centers to provide free or reduced-cost legal services to people living with HIV
- Programmes to educate, raise awareness among people living with HIV concerning their rights
- Are there programmes designed to change societal attitudes of stigmatization associated with HIV and AIDS to understanding and acceptance? IF YES, what types of programmes?

Overall, how would you rate the policies, laws and regulations in place to promote and protect human rights in relation to HIV and AIDS in 2007 and in 2005? Comments

Overall, how would you rate the effort to enforce the existing policies, laws and regulations in relation to human rights and HIV and AIDS in 2007 and in 2005? Comments