



REPORT OF THE MEETING
**UNAIDS Reference Group on
HIV and Human Rights**

Seventh meeting
12-14 February 2007
Geneva, Switzerland



The UNAIDS Reference Group on HIV and Human Rights was established in 2002 to advise the Joint United Nations Programme on HIV/AIDS on all matters relating to HIV and human rights. It advises UNAIDS on how it can strengthen the capacity of governments, civil society and the private sector to protect and promote human rights in relation to HIV, and how to operationalize human rights, gender and the principles of GIPA (Greater Involvement of People Living with HIV) in UNAIDS policies and technical support.

The Reference Group is comprised of people from many different perspectives with a common commitment to, and expertise in, the area of HIV and human rights. The group includes advocates, HIV programmers, lawyers, a High Court judge, people living with HIV, people working with sex workers and people who use drugs, an ethicist, academics and the UN Special Rapporteur on the Right to Health.

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Donna Higgins, WHO

United Nations Development Programme:

Julian Fleet

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Welcome, opening remarks and update report

1. **Mark Heywood**, Chair of the Reference Group, opened the meeting and welcomed all those present. He gave a special welcome to new members who were attending their first meeting.
2. Following introductions, **Deborah Landey**, Deputy Executive Director, UNAIDS, welcomed the members on behalf of Peter Piot, Executive Director, UNAIDS, and said that UNAIDS was privileged to have the group's leadership, experience and guidance inform its response to the epidemic. Landey noted that, since the Reference Group last met, several major events had taken place: the Political Declaration on AIDS was adopted at the High-Level Meeting in June, solidifying the commitment to universal access; the Global Report on the AIDS epidemic was launched that same month; the International AIDS Conference in Toronto raised the place of prevention and women on the global AIDS agenda; and countries began setting targets for Universal Access to prevention, treatment, care and support. Among the many challenges, she highlighted the need to ensure scaled-up action to address the drivers of the epidemic; mobilize sufficient resources to implement universal access plans; strengthen international coordination and harmonization of efforts at country level; and support civil society to be fully involved in the universal access process, from target setting to the response at large.
3. **Purnima Mane**, Director, Department of Policy, Evidence and Partnerships, welcomed Mark Heywood as the new Chair of the Reference Group. She also welcomed new members and expressed support for the principle of rotation, as it provided an opportunity to bring new ideas and perspectives into the group. Mane stated that the universal access process represents an opportunity to intensify action against the underlying human rights issues that are closely linked to the drivers of the epidemic, e.g. stigma and discrimination, gender inequalities, and the marginalization of people living with HIV and other vulnerable groups. She emphasized that universal access has to support multi-sectoral action and engage a range of actors. This requires hard work, however, as many forces are at work to "re-medicalise" the response to the epidemic. Mane stressed that the contributions of the Reference Group are of utmost importance in this context. She noted that she sees the Reference Group as an extension of the capacity of UNAIDS in terms of the ability to advocate on key human rights issues in the response.
4. **Mark Heywood** stated that, at a political and normative level, human rights are probably better established now than ever in the AIDS response. Legal frameworks and political declarations, however, are not translating into reality on the ground. Heywood urged vigilance with regard to the defence of established standards. He noted that there are worrying signs that there has been an erosion of human rights and human rights principles in some places. In presenting the agenda for the meeting, Heywood identified three primary objectives to help orient the Group's discussions:
 - To identify global and regional human rights issues in relation to HIV that need urgent attention or intensified action.
 - To provide recommendations on policies and their implementation, e.g. provider initiated testing and counselling, male circumcision, the use of criminal law in the response to HIV, and the implementation of universal access.
 - To identify ways to improve the work of the Reference Group to increase its impact and usefulness to UNAIDS.

Update on recommendations raised at the last meeting

This session was presented by Susan Timberlake and Julian Fleet, and chaired by Mark Heywood.

5. **Susan Timberlake** gave an update on the follow-up to the recommendations from the last meeting of the Reference Group. She commended the group for its work and involvement since the last meeting, in particular its input on universal access target

setting guidance, comments on the draft WHO/UNAIDS guidance on provider-initiated testing and counselling (PITC), as well as participation in key meetings and events (e.g. High-Level Meeting on AIDS). She informed the group that their guidance and recommendations on the draft political declaration had been shared with UNAIDS staff providing technical assistance related to the drafting of the declaration, and UNAIDS provided extensive support to civil society leading up to and during the High-Level Meeting. She noted, however, that the challenge now is to make the gender and human rights provisions in the Political Declaration “operational”, and to ensure that there are monitoring and accountability mechanisms to track progress vis-à-vis human rights and gender equality commitments.

6. In reference to other action, Timberlake informed the group that, in follow up to discussions and recommendations of the April 2006 meeting, the human rights team of the UNAIDS Secretariat had worked towards finalizing the legal and ethical guidance on male circumcision and had inputted into the surgical manual on male circumcision, including by adding and strengthening provisions on informed consent and other human rights. She highlighted the continued need for strong global advocacy, particularly to guard against complacency and the “new denialism”. The report of the UN Secretary General and the UNAIDS assessment paper that went into the High Level Meeting both underscored the importance of intensifying action on human rights and gender equality. But there are new attacks on the scope of the epidemic and the contributions of human rights to the response. Funding levels for HIV are being challenged as some call for HIV and the response to it to be “normalized”.
7. Timberlake informed the members of the Reference Group that the Secretariat to the Reference Group had decided not to extend the contract beyond March of this year. However, both the Danish Institute for Human Rights and the Uganda Human Rights Commission would continue as members of the Reference Group.

Summary of discussion

8. The members of the Reference Group expressed their gratitude for the comprehensive update on the follow-up to the recommendations from the last meeting. It was noted that the implementation of some Reference Group recommendations could take time, and in turn was suggested that UNAIDS develop an implementation plan, with a limited number of issues and goals to be addressed, based on the advice and recommendations from the Group.
9. The members of the Group asked that their work (e.g. discussion papers, comments on draft guidelines and tools, recommendations) be made available on the UNAIDS website to guide and support the work of UNAIDS Co-sponsors and other partners working on HIV. UNAIDS was encouraged to explore ways to actively disseminate the recommendations and findings of the Reference Group to UNAIDS Co-sponsors.
10. The Reference Group noted the key role of the new WHO Director-General, Dr. Margaret Chan, in addressing HIV, and commended her statements on HIV, health in Africa and women, and urged her to continue addressing HIV and the underlying drivers of the epidemic.
11. **Julian Fleet**, Chief, UNDP HIV/AIDS Liaison Unit, provided an overview of recent UNDP activities in relation to HIV and human rights. He emphasized that the role of UNDP is not so much related to standards and policies, but rather focuses on programmatic issues and support to countries in the context of development, governance, legislation, human rights and gender. Some of the ways UNDP addresses HIV and human rights include: legislative reviews and analysis, advocacy and media campaigns to address stigma and discrimination and gender inequality, and support to networks and organizations of vulnerable populations. It supports national AIDS programmes to conduct gender assessments, protect and promote women’s inheritance and property rights, and address the causes and consequences of human trafficking in the context of the epidemic. Fleet

noted that, in addition to its joint activities with UNAIDS Co-sponsors, UNDP works through partnerships with a number of other agencies and programmes (e.g. Office of the UN High Commissioner for Human Rights, UNIFEM, World Trade Organization, Inter-Parliamentary Union), regional institutions (Arab League and the African Union), civil society organizations, government ministries and the media. Future priority areas in relation to HIV and human rights include: ensuring resource mobilization is addressed within the frameworks of existing development instruments and rule of law programmes; promoting policy coherence within UNAIDS and across country teams; working with positive law enforcement; and ensuring that men and boys are included when addressing gender issues.

Summary of discussion

12. The division of labour between UN agencies was discussed, and some Reference Group members asked why responsibility for HIV and human rights would not naturally be located with OHCHR. Fleet explained that being the lead UNAIDS Co-sponsor on an issue – e.g. HIV and human rights – does not mean that UNDP should do everything in this area, but rather that UNDP should push programmatic action and help facilitate the engagement of other agencies to address HIV and human rights within their mandates. The main focus is on deliverables and country support – ensuring that technical assistance to countries is coordinated and effective, advancing HIV-related human rights in a concerted manner. OHCHR is an essential partner, and UNDP welcomes its contributions in the AIDS response.

Key global developments in 2006

This session was presented by Sofia Gruskin and Mary Ann Torres, and chaired by Daniel Tarantola.

13. **Sofia Gruskin** provided an overview of key global developments in 2006, highlighting where there has been important expression of commitment to human rights and gender equality, and where there are persistent and emerging areas of concern. The High-Level Meeting on AIDS provided an opportunity to focus attention on human rights and gender issues in relation to HIV. This was evident in the UNAIDS assessment paper, the report of the UN Secretary General, and statements of the Secretary-General, the UNAIDS Executive Director, and the work of numerous civil society groups during the meeting. The goal of universal access in itself represents a major commitment in human rights terms. Gruskin noted, however, that reaching consensus on the outcome document was not easy. Issues in the draft Political Declaration relating to human rights and vulnerable populations were subject to lengthy and often difficult negotiation. Although commitment to human rights was affirmed in the Declaration, the reticence to name key population groups left many, including human rights organizations, concerned that human rights-based approaches were not truly embraced as an integral part of the response. Gruskin also noted a worrying reluctance among AIDS organizations to apply human rights-based approaches in their response to the epidemic.
14. The International AIDS Conference in Toronto provided a major opportunity to ensure that human rights and gender equality take a central position on the global AIDS agenda. Gruskin noted that, while there were a number of plenary presentations and sessions and other presentations in the formal conference programme, HIV and human rights were mostly relegated to parallel sessions external to the formal programme. She drew attention to the relative lack of attention given to these issues in the formal conference and noted that the parallel events mainly drew the participation of the HIV and human rights community. Gruskin noted also that regional fora have yet to make human rights a major focus of their efforts. Additionally, the place of human rights in national responses is variable – disappearing in some places, showing up as significant parts of strategic frameworks in others.

15. Gruskin identified some of the following challenges for attention in the coming year related to HIV and human rights:
- Addressing the re-emergence of the false dichotomy between a human rights approach and a public health approach
 - Ensuring that human rights and gender concerns are taken seriously in research, policy and programmatic discussions about male circumcision
 - Advancing advocacy for microbicides research in ways that go beyond the promise of a technological fix and address women's vulnerability to infection, and the broader inequality factors
 - Increasing the scale of human rights-based harm reduction initiatives to reach greater numbers of people who inject drugs and ensuring the availability of condoms, including for sex workers, adolescents and prisoners within the current global political climate
 - Ensuring that the greater focus on measurable and quantifiable targets does not inadvertently decrease the focus on underlying factors that are driving the epidemic and require concerted, longer-term attention, including human rights violations and gender inequality
 - Linking and integrating sexual and reproductive health and HIV concerns
 - Linking gender-based violence and HIV
16. Gruskin stated that the Reference Group needs to think about what accountability should look like in the context of shifting and diversified funding for the global AIDS response. The focus up until now has typically centred on the human rights obligations of governments and national AIDS programmes, with limited attention to the human rights obligations of governments beyond what they do in their national setting including, in particular, in the role of bilateral donor or actor in multilateral fora. She suggested that the accountability of private foundations, multi-national and global initiatives is an area that might usefully be addressed in a future Reference Group meeting.
17. Gruskin cautioned that addressing stigma and discrimination appears these days to be considered more politically palatable than addressing human rights in the context of the response. While addressing stigma and discrimination is an important part of promoting and protecting human rights, she suggested ensuring clarity about the differences to avoid stigma and discrimination replacing human rights policy and programmatic work. Stigma and discrimination do not encompass the broad spectrum of human rights challenges in the AIDS response, and of great concern are not attached to any larger issues of accountability. Gruskin urged greater attention to the promotion of programmatic action based on human rights standards, to overcome the continued gap between laws and policies and their implementation.

Report on HIV and human rights in Africa

18. It was noted that poverty; HIV-related stigma and discrimination; gender inequalities and marginalization of women; and the criminalization of men who have sex with men, sex workers and people who use drugs, form the difficult background against which programmes in most of Africa are being implemented. One member reported that a series of sub-regional conferences on HIV were held in Africa during 2006. Though progress has been seen, human rights have not been consistently integrated into strategies and programmatic responses to HIV.
19. There has been a significant scale up of access to treatment in Southern Africa, catalyzed by the 3 by 5 initiative. However, national authorities must deal with the difficult challenge of creating long-term financial sustainability for treatment programmes, not only the immediate infrastructure and human resources barriers.
20. It was reported that increased access to treatment has made existing inequalities starker in some places, as members of the most vulnerable groups have not been reached by either existing programmes or new ones. This is problematic from a human rights, as well as from a public health, perspective. It was emphasised that vulnerable groups have to be

reached if the epidemic is to be dented. Although the region faces a generalized epidemic, there are certain key populations – including men who have sex with men, people who use drugs, and sex workers – that are critical to ensuring success in responding to the epidemic.

21. It was reported that there has been some progress in integrating the protection of human rights of vulnerable groups into various legal and policy frameworks in the region. There remains, however, a considerable discrepancy between policies, strategies and plans and their implementation. In some countries there have been developments in the area of criminal law that may threaten the human rights of vulnerable groups, and risk heightening stigma and discrimination faced by people living with HIV.

Summary of the discussion

22. The Reference Group thanked their colleagues for the presentations, noting with great concern the situation of vulnerable groups. Members emphasized the importance of engaging the media and civil society groups on issues of HIV and human rights, and fostering compassionate and sound leadership that will speak strongly for the needs and rights of vulnerable and marginalized populations, especially men who have sex with men, sex workers, people who use drugs, and prisoners.
23. It was noted that access to treatment has been heralded as a great force to “normalize” HIV and counter stigma and discrimination. In many places, however, it has been observed that treatment has enabled people to avoid a visible deterioration in their health status, and thereby keep from inadvertently disclosing their HIV status. Rather than make HIV more public and more “normal”, treatment has reportedly made HIV more secret and discreet in some places. The Reference Group encouraged UNAIDS to stimulate research on the impact of increased access to treatment on human rights, stigma and discrimination, with a view to gathering information on what treatment expansion efforts can do to make a positive contribution to efforts to counter stigma and discrimination, and human rights violations more broadly.
24. Members of the Group noted that there is need to provide greater support to national AIDS programmes to address gender-based violence, sexual and reproductive health and rights, the needs of children orphaned or affected by AIDS, and children living with HIV.

Report on HIV and human rights in Eastern Europe and Central Asia

25. A presentation was given on the key developments and challenges in Eastern Europe and Central Asia. It was noted that the region is facing the fastest growing epidemic, and treatment scale-up is lagging. Civil society groups working on HIV report facing difficulties in organizing or formally registering as organizations. Law enforcement is interfering with the response in many places, with reports of police meeting their monthly arrest quotas by “rounding up” around drug treatment and harm reduction facilities. There have been positive developments in the region, however, including the hosting of the first regional conference on HIV/AIDS in Eastern Europe and Central Asia (Moscow, May 2006). It was noted that some countries have seen progress in introducing and scaling up opioid substitution therapy to people who use drugs, although it remains a challenge in many countries, including Russia and Tajikistan. Stigma and discrimination faced by people who use drugs is a significant problem and also serves as a barrier to accessing treatment.
26. Among the issues of greatest concern in the region:
 - Insufficient attention to the sexual and reproductive health rights of women and girls living with HIV, and women and adolescent girls who use drugs. Lack of accurate information about the risks of HIV during pregnancy; reports of HIV-positive women being coerced into terminating their pregnancies.
 - Access to harm reduction programmes is growing, albeit availability is still far too limited. Services that are available are often undermined by harsh law enforcement

policies and practices, which violate the human rights of people who use drugs, and increase stigma and discrimination against them.

- Access to ART and other health care services for people who use drugs is extremely limited, and there is no momentum for expanding it.
- Prisoners often do not have access to HIV prevention, care and treatment.
- Reports of lax infection control standards in healthcare settings are deterring people from seeking care.

27. Civil society response in this region is growing in places, but is still weak, and it rarely focuses on human rights. There is no clear imperative that civil society be consistently at the table. It was reported that donors are increasingly paying attention to injection drug use, but treatment scale-up efforts, evidence-based prevention, and the situation of women and children are not getting the support that is necessary. Some positive lessons can be learnt from Romania, where programmes are underway to promote “positive prevention” for adolescents who were infected while in institutions during and following the Ceausescu period. Women living with HIV have limited reproductive choice. Those who wish to have a baby are not supported to do so, and those who wish to terminate their pregnancy do not have access to safe abortion, even in major urban centres. Sexual and reproductive health education is not part of the school curricula – it is left to the streets.

Summary of discussions

28. The Reference Group expressed its grave concern about the situation in Eastern Europe and Central Asia and urged UNAIDS to address the issues of sexual and reproductive rights of women, access to opioid substitution therapy and needle exchange programmes, as a matter of priority.

29. Members of the Reference Group voiced concern about reports of HIV-positive pregnant women being coerced into terminating their pregnancy. They noted that the gravity of this human rights violation is compounded by the lack of access to safe abortion. Members called for UNAIDS to advocate with governments – and provide accompanying technical assistance – to enable an expansion of sexual and reproductive health services for HIV positive pregnant women, provision of sex education in schools, and public campaigns against stigma and discrimination.

30. Members expressed concern about reports that the development of WHO/UNAIDS guidance on provider-initiated testing and counselling is being interpreted in some quarters as an “endorsement” of mandatory testing. Members urged that UNAIDS and WHO develop a strategy to clearly communicate the intentions of the guidelines, and the ongoing need for informed consent.

Report on HIV and human rights in Asia

31. A presentation was given on regulation and policy that had been promulgated by the central government in China in 2006, notably those which promote the rights of HIV positive persons and their families, including the right to be free from discrimination, the right to marriage, work, medical care and schooling. Among the significant recent developments in the country, regulations, policies and programmes have been put in place to increase access to condoms, voluntary counselling and testing, and harm reduction programmes for people who use drugs.

32. While the developments are positive, it was noted that there is a discrepancy between the regulations and their implementation in many parts of the country. There continue to be reports of discrimination against people living with HIV, including in relation to obtaining adequate medical care. Members of vulnerable groups, such as men who have sex with men, people who use drugs, and sex workers, face discrimination and harassment by local authorities.

33. Members of the Reference Group expressed their concern about media and list serve reports that activists from civil society organizations working on HIV are being harassed and intimidated. Members welcomed the commitment of the Government to expanding access to prevention, treatment, care and support, but at the same time expressed concern about HIV-related human rights violations.
34. With regards to India, it was noted that there are increasing reports of violations of the rights of men who have sex with men, and people who use drugs. Some groups have reported that kothis are wearing shirts and pants in order to avoid attracting police violence. Caste-based discrimination is affecting access to prevention and treatment. Interveners spoke of the challenge of strengthening the role of human rights as an integral part of the public health approach to the epidemic.
35. Expanding access to prevention services for pregnant women is a major challenge. Although access to HIV treatment has increased, there has been little impetus to scale up access to PMTCT programmes as mother-to-child transmission is not seen as a key driver of the epidemic. Discrimination by healthcare providers varies from setting to setting. It was reported that this is one of the reasons why there are calls for expansion of some vertical programmes that serve members of key population groups. People using these programmes have said that they feel more comfortable, and receive better care, than in the mainstream health system.
36. There have been important examples of people using the courts, but access to the legal system is still insufficient. It was noted that some important intellectual property and access to medicine cases have been won at lower levels, one of which was being heard at the Supreme Court level and argued at the time of the meeting by Reference Group member Anand Grover.
37. Members expressed concern that the new guidelines on provider-initiated testing and counselling that were under development by WHO and UNAIDS could be misinterpreted in the country and invoked to support mandatory HIV testing and counselling in the health system.

Report on HIV and human rights in Latin America

38. A presentation was given on the current situation and challenges in Latin America. It was noted with concern that there are continued reports of mandatory HIV testing of patients prior to surgery, and of pregnant women. Even where informed consent is sought, it is more about healthcare workers looking for a signature on a form than meaningful engagement about what is involved when finding out one's status. Among the other challenges and concerns in many countries in the region:
 - Lack of sexuality and reproductive health education, and a renewed opposition to sexuality education by the Catholic Church and the Episcopal Church
 - Limited access to testing, particularly in countries in the Caribbean region
 - Mandatory HIV testing in health settings, in prisons, and when applying for employment
 - Uneven implementation of the standards found in national legal frameworks
 - Lack of reliable information (statistics) about gender-based violence and its intersections with the epidemic
 - Reports of HIV-positive women being forcibly sterilized, and positive women being forced to terminate their pregnancy under unsafe conditions (because pregnancy termination is illegal)
 - Young people's limited access to condoms, and sexual and reproductive health information and services
 - Lack of specialized reproductive health services for sero-discordant couples and women living with HIV

- Stigma and discrimination as a barrier to using prevention of mother-to-child transmission programmes.
39. Members of the Reference Group noted that some faith communities in the region have been taking an increasingly constructive role in the response. There are examples of groups that have expressed their acceptance of the use of condoms, and others that are promoting condom use in the context of protecting life. These were acknowledged as positive developments. Some, however, noted with concern that the upcoming visit of the Pope to Brazil may be seized upon by conservative elements and used as a platform for promoting abstinence-based approaches to HIV prevention and undermining comprehensive prevention programming.

Summary of general discussion about key global and regional challenges

40. Reference Group members observed that there has been progress in developing and reforming legal and policy frameworks in recent years, but that significant implementation and enforcement gaps must be addressed if those reforms and developments are to have meaning in people's lives. The Group called for an increased focus on States' accountability for operationalizing human rights standards and commitments, and for UNAIDS to intensify support to Governments and assist them to operationalize policies, legal frameworks and human rights commitments. Members also noted the need for strengthening civil society capacity to claim their rights in the context of HIV.
41. Members of the group asked the UNAIDS Secretariat and UNDP to distribute the report on HIV in Eastern Europe and Central Asia to concerned staff and advocate that the issues it raises be taken on as a matter of priority. Members underlined the importance of monitoring the human rights situation in relation to HIV globally, including developed country epidemics. They noted that HIV has to be put onto the agenda of the UN Human Rights Council. Members urged UNAIDS and partners to address and counter the false dichotomy between a public health and a human rights-based approach. They also urged UNAIDS to engage in dialogue with private and global foundations on how to ensure that human rights are incorporated into their approaches and activities.

Provider-initiated testing and counselling

This session was presented by Teguest Guerma, Associate Director, Department of HIV, WHO, and chaired by Ruth Macklin.¹

42. **Teguest Guerma** thanked the Reference Group for their comprehensive comments on the draft provider-initiated testing and counselling guidance, and informed the group that many of the recommendations they made had been incorporated into the revised draft. She noted that the new draft would place provider-initiated testing and counselling more clearly in the context of other testing modalities (e.g. stand-alone voluntary counselling and testing centres), and it would acknowledge that many of the barriers influencing the uptake of voluntary testing and counselling would also influence on the uptake of provider-initiated testing and counselling. She also acknowledged the importance of supporting the monitoring of the implementation of the provider-initiated testing and counselling guidelines.
43. The members of the Reference Group thanked WHO for creating a participatory and transparent process for the development of the guidance, and noted significant improvements in the draft since the initial July 2006 version. They raised a number of concerns, however, including the use of "opt-in/opt-out" terminology in relation to the process of obtaining informed consent. The group recommended that WHO and UNAIDS

¹ Please see Issue Paper 1: "Provider Initiated Testing and Counselling in Health Facilities", available online at http://data.unaids.org/pub/BaseDocument/2007/070216_HHR_1_PITC.pdf, and the Reference Group comments on the draft WHO/UNAIDS "Guidance on Provider-Initiated Testing and Counselling in Health Facilities" (15 January 2007), available online at <http://data.unaids.org/pub/Guidelines/2007/RGcomments-PITCguidance.pdf>.

use the phrase “routine offer of test” or “routine recommendation of an HIV test” rather than “routine testing” or diagnostic screening as the ambiguity in these terms is potentially dangerous.

44. Members urged that WHO clearly communicate that voluntary counselling and testing remains a critical part of ensuring that people have opportunities to find out their serostatus, reinforcing prevention messages, and connecting people to treatment, care and support. Members expressed concern that donors could move their resources away from voluntary counselling and testing and towards provider-initiated testing and counselling in light of the new policy. The group underscored that much greater support to a broad range of voluntary counselling and testing services is needed. Some added their concern that the prevention-related benefits of provider-initiated testing and counselling have been “oversold”. No country should take testing in any form as a substitute for comprehensive prevention services.
45. The Reference Group noted that the success of the policy will depend on support to its implementation. It was recommended that WHO develop training materials for health care providers that enables them to obtain informed consent. The Reference Group strongly cautioned against supporting regional adaptations of the guidance. While regional workshops would be useful for developing strategies for the implementation of the guidelines and support to monitoring for adverse impacts, key principles – particularly those protective of human rights – should not be subject to regional interpretation.
46. The Reference Group requested the opportunity to review the next iteration of the draft guidance and was informed by WHO that WHO could share the very last version informally.

Political Declaration (2006), universal access process, civil society engagement

This session was presented by Paul De Lay, Director of Evaluation, UNAIDS, and Andy Seale, Team Leader, Civil Society Partnership Unit, UNAIDS, and chaired by Ruth Macklin.

47. **Paul de Lay** gave a brief presentation on the challenge of incorporating human rights in the monitoring and evaluation of the epidemic. He pointed at four areas where there have been advances in recent years in human rights terms:
 - Revision of the national composite policy index, which asks whether laws are in place, and invites comments on their content, enforcement and impact.
 - Support to the development of a “stigma index” by and for positive people.
 - Support to the AIDS programme effort index
 - Universal access target-setting at country level.
48. In 2006, UNAIDS provided support to civil society groups to enable them to develop “shadow reports” on national efforts to implement the Declaration of Commitment. Most reports included significant attention to human rights, and progress in addressing the needs of members of vulnerable groups. De Lay noted that the information this process generates is a valuable compliment to official government reporting.
49. **Andy Seale** underscored the importance of engaging civil society organizations as they are often best placed to support efforts by people living with HIV and others affected by the epidemic to claim their rights. Civil society is also an important force for promoting accountability in the move towards universal access. Seale noted that the UNGASS reporting process was a good illustration of how civil society can play an instrumental role in monitoring the human rights response and situation in a country.
50. The Reference Group underlined that monitoring and evaluation is crucial to tracking progress in relation to the commitments that have been made, especially those that are

significant in human rights terms. They also noted that the development of indicators can be seen as indicative of commitment – one measures what one values, and values what one measures. The group offered to provide assistance to the Department of Evaluation in the development of indicators.

51. The Reference Group welcomed efforts to engage civil society into the reporting process and suggested that new guidelines for comprehensive reporting should be developed that would further support the work of civil society organizations in this area.

PCB recommendations on gender and violence against women

This session was presented by Susan Timberlake and Judy Polsky, Global Coalition on Women and AIDS, UNAIDS, and chaired by Jeff O'Malley.

52. **Susan Timberlake** gave a brief presentation on the “Action framework to address rights and needs of females and males in national responses to HIV”, which had been developed by UNAIDS as part of the response to a request made by the UNAIDS Programme Coordinating Board in June 2006. She explained that the aim of the framework was to provide a structure that helps guide actions to take gender activities to scale in the national HIV responses, notably through the development of costed and funded plans.
53. Timberlake noted that a prerequisite for taking gender and HIV to scale is to identify how the drivers of the epidemic in each country are “gendered”, in the sense that males and females are differently affected by the epidemic and for different reasons. The programmatic response can then be directed towards the populations that are being infected with HIV and the factors that make these populations vulnerable to infection, ensuring that programmes address the gender-related aspects of treatment, care and support (e.g. equitable access, care-giving burden on women).
54. Preparation for the response to the PCB decision, which included a survey of UNAIDS country offices (July 2006), revealed that a number of countries have performed gender assessments of their national AIDS response in recent years. There is limited gender expertise at country level, however, to ensure gender is integrated into all aspects of the response, nor are there sufficient funds for programmes and activities that promote gender equality. One of the key challenges is to communicate what discrete programmatic responses can be implemented now. Timberlake informed the group that a PCB paper on gender would be finalized in late April, and put into production for the June PCB meeting.
55. **Judy Polsky** gave a presentation on addressing the intersections between violence against women and HIV.² She noted that there have been a number of calls for UNAIDS to provide leadership and guidance on how violence against women should be conceptualized and addressed in the context of national AIDS responses, and to use its broker role to pull together a range of possible partners for expanded work in this area. Polsky noted that conceptualisation issues are challenging and inevitably affect who is at the table. There are some advocating that the focus be limited to violence against women and HIV, whereas others advocate a broader focus (i.e., violence against women and children, gender-based violence). There is the further challenge of clearly articulating the relationship between violence against women and HIV in terms of causes and consequences, and what this means for the AIDS response and the allocation of domestic and international resources earmarked for AIDS.

² Please see Issue Paper number 7: “Scaling up work to address violence against women and children and its intersections with HIV”, available online at http://data.unaids.org/pub/BaseDocument/2007/070216_HHR_7_VAW.pdf.

56. The Reference Group thanked UNAIDS for the briefing on work to respond to the PCB decision on gender and HIV. In connection with the work on violence, the Group recommended that UNAIDS be clear about the epidemiology and elucidate the relationship between violence and HIV infection, including violence both as a cause and as a consequence of infection (e.g. in the context of disclosure, violence experienced by people living with HIV related to HIV status or other factors). The Group urged caution in terms of talking about “intersections” and “drivers” without being able to articulate the nature of the relationship more concretely. Members suggested that UNAIDS support rapid country assessments that articulate the relationship in individual countries, and the programmatic needs that would respond to local epidemiological evidence as well as the specific social and cultural context. The Group emphasized that it was important to address issues related to gender and violence in a holistic manner, and include a review of the legal framework, law enforcement systems and accountability mechanisms.
57. In carrying this work forward, it was recommended that other UN agencies and programmes be engaged (e.g. UNFPA, UNICEF, UNIFEM, WHO, UNDP) as well as civil society groups including women’s groups, and those working on sexual and reproductive health and rights. Members of the Reference Group suggested that UNAIDS develop a broad focus to address gender-based violence in relation to both women and men, with the understanding that efforts might first concentrate on violence against women. They noted the need to address male sexuality and male privilege, as well as violence against men having sex with men and transgender people, in both research and programmatic responses.

Prevention: update on the UNAIDS prevention strategy, including needs and rights of marginalized groups

This session was presented by Barbara de Zaluondo, Associate Director for Epidemic Monitoring and Prevention, Department of Policy, Evidence and Partnerships, UNAIDS, and chaired by Jeff O'Malley.

58. **Barbara de Zaluondo** presented UNAIDS’ work to develop practical guidance on prevention for national AIDS responses. She explained that universal access is being used to generate momentum around expanding access to prevention, although this is challenging as prevention does not have a clear “constituency” or “centre of gravity” the way treatment does (e.g. Ministry of Health). She emphasized that expanding access to prevention should be alongside efforts to expand access to treatment. Countries need to “know their epidemic” and focus attention where the needs are. Addressing the drivers of the epidemic in this context is crucial, e.g. gender inequality, low status of women, homophobia, criminalization of sexual and drug use behaviours and HIV-related stigma and discrimination. Partnerships need to be forged and expanded, involving people living with HIV, civil society organizations, faith based organizations, media, business and other sectors of society.
59. **Daniel Tarantola** gave a brief presentation on targeting HIV prevention programmes. He stressed the importance of providing intensive, targeted prevention programmes to respond to the needs and promote the rights of the most vulnerable populations, such as sex workers, men who have sex with men, people who inject drugs and partners of HIV positive persons. Assessments of programme and service coverage should be undertaken separately in each country, and address regional and local variations in what is driving the epidemic.
60. Reference Group members stressed the importance of UNAIDS leadership on prevention, and welcomed recent efforts. They underlined that legal barriers to HIV prevention have to be addressed urgently, e.g. in relation to laws that disproportionately criminalise vulnerable populations; laws and policies that deny HIV prevention information and technologies to groups such as in-school children; or deny employment to people on the basis of HIV status, such as soldiers.

61. Members encouraged UNAIDS to use the terminology “key populations” in its prevention guidance. Key populations are those groups that are key to the dynamics of the epidemic and key in the response to the epidemic. Involving key populations increases the relevance and effectiveness of prevention programmes and services.

Reference Group issues

This session was presented by Mark Heywood and chaired by Jim Welsh.

62. **Mark Heywood** gave a brief presentation where he identified three groups of issues that should be addressed:

First:

- The status of the Reference Group.
- How the Reference Group can engage with a wider range of UNAIDS co-sponsors and make its issue papers and recommendations more visible and accessible across the Programme.
- How the Reference Group can better support civil society and human rights organisations.

Second:

- Review of the terms of reference for the Reference Group.

Third:

- Support to the Reference Group through its secretariat.

63. Several members expressed concern that the work undertaken by the group was not sufficiently visible. Although it was acknowledged that the group’s input into the draft guidance on provider-initiated testing and counselling had been heard, it was also noted that none of the papers developed by the group on HIV testing had been referenced in the draft guidance. The group urged UNAIDS to make its decisions and its background papers available to a wider number of people in the Programme, Co-sponsors in particular.

64. The members of the Reference Group acknowledged the support and attention the group has received from Peter Piot, and saw this as an indication of the importance given to the issue of human rights by UNAIDS.

65. Members noted that the meeting agenda often addresses too many issues, which does not allow for in-depth discussions on key issues. The Reference Group noted that its impact is greater when it focuses its attention, for example, as it has in relation to HIV testing. The Group asked that meeting agendas be more selective, allowing for greater attention to a few issues of concern. Members suggested that the group could work through sub-groups and hold thematic video conferences between meetings as need arises. A few members underlined, however, that some in the group have limited capacity to provide substantial input to discussions between meetings.

66. Several members expressed the view that the Reference Group had the potential to be an advocacy tool to advance the discourse around HIV and human rights and advocate that human rights commitments under the Declaration of Commitment, the Political Declaration and human rights treaties be honoured. The group indicated that they felt it could be useful if they issued statements on select issues, under its own name, after due consultation with the UNAIDS Secretariat and UNDP.

Engaging the donor community

This session was presented by Ruth Macklin and chaired by Jim Welsh.³

67. **Ruth Macklin** gave a short presentation and pointed to the need for turning advocacy and standard setting on human rights and gender equality into national priorities that are costed, budgeted and implemented. However, she noted that there existed no strategy by which to engage donors on HIV-related human rights issues. She pointed at four challenges to engaging donors in the human rights response to HIV:
- The tensions between country ownership and conditionalities imposed by donors and the UN.
 - Differences in the interpretation of human rights obligations within the broad framework for mutual accountability.
 - The role of a voluntarily-funded UN programme in the promotion and protection of human rights issues among donors.
 - Lack of capacity and practical strategies to ensure funding for human rights in national HIV responses.
68. Macklin gave examples of how conditionalities in funding of programmes can be detrimental to certain aspects of the response, for example by limiting the ability to work with certain population groups, use certain prevention technologies, or allocate funds according to the dynamics of the local epidemic.
69. The Reference Group members expressed its concern about the potential negative impact that certain conditionalities from bilateral and private donors might have on the human rights response to HIV. Members pointed to the need for a strong national coordination mechanism that is committed to human rights and will prioritize programmes and services for vulnerable populations. Members noted the need for a system of monitoring how countries, as well as bilateral and private donors supporting national responses, promote and protect human rights.
70. The group encouraged UNAIDS to engage in dialogue with bilateral and multilateral donors, as well as private foundations, regarding how they can contribute to national efforts to realise human rights and advance gender equality through support to national AIDS programmes.

Criminalization and HIV

This session was presented by Niels Sando and chaired by Jim Welsh.⁴

71. **Niels Sando** gave a short presentation on the application of criminal law to HIV exposure or infection. He noted that several countries in Europe, Africa and Asia have applied or are planning to apply criminal law to HIV exposure/transmission. These actions have renewed concerns that misapplication of criminal sanctions could prove counterproductive to the response to the epidemic, notably by discouraging people from finding out their status, and increasing HIV-related stigma. While the application of criminal law in cases of intentional transmission could be justified in the sense that it responds to harms between individuals, it should be clear that there would be no public health benefits from such action. Clear policies on when it is feasible and justifiable to apply criminal law, and when it is not, should be developed to guide governments. He pointed to the double challenge of stating clearly that criminal law should not form part of a response to HIV, and at the same time providing guidance on how to apply criminal law to intentional

³ Please see Issue Paper 4: “Engaging donors in the protection and promotion of the HIV-related human rights”, available online at http://data.unaids.org/pub/BaseDocument/2007/070216_HHR_4_EngagingDonors.pdf.

⁴ Please see Issue Paper 3: “Criminalization of HIV transmission”, available online at http://data.unaids.org/pub/BaseDocument/2006/070216_HHR_3_Criminalization.pdf.

transmission of HIV with respect for human rights and in accordance with public health goals and policies.

72. Members of the Reference Group expressed their concern over the increased application of criminal law in cases of HIV transmission, and cautioned against the application of the law in ways that fuel stigma and discrimination, violate the right to privacy, or interfere with sexual and reproductive rights. It was noted that often one sees an enthusiasm for making law (criminalizing actions) to respond to the epidemic, but not for (removing laws) decriminalization when the law presents a barrier to effective responses – for example, consensual sex between adult men. The members of the Reference Group encouraged UNAIDS to maintain its position against the use of criminal law for public health purposes, as outlined in the *International Guidelines on HIV/AIDS and Human Rights*, and in the UNAIDS Policy Options paper “Criminal Law, Public Health and HIV Transmission”.
73. The Reference Group recommended that UNAIDS convene a multi-stakeholder consultation on criminal law and HIV to provide guidance on how the criminal law can be applied in a non-discriminatory manner in accordance with public health principles and human rights. UNAIDS was encouraged to involve experts in criminal law, scientific and technical experts, Ministry of Justice officials, representatives of national AIDS programmes, and networks of people living with HIV. Members recommended that the discussion on criminal law and HIV extend beyond sexual transmission to include occupational transmission, nosocomial transmission, transmission through contaminated injection equipment, and parent-to-child transmission. Caution should be taken to protect the rights of pregnant women and of employees, e.g. health care workers.

Programming response to human rights and gender at country level

This session was presented by Susan Timberlake and chaired by Jim Welsh.⁵

74. Susan Timberlake presented the paper “Human Rights Actions for Universal Access”, which was developed as a brief resource for UNAIDS staff to support their follow up to country and regional consultations on universal access to HIV prevention, treatment, care and support. The more than 100 consultations almost unanimously identified stigma, discrimination, gender inequalities and human rights violations as barriers to achieving universal access. The paper identifies 25 concrete actions that UNAIDS staff can advocate for as part of their ongoing work to support national AIDS programmes and overcome barriers to universal access.
75. The Reference Group commended UNAIDS for this work and noted the importance of providing concrete guidance on how to address human rights issues and the main drivers of the epidemic at country level.

Handbook on HIV and Human Rights for National Human Rights Institutions

This session was presented by Veronica Bichetero and chaired by Michael Kirby.

76. **Veronica Bichetero** gave a brief introduction of the draft Handbook on HIV and Human Rights for National Human Rights Institutions. She underlined the important role national institutions can play in the AIDS response, as independent bodies with a mandate to promote and protect human rights. The handbook, which is being developed jointly by UNAIDS and the Office of the UN High Commissioner for Human Rights, was reviewed by staff in the Uganda Human Rights Commission, the Danish Institute for Human Rights and the Kenyan National Commission on Human Rights in order to assess its usefulness and relevance, and suggest possible modifications and elaboration.

⁵ Please see the draft paper “Human Rights Actions for Universal Access in National Responses to HIV”.

77. Members of the Reference Group acknowledged the work of UNAIDS and OHCHR to develop the handbook, and the important contributions of the Reference Group secretariat. Members gave some specific comments with regards to case examples and other parts of the handbook, and agreed to provide further feedback via e-mail to the Reference Group secretariat.

Male circumcision

This session was presented by Catherine Hankins, Chief Scientific Advisor and Associate Director for Human Rights, Gender and Best Practice, Department of Policy, Evidence and Partnerships, UNAIDS, and chaired by Justice Michael Kirby.⁶

78. **Catherine Hankins** gave a brief update on recent developments in relation to the trials on male circumcision and transmission of HIV, including the December 2006 decision to suspend the two remaining trials in operation due to the recommendation of their Data Safety and Monitoring Boards. Hankins stated that an expert consultation would be convened by WHO and UNAIDS in March to examine the data and make recommendations for national AIDS programmes in light of evidence indicating an approximately 60% reduction in the acquisition of HIV in circumcised males having penile-vaginal sex. Hankins noted that there exists only observational data on the male to female and male to male transmission of HIV in the context of male circumcision. One trial was examining possible direct benefits for women.⁷ She informed the group that the guidance on human rights, ethics and law was being revised on the basis of feedback received in national and international meetings. The document stresses the importance of addressing safety, confidentiality, informed consent and counselling, and access to comprehensive information and prevention education.
79. Members of the group welcomed the progress made in the development of the guidance document. They expressed concern that the recent findings may cause policy-makers and community leaders to put excessive pressure on men and boys to be circumcised. Reference Group members also expressed concern about “risk compensation” and questioned whether newly circumcised men will develop a false sense of protection and feel free to have unsafe sex. The group underscored the importance of making comprehensive, easily understandable and culturally-appropriate information material widely available. Concerns were noted that gender and power differentials might make it difficult for women to negotiate condom use once male circumcision is introduced into communities and asked that this issue receive attention. They also urged attention to the risks and benefits for boys, and recommended that clear information be developed for parents, as well as mechanisms to ensure the boys are able to participate in decision-making according to their capacity.

Presentation of Reference Group Recommendations to the Executive Director, UNAIDS

This session was presented by Mark Heywood and chaired by Justice Michael Kirby.

80. **Mark Heywood** welcomed Peter Piot and commended him for his continued support to human rights and to the work of the Reference Group. Heywood briefly presented the discussions of the Reference Group. He noted with concern the continued existence of serious violations of human rights in relation to HIV and the disjuncture between law and policy on one side and the programmatic realities on the other. Although important international commitments have been made to promote and protect human rights, notably

⁶ Please see Issue Paper 6, “Male Circumcision”, available online at http://data.unaids.org/pub/BaseDocument/2007/070216_HHR_6_MaleCircumcision.pdf.

⁷ Note that this trial was subsequently suspended for futility (i.e. not likely to enrol sufficient numbers of participants in a suitable time frame, and therefore unable to produce scientifically significant results).

through the adoption of the Political Declaration and the Declaration of Commitment, there is need to be vigilant and to insist on accountability of governments, bilateral and multilateral donors, and private foundations. UNAIDS has an important role to play to help various partners translate commitments into realities.

81. Heywood noted that the Group had a productive discussion with WHO regarding provider-initiated testing and counselling. The Group was pleased that UNAIDS was seeking to expand its work on gender and gender-based violence. In relation to the discussions on criminal law and HIV, the group urged UNAIDS to maintain its position about the inappropriateness of criminal law sanctions as a public health tool, and encouraged further work in this area in partnership with legal experts and with the active participation of people living with HIV. Heywood noted that there is often great enthusiasm to add laws that do not help in the response to HIV, while laws that might be supportive of a response to HIV do not receive the same attention and support. In terms of the future role and status of the Reference Group, Heywood stated that the group discussed their desire to contribute more to UNAIDS, while at the same time have some independence and space to speak out on critical issues.

Remarks by Peter Piot, UNAIDS Executive Director

82. Piot welcomed the new members of the group, emphasizing the need for “new blood and new ideas” in response to AIDS. He urged the group to become a “living group with more osmosis with the world”. Piot underlined that, although there are still major challenges in relation to human rights and HIV, it should be acknowledged that real progress has been made. He noted that it could be counterproductive to the response to HIV if the achievements were not recognized. To make progress, the AIDS response – as any other social movement – needs a hope for a better future, and the capacity to build on results. Piot stated that, unlike in the early days of the epidemic, nearly everybody today agrees on the importance of addressing the drivers of the epidemic. However, not enough is happening on the ground, and that is our main challenge: to narrow the gap between declarations and implementation.
83. Piot noted that new issues and new challenges have occurred because of our previous successes. One of these issues is resistant strains of HIV, which would not have occurred without access to treatment. The new problems should not be seen only as problems, but also as entry points for advancing a comprehensive response to HIV. In social justice and human rights terms, Piot underlined that the HIV epidemic is not only about revealing injustices, but also about overcoming these injustices – one example being discrimination faced by gay men in Western Europe and North America. He emphasized that the situation of women within this epidemic begs a similar type of mobilization and transformation of society. HIV may provide the opportunity to overcome injustices faced by women that reach far beyond the epidemic itself.
84. UNAIDS has made the issue of accountability one of its priorities. Piot explained that the approach up to now has largely involved technical support to individual countries, but he noted that UNAIDS will likely do more “naming and shaming” in the future, in particular with regards to progress in achieving country targets for universal access to prevention, treatment, care and support.
85. Piot emphasized the essential role that civil society organizations play in addressing HIV and human rights. He cited in particular the shadow reports that were prepared for the High Level Meeting. Increasing civil society involvement in these and similar activities would require expanded support to capacity-building. If UNAIDS is to be outspoken on issues about HIV and human rights, it needs facts and credible data – a strong civil society could generate this type of essential information.
86. In commenting on the discussions and work of the Reference Group, Piot promised that the documents of the Reference Group would be put in the public domain, and he acknowledged the Reference Group’s desire for more independence. He suggested that

the group be selective in terms of the “battles it wished to pick” and choose those that would have major impact. Where the group wanted to speak or act independently, it should engage in dialogue first with the Secretariat and also ensure a democratic process within the group.

87. He welcomed the group’s attention to issues of concern in the regions. With respect to harm reduction in Eastern Europe and Central Asia, he noted that the United Nations Office on Drugs and Crime (UNODC) had been increasing its technical support. Piot encouraged the group’s engagement with UNODC on how to protect and promote the rights of people who use drugs in the region. He suggested that the group could consider following the issue over a 2 – 3 year period, addressing the legal system and the enforcement of laws and policies.
88. Piot stated that gender-based violence and gender inequality is a priority issue for UNAIDS. The focus has to be on documenting the local situation and making social and programmatic action happen at country level. The world does not need another international study saying that violence is rampant and that there are implications for the AIDS epidemic.
89. With regard to the draft provider-initiated testing and counselling guidance document, Piot acknowledged the lead of WHO in this area and stated that he agreed with the Reference Group that “routine offer of testing” is more appropriate as terminology than “opt-out”. He also rejected use of the term “HIV screening”. He expressed concern that the AIDS response was entering a dangerous zone of medical hubris and over-medicalization. Although the health sector certainly has an important role to play, particularly when it comes to testing and treatment, making real headway in the response to AIDS requires engagement going beyond the health sector.
90. Piot noted the complexity of criminal law issues and stated that there is need for an expert group to give this attention, with human rights expertise at the core. He suggested that one might consider looking at the law broadly, linking to discussions regarding the repeal of anti-sodomy legislation, and reforming laws related to sex work. Guidance in this area has to be technically sound and relevant to all legal systems. He added that there is also need to consider how best to promote appropriate use of the law in the context of the epidemic, e.g. through peer education among judges.
91. Piot spoke about the need to ensure sustained leadership in the response to HIV. He noted that the UN and WHO had recently changed leadership, and several countries that have been actively engaged in the international AIDS response are likely to see a change in leadership in the near future, e.g. France, Nigeria, United Kingdom, and the United States. Ensuring the commitment of the new leadership in these countries and organizations is essential to the continued vitality of the response to the epidemic.
92. Another key priority is “making the money work”, ensuring that resources are used properly for the benefit of the poor and those most vulnerable. Piot noted that there has been a substantial increase in funding for HIV, and while the overall need is far greater than what is available, a number of countries faced implementation crises. Piot stated that the inability to implement now could create problems in the future if the currently available funding is not absorbed.
93. On dissemination and publications of Reference Group materials, Piot noted that such information should be in the public domain. It was agreed that background papers and other materials from the meeting would be more visibly posted on the web site.

Next meeting

94. Timberlake shared with the Reference Group the idea of the Group participating in the UNAIDS Global Staff Meeting in October, on the day that will address human rights, gender equality and the greater involvement of people living with HIV (GIPA). She indicated that this had not yet been approved by UNAIDS Senior Management, but she wanted to know before formally proposing it whether it would be in principle agreeable to the Members of the Group. The Members agreed in principle to participating in the UNAIDS Global Staff meeting seeing it as a unique and important opportunity to interact on a number of key human rights concerns with the staff. However, they requested that there should be at least some time outside of the Global Staff Meeting devoted to a dedicated meeting of the Reference Group.