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24th Meeting of the UNAIDS Programme Coordinating Board
Geneva, Switzerland
22-24 June 2009

Report by the NGO representative

Document prepared by the NGO Representatives

Additional documents for this item: *none*

Action required at this meeting - the Programme Coordinating Board is invited to: (See decision paragraphs below)

43. *request* that UNAIDS ensure that universal access targets and indicators are more accurate and appropriate, specifically supporting data collection on key affected populations and developing improved indicators on enabling legal environments and restrictions on entry, stay and residence based on HIV status, as well as on criminalization of certain behaviors, beyond the current National Composite Policy Index (NCPI) questions. We encourage UNAIDS to ensure meaningful, consistent civil society participation in work to revise and verify universal access targets and indicators.

48. *request* UNAIDS to incorporate “non-discrimination” as the fourth pillar of universal access, with programmatic implementation comparable to prevention, treatment, and care and support, to realize the human rights and law commitments made by Governments in the Declaration of Commitment on HIV/AIDS (2001) and the Political Declaration on HIV/AIDS (2006); and intensify efforts to address the policy and other barriers which inhibit effective responses to the needs of key affected populations, and to enhance their direct participation in global and national programs;

50. *encourage* governments to reaffirm commitment to, and intensify harm reduction efforts in, relation to HIV, including needle and syringe exchange and opiate substitution, essential for reaching universal access to comprehensive HIV prevention, care, treatment and support for people who use drugs;

57. *request* the UNAIDS Secretariat and WHO to support countries in the implementation and improved surveillance of hepatitis B and C including co-infection with HIV in all countries, and to develop the necessary guidelines for Member States to elaborate policies, strategies and other tools to prevent and control hepatitis co-infection in people living with HIV;

NOTE: draft decision paragraphs 50 and 57 will be introduced under this item but tabled for agreement under PCB agenda item 3: *HIV prevention among injecting drug users*

61. *request* the UNAIDS Secretariat to report at the 25th Board meeting on the anticipated impact that the financial crisis will have on countries' ability to meet their universal access targets and to include recommendations and mitigation strategies;

NOTE: draft decision paragraph 61 will be introduced under this item but tabled for agreement under PCB agenda item 2: *2010-2011 UBW*

Action required at this meeting - the Programme Coordinating Board is invited to (cont.): (See decision paragraphs below)

75. *request* UNAIDS to:

- i. *ensure* that staff at global, regional and national levels facilitate the incorporation of mobile populations into regional and national AIDS strategies to achieve universal access to prevention, treatment, care and support services, paying particular attention to HIV-specific restrictions on entry, stay and residence to ensure that people living with HIV are not excluded, detained or deported on the basis of HIV status; and
- ii. *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.

NOTE: the PCB NGOs will raise the content of the draft decision paragraph 75 as part of discussions under the thematic segment, however, given the order of agenda items the draft decisions will be tabled for agreement under agenda item 1.6.

Cost implications for decisions: *none*

EXECUTIVE SUMMARY

1. The NGO report to the Programme Coordinating Board attempts to balance the concerns from the communities and individuals who input into this paper with the set agenda for the meeting. The report this year reflects input from 35 interviewees and more than 380 consultation respondents. The consultation questionnaire focused on barriers to universal access, as well as some key questions relevant to mobile populations in relation to the thematic session of "*People on the Move*."
2. When queried about the challenges in achieving universal access to prevention, treatment, care and support of HIV and AIDS, the majority (roughly two-thirds) of respondents rated stigma and discrimination and associated policies toward key affected populations as matters needing urgent action. Discrimination against persons living with HIV and marginalization of key affected populations, including women and girls, exacerbates the barriers to achieving universal access. Moreover, criminalization of HIV transmission and of behaviors further marginalizes key affected populations, and is conducive to violence, especially against women and girls. Respondents to the PCB NGO consultation confirmed that evidence-based prevention is still lacking, as are quality prevention, treatment, care and support services that are appropriate and accessible to all in need. As a result of the analysis presented in this paper, it is clear that barriers to universal access can only be overcome through the harmonization of national legislation and policies in accordance with international guidelines for rights-based programming and policy setting. This approach must include accurate, specific and measurable targets and indicators, for which data can and should be adequately collected.
3. This report also emphasizes the necessity of ensuring that harm reduction strategies remain an aspect of the response to HIV and AIDS; the importance of the inclusion of sex workers in any policy that affects them; the recognition of Hepatitis co-infection in addressing HIV; and a request for an analysis of the impacts of the current financial crisis on achieving universal access.
4. The report makes general recommendations to the Joint Programme based on this consultation.

INTRODUCTION

5. Each year, the NGO Delegation's report to the PCB aims to highlight the major concerns stemming from our constituents, specifically those challenges which impede universal access to prevention, treatment, care and support of HIV/AIDS. Reflected in this overview are a myriad of complex and key issues at the very heart of our joint efforts to ensure universal access. This year's report is written in a difficult financial climate, one in which we must reaffirm that there is absolutely no alternative to reaching our universal access goals, and that shirking on dedicated resources now will only result in greater expenditure later, at the cost of additional lives.
6. We have used the NGO Delegation's Communications Facility (CF) to extend our consultation globally to identify the key issues raised in this report. As such, it is based on key interviews with global and regional networks, as well as an electronic consultation which was translated from English into Arabic, Chinese, Russian, Spanish, French and Portuguese. More than 380 persons provided input into the online consultation, and we have used that data, plus 35 detailed interviews by

Delegates and CF staff, as well as research reports and policy papers, to produce this report.¹

7. The survey and interview questions were divided around main challenges related to universal access and topics related to migration and mobility (people on the move). The full survey and results can be found in the last section of this report. The findings and recommendations summarized here reflect those matters that came up repeatedly and resonated across constituencies.
8. The NGO Delegation's goal in this report is to bring to the attention of the PCB the concerns and voices of people on the ground - the people who are at risk for HIV, those living with the virus, and those who serve them in community based organizations. The overarching message that came from respondents is that we are still in denial over many of the populations at risk for, and living with, HIV – in denial of the existence of these groups, the behaviors that place them at risk, and the interventions required to adequately provide prevention, treatment, care and support. To turn the tide of the epidemic, we have to move beyond that denial, and address the issues at hand with adequate resources, evidence-based policies, persistence and courage. Stigma and discrimination topped the list of barriers to universal access. Stigma is linked to many of the challenges mentioned and underlies our inability to respond adequately. We have much to do, but we cannot lose sight of our goals because there are lives - and deaths – behind these issues. To respect, protect, and fulfill the human rights of people living with HIV is essential to curbing the HIV and AIDS epidemic and mitigating its devastating effects.

KEY CHALLENGES TO UNIVERSAL ACCESS

9. Stigma and discrimination, and the policies that stem from and reinforce them, emerged from this consultation as widespread and critical barriers to reaching universal access. This section is devoted to providing more detail on nine key challenges to reaching universal access that came up often in the consultation. As a summary, it leaves out much of the richness of the responses we received. Detailed results and the list of questions can be found in the final section of this report.

A. Identifying and reaching key affected populations, including women and girls

“China’s four Free One Care policy, means providing free counseling, testing services, ARV treatment, prevention of mother to child transmission, and support for children or people living with HIV and AIDS. But in reality, groups such as migrants or people who use drugs cannot benefit fully from the policy.”²

¹ This report reflects input from anonymous and named members of civil society who were kind enough to interview or make comments in the questionnaire. We greatly appreciate all the feedback. Quotes from survey comments and interviews are left anonymous in the report. Feedback includes input from members of ActionAid, GNP+, World AIDS Campaign, ICW, CARAM Asia, ACHIEVE Philippines, ITPC, HIV and AIDS Alliance, Sex Work Project, Canadian Aboriginal AIDS Network, International Indigenous HIV/AIDS Secretariat, Canadian HIV/AIDS Legal Network, Coalition for Accessible AIDS Treatment, Women's Health in Women's Hands, African and Black Diaspora Global Network on HIV/AIDS, Raks Thai Foundation, Ecumenical Advocacy Alliance, TAMPEP Network, HEARD, NAP+, CANASO, African CSO Coalition, PWW Netherlands, Eurasian Harm Reduction Network, HIV-Sweden, Center against Stigma and Marginalization (CASAM), The Network of Sex Work Projects, Jamaica AIDS Support for Life, Juncata Juvant Friendly Society, Sunshine Cathedral Jamaica.

² Interview quote, Asia

10. The global HIV and AIDS response has not adequately reached key affected populations, including women and girls, which have concentrated or generalized epidemics. Notably in Africa, gender inequality and the socio-economic status of women have led to the fueling of the epidemic. This is due to a number of factors, including political will and stigma and discrimination. In order to achieve universal access and best address concentrated epidemics before they become generalized, we have to identify, name and engage with members of these key groups. Women and girls, people who use drugs, incarcerated persons, indigenous peoples³, sex workers, and men who have sex with men continue to need tailored and focused efforts at all levels. Especially relevant to the discussions of the 24th PCB, migrants, temporary and permanent, documented and undocumented and persons in transit, refugees and asylum seekers must be addressed as well.

B. Stigma and discrimination

“There are multi-faceted, intersecting dimensions of stigma and discrimination based on HIV status, race/racism, gender, sexual orientation, poverty/unemployment/underemployment and immigration status.”⁴

11. Stigma and discrimination were constantly mentioned as obstacles to universal access regardless of region or constituency group. Stigma and discrimination produce barriers to representation and mobilization, restricting access to services for those in need; serving as justification for reallocation of funds to those less politically sensitive; and affecting the families, health and personal safety of people living with HIV, as well as groups such as sex workers, people who use drugs, and men who have sex with men (MSM). Stigma limits disclosure to partners and discourages persons living with HIV to seek treatment or confirmation of their status via testing.⁵
12. In practice, stigma and discrimination can mean that spending is disproportionate to need. For example, in Africa and in the Caribbean, harshly condemnatory laws and policies on sex between men and legal restrictions on sex work are common in a context of disproportionately high rates of HIV infection amongst these groups. In practice, they receive practically no direct funding for prevention because these groups are not recognized. Many governments in Eastern Europe and Central Asia do not recognize that HIV epidemics in each of the countries in the region are driven primarily by injecting drug use, and provide low levels of national funding to harm reduction programs (in some countries, all prevention programs are supported by external donors). This can be attributed to the wide-spread stigma of and discrimination against people who use drugs.
13. Stigma is present at all levels of society. Some respondents suggested that to understand what is driving stigma, we need to start at family and community levels. Some respondents from Africa and elsewhere reported greater acceptance of marginalized communities by health workers, but globally stigma still pervades the current system of health service provision. Health workers may make treatment for sex

³ It is a challenge that countries where there are the largest Aboriginal populations are often the richest (Australia, Canada, NZ, US, Northern Europe). This leads to an under attention globally despite these populations having epidemics, and living conditions, that are more similar to developing world situations. There is great need for an international forum that can mobilize attention and act as knowledge exchange for HIV/AIDS issues in indigenous peoples. – NA Interview

⁴ Interview quote, North America

⁵ This is much documented, for example in the Human Rights Watch Report, *Hated to Death*: www.hrw.org/en/node/11894/section/1

workers or MSM humiliating and difficult to the point that they will not access services.⁶ In India, Hijras and IDUs are regularly denied access to services. Stigma is also undermining sexual and reproductive health programs particularly for positive women. Sexual and reproductive health and family planning needs go unmet, for example in parts of Asia, due to discrimination in health care settings. Or in Latin America, health workers often judge PLHIV, especially men who have sex with men; as one interviewee said “some of the health workers think we deserve to die.”⁷

14. The faith based organizations (FBOs) which were interviewed recognize stigma as a major barrier and are working to fight it. While recognizing that more needs to be done by all, many FBOs remain an active part of the civil society response to stigma and discrimination. The challenge for many Caribbean faith-based organizations is to resist preaching redemption or conversion that focuses on pushing members of key populations to convert and change their lifestyles. This has been cited as a major deterrent to these groups accessing services. One particularly progressive reverend said “we do not want persons to change their sexuality or, in the case of sex workers, their profession. All persons, especially sexual minorities and sex workers, are welcomed to access all our services. We affirm their sexuality and profession.”⁸
15. Stigma exists specifically around migrant populations. Commonly held beliefs that migrants are “carriers of disease” or will serve to “bankrupt” the existing health system reinforce stereotypes and ill-feelings towards migrant communities. Discrimination based on sex, sexual orientation, as well as stigma based on migration status often overlap with stigma around HIV and reinforce discrimination, thereby further limiting access to services.
16. People from the ‘South’ who relocate to the ‘North,’ whether they be from Africa, the Caribbean, Asia or Latin America, face tremendous stigma, discrimination, and stress related to migration and resettlement. Cultural isolation, poverty, unemployment, underemployment, and lack of access to health services, education, and information, adds to this and HIV becomes one more additional burden to the struggles of daily living. The stigma of HIV and migration makes disclosure and access difficult even where services are available.

C. Criminalization of persons, behaviors and transmission impedes universal access

“Today one of the most pressing issues in the AIDS epidemic is the use of criminal statutes and criminal prosecutions against HIV transmission. Such laws are increasingly wide in their application and frightening in their effects. HIV is a virus, not a crime. That fact is elementary, and all-important. Too often law-makers and prosecutors overlook it.” - Edwin Cameron, Justice of the Supreme Court, South Africa⁹

17. Laws and policies that counter rights-based and evidence-based approaches have led to increasing fear among various communities. Criminalization of communities leads to

⁶ One potential solution to this is the presence of NGO personnel, but this level of accompaniment requires that enough NGO staff be available to do this. NGOs simply do not have the human resources to be available for this support.

⁷ Interview, Latin America

⁸ Interview, Caribbean

⁹ IPPF press release on publication: “Verdict on a Virus: Public Health, Human Rights and Criminal Law,” 13 November 2008.

further marginalization and stigma and discrimination, and less access. Forcing already marginalized communities of key affected populations into hiding by criminalizing sexual behaviors, sex work and transmission of HIV hinders universal access. In places where HIV transmission is criminalized or where it can be used as evidence of a crime of a sexually-related activity (adultery or sex work), people will not seek treatment or voluntary counseling and testing. They may avoid testing, treatment or care, or go to informal health practitioners out of fear. These points are not new, and the fact that they are still raised at community levels as key issues means that we have not yet found, advocated for, shared or implemented the right approaches at global and country levels.

18. HIV transmission is still criminalized in too many countries. In 2008, no less than 86 member states of the United Nations still criminalized consensual same sex acts among adults. Among those, seven have legal provisions with the death penalty as punishment. In most countries around the world, drug use is regarded as a criminal or administrative offense.
19. Criminalization “model” laws remain a concern in Africa. In places where stigma is rampant, criminalization laws become a mechanism for further exclusion. The problem is not just restricted to the global south; in northern countries as well, HIV criminalization laws are bringing prosecutions and debate.¹⁰ Breaches of confidentiality by medical practitioners around patients’ HIV status is contrary to human rights and leads to further discrimination, especially in settings where transmission is criminalized.¹¹

D. Lack of harmonization of national laws with international legal frameworks

20. Beyond the challenge of having constructive (rather than destructive) laws, national laws need to be harmonized with international laws, particularly international human rights law. National legal frameworks that provide a supportive, rights-based environment are important to achieving universal access. In the case of reducing the risk and vulnerability of women and girls to HIV, for example, the legal framework of every country must support: equality and non-discrimination on the basis of sex; equal access to inheritance and property laws; agreed consent to marry; the liberty to make free and informed choices over their sexuality and reproduction, including deciding on the number and spacing of children; sexual and reproductive rights; ending violence against women, including rape and rape within marriage and all forms of sexual violence; freedom of association and political participation; education and health care; equal opportunity and equality in the labor market.
21. Harmonization of national and international laws is fundamental to many key affected populations, as well as people on the move who may be able to access services in one country but not in another. Mandatory testing is one important example where national policies often contradict one another and international human rights standards. In the case of migrants, mandatory testing is discriminatory and used to refuse entry and stay by destination countries. In some cases in Asia, national polices prevent mandatory testing, but migrant workers are excluded from such protections. This mandatory

¹⁰ NA interview and see, for example, case in Switzerland, 11 March 2009.

<http://criminalhivtransmission.blogspot.com/2009/02/switzerland-swiss-courts-accept-swiss.html>

¹¹ The recently proposed HIV and AIDS Prevention and Control Bill in Uganda, for example, criminalizes HIV transmission and allows medical practitioners to disclose status at their discretion.

testing is often carried out without informed consent or counseling.¹² Confidentiality is breached when test results go directly to the recruiting agency and such information is shared with other recruiters.¹³ In Latin America and in the Caribbean, mandatory testing for visa applications to the US encourages people to use dangerous alternative entry routes.

22. Once in a country, mandatory testing makes individuals vulnerable to unethical deportation. In most countries of Eastern Europe and Central Asia (except for Azerbaijan, Georgia and Kyrgyzstan), HIV testing is mandatory for foreigners. Each time a person needs to prolong his or her visa, s/he needs to present a certificate of HIV status. If one is reported HIV positive, s/he is subject to immediate deportation. This practice often leads to incarceration and disruption of treatment.
23. Some migrants are able to access services based on their HIV status while their residency status is unstable. They may have access to ART, based on a temporary residency permit, but as the status of their residency application changes, they may lose access. A recent study from the Netherlands¹⁴ discussed the case of treatment access and irregular migrants and found that an individual can only voluntarily return to the country of origin if care and treatment are available and accessible in a supportive environment. Their recommendations can only be upheld in a harmonized international legal environment, where all countries respect the same protocols.

E. Violence, especially violence against women

“Rape and violence against women and girls in Latin America due to the rampant macho culture is a fact, but the linkages with HIV infection, risk and vulnerability are not made explicit for health workers, policy makers or even the women and men. The opportunities for women and girls are scarce and the cultural system encourages the continuity of systems that silence women and encourage men not to take responsibility.”¹⁵

24. Violence against women was highlighted as a prime issue in every region; yet the international community is not sufficiently linking violence against women and HIV on the ground. Violence against women includes all women - women in marriage who remain at home, women who work as sex workers, young women who are still living in their parental households, girls, women who are mobile. Women’s vulnerabilities in each of these situations are different and are not being adequately addressed.

¹² The women working group of the Asia Pacific Network of People Living with HIV and AIDS (WAPN+) study of positive women and girls with HIV and access to services supports these conclusions: “Of the Chinese respondents, 70.4% said they did not know they were being tested for HIV at the time and only 36.5% received counseling after their diagnosis. Women who identified as sex workers were more likely to know that they were being tested compared to other women (73.5% vs. 61.2%). Whether or not women knew they were being tested for HIV was significantly related to their reason for testing: only 32.1% of blood donors and 45.0% of respondents who tested for employment purposes were told they were being tested for HIV beforehand. Many migrant workers had mandatory testing in the host country without counseling.” From APN+ Women working group (WAPN+), “Research on Access to HIV Treatment and services for Women and children,” March 2009.

¹³ CARAM Asia, “Removal of Mandatory HIV Testing for Migrant Workers” policy brief.

<http://www.caramasia.org/programs/policybrief6.pdf>

¹⁴ IOM, “Health, Hope and Home?” January 2009. In this case, the study concluded that the voluntary return of HIV-positive Africans living in the Netherlands as irregular migrants could only be feasible if:

- a. Necessary medical treatment is available and the returnee has durable access to such treatment;
- b. Returnee can acquire sufficient income to cover regular expenses of him/herself and the family and to cover all costs related to medical treatment;
- c. The returnee finds a place within a supportive social network.

¹⁵ Interview, Latin America

25. One in three women will face some form of violence during her lifetime. In high-prevalence countries, HIV risk may be up to three times greater for women who have experienced violence, than for those who have not. It is known that women report that violence and fear of violence make it even more difficult to disclose their HIV status and to seek treatment, care and support services. Violence against women, and the fear it generates, diminish women's ability to negotiate risk reduction with their sexual partners.¹⁶
26. Some women are doubly vulnerable, such as women who are sex workers and women who are injecting drug users. Respondents mentioned cases of sexual abuse of undocumented workers, terrorizing drug users, the specific vulnerability of migrant sex workers, and sexual harassment of female drug users in Asia. Amongst people on the move, special attention must be paid to women, especially as more women migrate alone.¹⁷
27. Violence on the part of law enforcement during raids was also frequently mentioned. These gross violations of human rights that result from policies that intend to curb commercial sex work, often result in psychological and physical violence towards the persons involved. After such measures, persons living with HIV in detention are often denied access to life-saving medications and treatment. In some instances, respondents note that this has led to first line treatment resistance. Furthermore, sex workers report that they often experience violence from their customers, as well as from authorities.¹⁸ Violence targeted at sex workers is usually carried out by those unlikely to be prosecuted for their actions. The police and military in many countries abuse their power with impunity knowing that the likelihood of a sex worker reporting the crime is low.
28. Policymakers and law enforcement officials must address and condemn violence against women and girls. HIV programs must also confront police violence and enable support programs to sensitize police and prosecute law enforcement officers for crimes committed; ensure sexual assault and psychological counseling for victims of violence; and ensure legal protections and needed legal support for women in situations of violence, including within their homes. Furthermore, women's access to comprehensive sexual and reproductive health services, including confidential VCT and protection from violence, stigma and discrimination that may result from disclosure of status, are necessary to stop violence against women and to lower the impact of HIV.

¹⁶ Women Won't Wait: www.womenwontwait.org

¹⁷ Feminization of migration is the recent trend, with more women migrating alone, rather than for family reunification. Global population mobility is a complex, heterogeneous and growing phenomenon. In 2005, 3% of the global population (United Nations Department of Economic and Social Affairs/Population Division: Trends in Total Migrant Stock: The 2005 Revision/International Labour Organization: HIV/AIDS and Work in a Globalizing World) were migrants. In the same year, 8.4 million refugees UNHCR: 2005 Global Refugee Trends. Statistical Overview of Populations of Refugees, Asylum-Seekers, Internally Displaced Persons, Stateless Persons, and Other Persons of Concern to UNHCR,) and 23.7 million internally displaced people in 50 countries (UNHCR (2006): Internally Displaced People) were seeking shelter and safety. Due to various gender-related factors, the proportion of migrants who are women is increasing, with women now accounting for approximately half of the global migrant population.

¹⁸ Highlighted at <http://jamaicaaidssupport.com/humanrights/index.htm>. Their vulnerability to HIV and also their inability to access treatment are further highlighted by the documentary "Simple Solutions to Complex Things."

F. Inadequate evidence-based prevention

29. The increased attention on prevention, as noted by Michel Sidibe in his letter to partners as well, is welcome and the need to scale up evidence-based prevention was echoed in this consultation.
30. Basic prevention supplies such as male and female condoms, lubrication and clean needles remain unavailable, inaccessible, in short supply, and, in many places, of poor quality. Condom stock outs still occur in South Asia and Africa, among other places. Prevention must include providing effective, widespread and scaled up production and availability of female condoms as well as condoms and lubrication for men. In some cases, outreach workers limited the number of condoms they give out or who can access condoms, somehow equating a moral judgment with sexual activity. In the same vein, we must continue to push for evidence and not ideology-based prevention programs. Piloting and scaling up successful interventions to build an evidence base is also important to working quickly and continuously to reach those in need. Some faith based organizations feel excluded, and that there is a bias in engaging FBOs in prevention due to perceived attitudes toward condom use and sexual and reproductive health programs.¹⁹
31. Prevention must include comprehensive sexuality education and access to comprehensive sexual and reproductive health services and information, including for young people. Prevention and treatment services must be available and affordable, and also accessed voluntarily, without judgment or coercion, and free of stigma and discrimination.
32. Harm reduction practices continue to be debated despite clear evidence supporting their importance to HIV prevention. Prohibitionist and coercive measures to limit sexual and drug using behavior are known to perpetuate risk whereas harm reduction practices have been shown time and time again to significantly reduce transmission. Prevention policies must reflect current scientific evidence which support harm reduction practices especially in prisons, among drug users, street youth and among sex workers.

G. Limited accessibility to, and low quality of, services

“In Central Asia, where the health care service is still limited and the quality of services is not as high, PLHIV still suffer from not being able to receive appropriate basic health care services. Distance often plays an important role. In many cases PLHIV in Central Asia have to travel from one province to another to get basic health care, not to mention HIV treatment that PLHIV need to be receiving on a regular basis. ARV drugs, CD4 test and viral load tests are also far from being affordable (if not because of the distance). These factors have a huge influence on the lives of PLHIV both in Central Asia and some countries in South East Asia, most of which live in rural areas and below the poverty line.”

33. “PLHIV often report incompetence of health care service providers. Confusing referral services and traditional long and complicated bureaucratic process at hospitals often scare PLHIV and prevent them from seeking treatment and necessary support. Many PLHIV find the NGO sectors to be more useful sources of information regarding HIV.”²⁰

¹⁹ Interview, Europe

²⁰ Interview, Europe

34. Women need a full range of comprehensive sexual and reproductive health services, including maternal and child health services. This includes continuing support for women, both before, during and after giving birth, so as to ensure comprehensive services within a continuum of care, not just to prevent vertical transmission.²¹
35. Mobile workers may be able to access treatment in one area but not in another. In China for example, mandatory household registration means that a worker may have to travel many miles to return to the province where his or her household registration is based to access HIV-related services and treatment. Migrant fishermen, for example, may be able to access services in treatment in one port but not another, making health care inconsistent and influencing adherence to treatment.

H. Inappropriate services

“Access to information, treatment and services is limited by language, social cultural and structural barriers.”²²

36. There is no one formula for HIV programming that meets the needs of a diversity of individuals and their specific residence, language, culture and mental states. Stigmatizing and condescending behavior on the part of health workers has already been mentioned as one barrier to accessing and providing services. In addition, the appropriateness of services is important. Services modeled on the needs of gay men and drug users rarely fit the needs of ethno-culturally diverse populations. All regions mentioned language translation and presentation of information in a culturally appropriate manner as immediate needs to reach key affected populations, including women and girls.
37. In many cases, there are no strategies in place that incorporate migrants, whether temporary workers or people seeking permanent migration. Migrants’ realities are not addressed. Beyond differences in language, culture, and education levels, there are psychological pressures associated with fear, instability and general feelings of being unwanted or hidden from the system or population.

I. Weakness of targets and indicators for universal access

38. Ideally, one of the key areas of civil society engagement should be in the setting of targets and development of key indicators to measure universal access targets and impact. This is especially critical where populations are marginalized through stigma, discrimination and social and political norms, as the capacity of governments to engage these populations is highly restricted. Therefore, the support and participation of civil society is essential to ensuring an effective, evidence-based national response. Civil society is therefore vital to the monitoring process, yet communities report that participation is limited and uneven across the globe. There remain countries where there are no openly HIV-positive people involved in planning and monitoring activities. In the case of key affected populations, involvement of civil society in setting targets is the exception rather than the norm, due to the criminalization of behaviors such as sex work, drug use, and sex between men and very high levels of stigma and discrimination, limiting the capacity of affected communities to organize and the level of trust in ‘official’ processes.

²¹ Interview, North America. And comment from Africa that PMTCT uptake is still greatly needed in many countries, especially in Africa.

²² Interview, North America

39. For example, in the Ukraine, a participatory process saw key stakeholders set targets and devise a method to estimate population sizes of key affected populations. In other countries, this involvement was seen as more tokenistic, or not adapted to local circumstances. In Latin America, regional networks of MSM, sex workers and transgender people report attitudes which vary from open acceptance of the challenge faced by a country to what amounts to an official denial of the reality of the epidemic. Of the Latin American countries with published universal access targets, only half have included targets related to key affected populations – despite the presence of concentrated epidemics in all of them.²³
40. As the ICASO review on progress in the Declaration of Commitment points out: “The continued lack of appropriate indicators and data collection related to key populations most relevant to the dynamics of the epidemics, especially on human rights and legal protections, is a fundamental barrier to monitoring progress in implementing the commitments.”²⁴ The panel on leadership in concentrated epidemics at the June 2008 UN HLM held in New York heard that, in the case of some key affected populations, less than 25% of countries reported against all indicators in respect of those populations.
41. Equally important to the standard and applicability of the indicator is the ability of a country to collect data. A country may not adopt a given indicator, or, in many cases, a country may lack the will or capacity to collect accurate and complete data. Most importantly, while some indicators single out key affected populations, including women and girls, governments are not required to use or report on those indicators. In concentrated or low-level epidemic scenarios, this means that governments can meet a population-wide target while overlooking rapid rises in prevalence among key affected populations. Therefore, the temporary success in reaching a target does not necessarily reflect progress as a whole against the spread of HIV, nor will it prevent a concentrated epidemic from becoming generalized. In short, it is not an accurate measure of progress toward universal access. In many cases governments are reporting on their own compliance, with no outside verification.
42. As we have seen in the “What Countries Need” report, the cost estimates for reaching universal access within countries are based on “country-led” targets in the 111 countries that have fixed targets and a composite in cases where countries have not yet set targets. The use of a composite number does not necessarily accurately reflect reality, as the epidemic differs from country to country and community to community. As well, the legitimacy of the country level targets being inclusive of all stakeholders is questionable in some countries. Civil society had repeatedly pointed this out and attempted to engage with UNAIDS in the process of developing targets, but that engagement has varied in quality and consistency, as evidenced above.
43. **Therefore, the Programme Coordination Board is invited to request that UNAIDS ensure that universal access targets and indicators are more accurate and appropriate, specifically supporting data collection on key affected populations and developing improved indicators on enabling legal environments and restrictions on entry, stay and residence based on HIV status, as well as on criminalization of certain behaviors, beyond the current National Composite Policy Index (NCPI) questions. We encourage UNAIDS to ensure meaningful,**

²³ From International HIV/AIDS Alliance, Briefing for 2008 UN High Level Meeting on AIDS

²⁴ ICASO, *Declaration of Commitment on HIV/AIDS and Political Declaration on HIV/AIDS: A review on progress from the community sector*, 2008.

consistent civil society participation in work to revise and verify universal access targets and indicators.

44. Another cause for concern is the dramatic downward revision in the financial estimates, which has provoked debate and requests from civil society for more information. National targets were not linked to costing and budgeting in many countries. UNAIDS should focus on how national budgets are linked to universal access targets and provide assistance to governments in making these links. This will be especially relevant in the current economic climate.

45. UNAIDS should work to align universal access goals and its own unified budget and work plan. Recalling the decision of the 23rd PCB in which the PCB:

“5.2 Agrees that future planning and reporting should: focus on results, take into account lessons and obstacles; include indicators that relate to wider development; aim to simplify data; include information on the impact of activities, qualitative and quantitative reporting, cross-cutting issues such as gender equality and human rights; and data disaggregated to the extent possible by categories such as country, Co-sponsor, age and sex;”

46. There is a need to ensure that future planning and reporting data also include key affected populations and reiterate the need for information on human rights and disaggregation by sex and age. In gathering country-related information, efforts should be made to include data on people on the move, attempting to differentiate reasons for and type of mobility.

47. Given all of the above the PCB NGOs wish to emphasize the need for the application of a rights-based approach to universal access in a new era of UNAIDS leadership. A rights-based approach is one that ensures that all persons in need have equal access to HIV prevention, treatment care and support, including the most marginalized; that all affected populations have the right to participate in program design and delivery; that governments, donors and the UN system are transparent and accountable; and that specific programs are implemented to support affected populations and communities to have access to justice in the context of HIV. The rights-based approach also helps to avoid the polarizing vertical versus horizontal debate.²⁵ A rights-based approach will promote harmonization of national and international laws, of law enforcement practices and public health initiatives. All persons affected by HIV, including migrants who may be less familiar with local legal environments, need to know their rights and laws that will help them to avoid infection and live positively.

48. Therefore, the Programme Coordinating Board is invited to request UNAIDS to incorporate “non-discrimination” as the fourth pillar of universal access, with programmatic implementation comparable to prevention, treatment, and care and support, to realize the human rights and law commitments made by Governments in the Declaration of Commitment on HIV/AIDS (2001) and the Political Declaration on HIV/AIDS (2006); and intensify efforts to address the policy and other barriers which inhibit effective responses to the needs of key affected populations, and to enhance their direct participation in global and national programs.

²⁵ UNAIDS Reference Group on HIV and Human Rights, Recommendations Brief to Michel Sidibe, UNAIDS Executive Director, January 2009, p. 1.

ADDITIONAL ISSUES OF CONCERN

A. Commission on Narcotic Drugs

49. Civil society applauds the fact that the United Nations Declaration on International Cooperation towards an Integrated and Balanced Strategy to Counter the World Drug Problem finally mentions HIV and reaffirms their commitment to universal access to comprehensive HIV prevention and care. However, the final text of the Political Declaration significantly undermines harm reduction as an evidence-based strategy of HIV prevention, care, treatment and support for injecting drug users. In a set back to the advances made in the PCB, notably the UNAIDS Policy Position Paper on Intensifying HIV Prevention,²⁶ the report of the 52nd Commission on Narcotic Drugs session omitted direct mention of harm reduction measures in relation to HIV, including needle and syringe exchange and opiate substitution that most international public health experts endorse as essential for successful HIV prevention and treatment. Unfortunately an international coalition of nations opposed to referring to harm reduction is insisting on an international approach to drug control established in 1998 that focuses on restricting supply, and has not proven effective.²⁷
50. **Therefore, the Program Coordinating Board is invited to *encourage* governments to reaffirm commitment to, and intensify harm reduction efforts in relation to HIV, including needle and syringe exchange and opiate substitution, essential for reaching universal access to comprehensive HIV prevention, care, treatment and support for people who use drugs.**

B. Guidance note on sex work

51. The policy of UNAIDS must be inclusive and realistic to be effective. Consultations with civil society and the meaningful engagement of sex workers themselves in the development of the guidance note must be taken seriously. The framing of the guidance in a participatory, rights-based approach means that we are addressing the issue of HIV within sex work, not combating the existence of sex work itself. In addition to that any programming on sex work must be expanded to include transsexuals, MSM and heterosexual men in addition to women.
52. The guidance note fails to address decriminalization. While it quotes from the guidelines on HIV and human rights, it fails to endorse the premise that criminal laws targeting sex workers must be removed in order to implement HIV programs and to protect the human rights of sex workers.

²⁶ In the 2001 Declaration of Commitment, Member States recognized that “effective prevention, care and treatment strategies will require behavioral changes and increased availability of and non-discriminatory access to, inter alia, [...] sterile injecting equipment” and committed to taking action to “develop and/or strengthen national strategies, policies and programmes [...] to promote and protect the health of those identifiable groups which currently have high or increasing rates of HIV infection [...] and most vulnerable to new infection as indicated by such factors as [...] drug-using behaviour [...]”

In the PCB, Member States endorsed the UNAIDS Policy Position Paper: Intensifying HIV Prevention that identifies the essential HIV prevention policy and programmatic actions. These include “Preventing transmission of HIV through injecting drug use—by developing a comprehensive, integrated and effective system of measures that consists of the full range of treatment options, (notably drug substitution treatment) and the implementation of harm reduction measures (through, among others, peer outreach to injecting drug users, and sterile needle and syringe programmes), voluntary confidential HIV counselling and testing, prevention of sexual transmission of HIV among drug users (including condoms and prevention and treatment for sexually transmitted infections), access to primary healthcare, and access to antiretroviral therapy.”

²⁷ <http://www.aidsmap.com/en/news/F4D04E80-FA29-4ECD-8A75-5722558DE46A.asp>

53. In addition, the guidance quotes from the “Independent Commission on AIDS in Asia”²⁸ report but fails to call for the decriminalization of sex work and male to male sex; or a review of laws criminalizing drug users and services for drug users (all of which was suggested in the report and supported by the UN Secretary General).
54. Finally, the document encourages evidence-based programming, yet promotes strategies that have no evidence base, such as microfinance as an alternative to sex work and the goal of ending male demand for commercial sex.
55. “As funding continues to be available for programs addressing the health needs of sex workers, it is imperative that sex workers themselves inform the decisions made about their lives and their communities. This is more than just an ethically-sound approach to public health; it is essential for effective, efficient and sustainable programming. Conflating sex work with trafficking, terrorizing brothel areas, giving women sewing machines as tools of “salvation,” and forcing condom use are all examples of policy informed by ideology and not evidence. Preventing HIV/AIDS and creating meaningful change in sex workers’ lives is a real possibility with proven success stories and we must continue promoting sex workers’ rights and not policy makers’ ideologies.”²⁹

C. Recognition of the critical role hepatitis co-infection plays in HIV prevention, care, treatment and support, among injecting drug users and other people living with HIV

56. One of the many effects of stigma and the lack of recognition of key affected populations is the slow move to address Hepatitis C and HIV co-infection. We recognize the advancements made in drawing attention to tuberculosis and HIV co-infection, which remains a key issue and leading cause of death in PLHIV in Africa. We applaud the focus on tuberculosis in the thematic session of the 22nd Programme Coordinating Board, in which the Board requested *“that WHO and the UNAIDS Secretariat to look at ways in which they can initiate work among the Cosponsors on HIV and Hepatitis C Virus co-infection and report back at a future Programme Coordinating Board meeting”*.
57. **To move to action on this issue, the Programme Coordinating Board is invited to request the UNAIDS Secretariat and WHO to support countries in the implementation and improved surveillance of hepatitis B and C including co-infection with HIV in all countries, and to develop the necessary guidelines for Member States to elaborate policies, strategies and other tools to prevent and control hepatitis co-infection in people living with HIV.**

D. The current economic crisis

58. The current global economic and financial crisis is likely to severely limit the ability of resource-poor countries to scale up their efforts to meet universal access targets. The annual growth rate in most developing countries is expected to be cut by one third to half.³⁰ With less revenue available, many countries will have trouble meeting current

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[http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/20080326_asia_commissi
on.asp](http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/20080326_asia_commissi
on.asp)

²⁹ Interview, Asia

³⁰ World Bank and IMF estimates, November 2008, January 2009 and February 2009.

[http://web.worldbank.org/WBSITE/EXTERNAL/NEWS/0,,contentMDK:22121605~pagePK:64257043~piPK:437
376~theSitePK:4607,00.html](http://web.worldbank.org/WBSITE/EXTERNAL/NEWS/0,,contentMDK:22121605~pagePK:64257043~piPK:437
376~theSitePK:4607,00.html)

commitments let alone undertaking ambitious efforts to scale up prevention, care, treatment and support.

59. As one of the major funders of programming in HIV and AIDS, The Global Fund is projecting a shortfall of between 4 and 10 billion to meet the funding needs over the next two years.³¹ Under the current economic climate, donor countries may find it difficult to maintain their current commitments, never mind increasing their pledges to meet the growing funding required as programs are scaled up.
60. We have already received reports from some NGOs providing treatment saying that their reduced funding will result in fewer people being enrolled in treatment programs. We are concerned that if supplies of ARVs are limited there may be interruptions in treatment which is likely to cause resistance, which in turn would require evermore expensive drug combinations. Treatment regimes may be changed to accommodate fewer drugs being available. Limited funding may cause some to consider denying access to treatment for key affected populations.
61. **Therefore, the Programme Coordinating Board is invited to *request* the UNAIDS Secretariat to report at the 25th Board meeting on the anticipated impact that the financial crisis will have on countries' ability to meet their universal access targets and to include recommendations and mitigation strategies.**

GENERAL RECOMMENDATIONS FOR THE JOINT PROGRAMME

62. The feedback from civil society in this report points overwhelmingly to stigma and discrimination as barriers to universal access. While there is no one mechanism to overcoming stigma and discrimination, breaking down stereotypes and including persons from key affected populations in design, implementation and monitoring of programs are critical steps in overcoming the negativity and biases that lead to marginalization, in tandem with ensuring an enabling legal environment. This section reflects general recommendations that came from consultations, many of them focused on the role of UNAIDS.

A. Ensure more, accurate, disaggregated data collection for evidence-based policy making

63. In several countries, low prevalence equals low funding and prioritization when it should mean high concern. Respondents pointed out missing or unreliable data from low prevalence countries, such as, Slovakia, Czech Republic, and other countries in Central and South Eastern Europe, as well as Arab and Muslim countries, where AIDS is less recognized as a priority social and health issue. UNAIDS must strengthen data collection mechanisms to ensure evidence-based programming designed on an accurate understanding of local epidemics.
64. Accurate data in health facilities can help to build an evidence base that dispels myths around health care access. In one informal country study, for example, data collection showed that, contrary to stereotypes of migrants "bankrupting" health systems, nationals consume the majority of health budgets compared to migrants.³² Evidence such as this will help break down stereotypes and fight stigma and discrimination.

³¹ See updated demand estimates of the Global Fund as of March 2009 at http://www.theglobalfund.org/documents/replenishment/caceres/Updated_Demand_Estimate_March2009.pdf, GF press releases and UNAIDS website appeal from Secretary General

³² Interview, Europe

Collecting data about different types of persons on the move can also help to better identify needs of different types of migrant communities. We recommend that UNAIDS support governments and national and community health workers in collecting accurate, anonymous and disaggregated data on the use of health services.

B. Convene UN agencies, governments and civil society

65. UNAIDS must do more to harmonize policies and facilitate interactions amongst Co-sponsors and across the UN system. UNAIDS is well placed to bring together needed expertise from across different agencies and sectors. Because no one place has all the requisite expertise, it is imperative that UNAIDS work to fulfill this role. The Commission on Narcotic Drugs is but the most recent example of the need for greater harmonization and policy coherence across the Programme and the UN system.
66. UNAIDS is also well placed to convene different parts of national governments (including the executive, legislative and judicial branches) and hold regional meetings to bring together different governments. This role is especially critical to address cross-cutting and cross-border issues. In cases where there is no strategy for migrant populations, it is often unclear who is responsible for service provision.³³ We recommend that UNAIDS use its role as convener to promote universal access to prevention, treatment, care and support services all along the mobility and migration continuum from departure, through travel, through settlement in destination community or country and to return and reintegration, including for undocumented persons.

C. Facilitate technical assistance

67. In many cases, organizations within UNAIDS are seen as the facilitator of technical support. Some respondents reported difficulty in accessing regional Technical Support Facility (TSF) funds. As part of the implementation of decision 3.2 of the 23rd Programme Coordinating Board which requested *“UNAIDS update its technical support and capacity development strategy through an inclusive process involving implementing countries and civil society”*, we recommend that UNAIDS review TSFs with the intent of making them more user friendly and less bureaucratic, and to determine what technical assistance is not covered by TSF support in order to develop long term, comprehensive capacity.
68. Civil society brings concrete results and is present to provide services on the frontlines, but struggles to increase funding to improve its own capacity. One of the most high profile arenas of civil society participation at country level is on the Country Coordinating Mechanisms (CCMs). As the October 2008 report on *“Missing the Target”* points out, much more needs to be done to strengthen this role.³⁴ Specifically, civil society organizations at local levels must be able to advocate for their own issues, in a manner that is appropriate to their situation and maintains local pressure. The reach of global bodies is not sufficient to ensure pressure to change at the country level; only national and local civil society can do this. We, therefore, suggest that

³³ With the addition of parliamentarians, the NGO Delegation supports the recommendations coming out of the High Level Multi-Stakeholder Dialogue on HIV Prevention, Treatment, Care and Support for Migrants in the ASEAN Region, notably the suggestion to: “Involve relevant stakeholders, such as Ministries of Foreign Affairs, Health, Labour, Interior and Social Welfare, as well as civil society organizations, migrant representatives, the private sector and United Nations agencies and international organizations as equal partners in addressing the needs of migrant workers and ensuring that there is sustainable financial means to support their collaborative action that will ensure access to HIV services for migrants.”

³⁴ ITPC, “CCM Advocacy Report: Making Global Fund Country Coordinating Mechanisms work through full engagement of civil society,” October 2008.

UNAIDS allocate technical assistance to building local advocacy capacity of civil society in order to support global advocacy and accountability at all levels.

69. There is also a need for UNAIDS to clarify its role in technical assistance and its relationship in supporting health systems strengthening. The MOU with the Global Fund is a first step, but this needs to translate to clarity on the ground. Within the CCMs, UNAIDS could facilitate technical assistance and more clearly take on the role of developing a technical assistance plan (not necessarily carrying out TA itself but ensuring that the needed technical assistance is brought together).

D. Advocate with clear policy positions

70. Within UNAIDS, influence should be used to encourage harmonization of national with international policies; speak out and provide clear, unequivocal policy guidance, notably in areas of criminalization and mandatory testing, but also in encouraging governments to comply with more established recommendations, such as dedicated 0.7% of national budgets to Official Development Assistance or encouraging compliance with the use of TRIPS exceptions³⁵ to enable generic drug development and propagation.
71. When advocating with national governments, UNAIDS should not only focus on the “south.” Wealthier countries should also have national AIDS strategies; be held accountable for their own global commitments on HIV; and be empowered to tackle issues of immigrant communities in northern countries. There is global relevance, in as much as people travel back and forth and amongst countries, and every individual is entitled to universal access regardless of where he or she lives. Reports that 3 % of Washington, DC residents have HIV or AIDS should bring this point home.³⁶

E. Incorporate People on the Move into HIV and AIDS strategies

72. UNAIDS is well placed to encourage and facilitate the incorporation of people on the move in national and regional level plans that ensure that the realities of people on the move, including language, culture, and mobility are taken into account to provide continual and consistent access to prevention, treatment, care and support services. In many cases, national HIV plans do not provide services for people on the move, leaving this important aspect of an effective national response to HIV to understaffed and resourced NGOs. In order to reach all migrant populations, it will be important to revise national and regional plans to sufficiently cover service provision for these populations, with appropriate bilateral and international assistance where necessary.
73. These plans should ensure that all persons, regardless of legal status or home residence, are protected under a human rights framework and not subject to restrictions on entry, stay or residence based on HIV status, or mandatory testing for HIV. This planning could begin with a mapping by UNAIDS of what is already in place, what services are available and working, and what best practices can be recommended.
74. Specifically, program design must be linguistically and culturally appropriate for people on the move. By including migrants in the design of programs that affect them, service providers will be better able to address the challenges of delivering services to mobile

³⁵ Trade-related Aspects of Intellectual Property Rights

³⁶ http://www.washingtonpost.com/wp-dyn/content/article/2009/03/14/AR2009031402176_pf.html

populations. HIV programs need to include measures to understand migratory routes, and provide key services at different points along the way.

75. Therefore the Programme Coordinating Board is invited to *request* UNAIDS to:

- i. ensure that staff at global, regional and national levels facilitate the incorporation of mobile populations into regional and national AIDS strategies to achieve universal access to prevention, treatment, care and support services, paying particular attention to HIV-specific restrictions on entry, stay and residence to ensure that people living with HIV are not excluded, detained or deported on the basis of HIV status; and**
- ii: 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.³⁷**

³⁷ See also CARAM Asia recommendation against mandatory testing

Annex 1: Detailed Survey Information

A. Key issues raised in addition to the nine in the report:

1. Treatment is still out of reach:
 - Drug prices, testing and diagnostics remain high, making treatment out of reach
 - Pharmaceutical companies are not acknowledging and governments are not using TRIPS flexibilities and hindering generics production
 - Second line treatment is unavailable in many places, despite increasing need³⁸
 - The effect of user fees and other financial barriers on limiting access³⁹
2. Access to services and commodities is irregular due to weak health systems that cannot ensure consistent supply of medicines and commodities.
3. Indirect costs such as transportation and time away from work remain barriers to care and treatment: *“Many women in the [ASEAN] region, and migrant workers in particular, are not protected under labor laws, and receive pay on a day-to-day basis, so leaving work to attend health care services usually means loss of income. In several countries respondents said that they knew people who were unable to get access to treatment and subsequently died.”*⁴⁰
4. Strong political leadership in addressing AIDS is still lacking, especially around stigma and discrimination, financing and inclusion of universal access in national plans.
5. Lack of health insurance systems in many places, or lack of state provision to provide services.
6. Governments are not fulfilling financial commitments to achieve universal access (including Global Fund funding and strengthening of health services), and nor are we generating enough local funds for HIV responses or local political will to address HIV and AIDS adequately: *“My problem is the impossibility of knowing what is there in the future for us as PLHA since all our medications depend on the Global Fund , but what if they don’t approve the next round? Our government does not see the HIV/AIDS epidemic as a priority.”*⁴¹
7. Persons with disabilities are not reached well enough: *“In Jamaica, it has been established that the hearing impaired are at high risk and that there is a communication barrier that prevents quality care and prevention information.”*⁴²

³⁸ As just one example, take an ITPC posting from India (March 2009), "Under National ART Programme the following categories of people are eligible to avail free Viral Load Testing and second line ART- 'a) PLHA below poverty line (BPL), widows and children. b) PLHA under treatment in Government ART Centers continuously for at least two years, irrespective of income status.' The above mentioned answer means families under Above Poverty Level (APL) category may earn Rs.5000/- per month, still they have to buy 2nd line ART of their own which costs at least Rs.8000/- per month!"

³⁹ Sylvie Boyer, Fabienne Marcellin, Pierre Ongolo-Zogo, Séverin-Cécile Abega, Robert Nantchouang, Bruno Spirea & Jean-Paul Moatti, "Financial barriers to HIV treatment in Yaoundé, Cameroon: first results of a national cross-sectional survey,"

Bulletin of the World Health Organization, Volume 87, Number 4, April 2009, 279–287.

⁴⁰ APN+ Women working group (WAPN+), "Research on Access to HIV Treatment and services for Women and children," March 2009.

⁴¹ Interview, Latin America

⁴² Interview, Caribbean

8. Food insecurity in Sub-Saharan Africa is an increasing concern in light of climate changes and global financial limitations: *"We should be thinking about local food production to support PLHIV in ARV treatment; in many cases the cause of treatment withdrawal is due to side effects of drugs."*⁴³
9. Education for women and girls, which would help specifically increasing their knowledge of prevention and human rights, is still lacking, especially in Africa.
10. Shortage of health workers remains a key issue of concern.

B. Details of the survey process and questionnaire

Methodology: The PCB NGO Delegation, with the support of its Communications Facility, conducted an online survey to gather supporting information for its annual report to the UNAIDS board. The survey was conducted online with support from Health and Development Networks (HDN) from February 15 to March 6th 2009. The invitation to submit the survey was circulated through emails to key civil society organizations, networks and activists. The survey consisted of 14 key questions with several sub-questions. To ensure broader outreach to constituents the survey was translated and hosted online in 7 languages: English, Chinese (simplified), French, Spanish, Portuguese, Russian and Arabic (due to technical difficulties it was not possible to upload the online version in Arabic and respondents were requested to submit via email).

Survey Limitations: The survey was limited because of the following factors:

- Level of access to the internet varies from country to country
- Because the survey was done by forwarding open invitation emails (self-selecting respondents), more participation came from people with strong opinions.
- In order to keep the survey short and to enable translation, the survey was limited to multiple choice questions. For more examples and detail in the actual report, the survey was supplemented by 25 more detailed interviews and one focus group with key stakeholders. The NGO delegation and the Communications Facility interviewed a broad range of constituents.
- The last question on the UNAIDS evaluation turned up conflicting data; therefore the results to the last section are omitted in the report.

⁴³ NGO online Survey comment

Questionnaire with overall results

No	Question	Components	Variables	Result
1	Where do you live?		Africa	87
			Asia and Pacific	74
			Europe	100
			North America	26
			Latin America and the Caribbean	82
2	Which term best describes your group or organization?		Community based organization	87
			National NGO or network	108
			Regional NGO or network	37
			International NGO or network	56
			Group or network of people living with HIV	83
			Academic or research organization	18
			Individual/not affiliated with an organization	17
Other	228			
3	Which population does your group identify with, or serve?		People Living with HIV	304
			Women and girls	198
			People who use drugs	129
			Sex workers	150
			Gay men and other MSM	144
			Youth	211
			Children	134
			Older persons	76
			Indigenous communities and ethnic minorities	68
			Mobile communities	97
			Transgendered	69
			People with disabilities	80
			Prisoners	90
Other	26			
4	Do you have experience with mobile populations?		Yes	97
			No	223
			Not sure	44
5	What are the largest challenges/barriers to achieving universal access to HIV prevention, care, treatment and support in your country/in your experience?	Prevention services and commodities (male and female condoms/needles/ testing, etc)	not important	13
			low importance	47
			medium importance	84
			high importance	206
		Sexual and reproductive health information and services	not important	6
low importance	45			

	medium importance	87
	high importance	216
General health: Access to basic medical care	not important	20
	low importance	48
	medium importance	94
	high importance	187
Co-infection (TB/Hep C) services: diagnosis, treatment, care	not important	18
	low importance	42
	medium importance	103
	high importance	186
Availability of and access to HIV treatment	not important	23
	low importance	53
	medium importance	66
	high importance	207
Availability of and access to second-line HIV treatment	not important	26
	low importance	57
	medium importance	104
	high importance	158
Stigma and discrimination/Perceptions of what others think	not important	3
	low importance	26
	medium importance	83
	high importance	247
Policies concerning key populations (women and girls, prisoners, young people, drug users, MSM, etc)	not important	10
	low importance	41
	medium importance	83
	high importance	220
Safety (instances of violence, rape, killing, kidnapping, etc.)	not important	43
	low importance	76
	medium importance	100
	high importance	121
Gender inequality	not important	18
	low importance	68
	medium importance	122
	high importance	146
Criminalization of sexual behaviors	not important	39
	low importance	71
	medium importance	108
	high importance	131
Criminalization of drug use	not important	26
	low importance	66
	medium importance	126

			high importance	125
		Criminalization of HIV transmission	not important	35
			low importance	73
			medium importance	95
			high importance	140
6.a	Do you or your clients/constituents have access to health insurance?		Yes	154
			No	160
			Not sure	50
6.b	Does that insurance cover HIV-related services and treatment?		Yes	161
			No	104
			Not sure	72
7	Are you aware of travel-related restrictions for people living with HIV in your country?		Yes	185
			No	134
			Not sure	45
8	What groups of mobile populations are important in your country (especially as relates to HIV)?		PLHIV	205
			Sex workers	248
			People who use drugs	149
			Foreign workers	139
			Immigrants	155
			Refugee	128
			Displaced persons	112
			Undocumented Workers	148
			Trafficking victims	114
			Tourists	120
	Others	18		
9	What issues related to HIV, migration and mobile populations are important in your region right now?	Abuse of undocumented workers	not important	33
			low importance	56
			medium importance	89
			high importance	132
		Discrimination of migrants and mobile populations	not important	24
			low importance	57
			medium importance	98
			high importance	138
		Migrant and mobile populations do not know their rights	not important	20
			low importance	32
			medium importance	90
			high importance	180
Human trafficking	not important	32		
	low importance	55		
	medium importance	119		

	high importance	106
Access to HIV-related treatment	not important	18
	low importance	30
	medium importance	79
	high importance	212
Access to HIV-related prevention information and services	not important	10
	low importance	25
	medium importance	89
	high importance	212
Mandatory testing	not important	60
	low importance	68
	medium importance	73
	high importance	125
Inability to access health services due to legal status	not important	30
	low importance	51
	medium importance	87
	high importance	159
Actions aimed at preventing migration and decreasing mobility	not important	46
	low importance	68
	medium importance	95
	high importance	103
Language/cultural appropriateness limiting information	not important	33
	low importance	66
	medium importance	97
	high importance	120
Fear of authorities	not important	30
	low importance	50
	medium importance	106
	high importance	135
Disruption of treatment due to forcible rescue, police arrests and detaining	not important	45
	low importance	67
	medium importance	77
	high importance	121
Disruption of treatment due to displacement due to conflict (internal or cross border displacement)	not important	79
	low importance	72
	medium importance	62
	high importance	98
Disruption of treatment due to displacement due to natural disaster (i.e. weather or climactic changes)	not important	102
	low importance	76
	medium importance	67
	high importance	66

10	What are the challenges/barriers to reducing HIV risk and vulnerability among mobile populations in your country?	Lack of knowledge and understanding of People on the Move	not important	3
			low importance	34
			medium importance	105
			high importance	195
		Lack of reliable data and adequate qualitative information on HIV among them	not important	5
			low importance	24
			medium importance	103
			high importance	207
		Lack of evidence-based models of intervention	not important	8
			low importance	37
			medium importance	105
			high importance	182
		Lack of well-funded evidence-based models	not important	9
			low importance	24
			medium importance	81
			high importance	213
		Inappropriate models in place, such as travel restrictions, rescue raids, etc	not important	42
			low importance	62
			medium importance	84
			high importance	133
Lack of community-based programs	not important	8		
	low importance	34		
	medium importance	107		
	high importance	185		
11	Does your country's national AIDS strategy include migrants, mobile populations and asylum seekers?	Yes	73	
		No	149	
		Not sure	130	

[End of document]