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

Ninth meeting
24-26 November 2008
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 (UNAIDS) on all matters relating to HIV and human rights. The Reference Group speaks with an independent voice; thus, its views are not necessarily the view or positions of the UNAIDS Secretariat or the UNAIDS Cosponsors. The Reference Group 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 equality 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.


This report contains the views and recommendations of the UNAIDS Reference Group on HIV and Human Rights, an independent international group of experts convened by the Joint United Nations Programme on HIV/AIDS, and does not necessarily represent the decisions or the stated policy of the UNAIDS Secretariat or any of the UNAIDS Cosponsors.

The designations employed and the presentation of the material in this report do not imply the expression of any opinion whatsoever on the part of the Joint United Nations Programme on HIV/AIDS concerning the legal status of any country, territory, city or area, or of its authorities, or concerning the delimitation of its frontiers or boundaries.

All reasonable precautions have been taken by the Joint United Nations Programme on HIV/AIDS to verify the information contained in this document. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the Joint United Nations Programme on HIV/AIDS be liable for damages arising from its use.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome: introduction of new members, purpose of meeting</td>
<td>1</td>
</tr>
<tr>
<td>Dialogue with UNAIDS Executive Director Peter Piot – human rights priorities for the response to HIV</td>
<td>2</td>
</tr>
<tr>
<td>Discussion of draft recommendations to the incoming UNAIDS Executive Director</td>
<td>2</td>
</tr>
<tr>
<td>Dialogue with UN High Commissioner for Human Rights</td>
<td>3</td>
</tr>
<tr>
<td>Universal HIV testing with immediate antiretroviral therapy: discussion of the mathematical model published in the Lancet</td>
<td>5</td>
</tr>
<tr>
<td>Special WHO/UNAIDS, OHCHR event in honour of Jonathan Mann and the 60th Anniversary of the Universal Declaration of Human Rights</td>
<td>6</td>
</tr>
<tr>
<td>Update on recommendations raised at eighth meeting; developments in UNDP and in the UNAIDS Secretariat</td>
<td>7</td>
</tr>
<tr>
<td>Programming to support human rights in national AIDS responses</td>
<td>8</td>
</tr>
<tr>
<td>Focus on prevention and intersections with human rights</td>
<td>9</td>
</tr>
<tr>
<td>Expanding availability of HIV testing and counselling</td>
<td>11</td>
</tr>
<tr>
<td>Promoting gender equality</td>
<td>13</td>
</tr>
<tr>
<td>Universal access to HIV prevention, treatment, care and support – two years to go</td>
<td>13</td>
</tr>
<tr>
<td>HIV legislation</td>
<td>16</td>
</tr>
<tr>
<td>Key developments since last meeting</td>
<td>18</td>
</tr>
<tr>
<td>Reference Group issues</td>
<td>18</td>
</tr>
<tr>
<td>Presentation of Reference Group conclusions/recommendations</td>
<td>21</td>
</tr>
</tbody>
</table>
Welcome: introduction of new members, purpose of meeting

1. Mark Heywood, Chair of the Reference Group, welcomed participants and, in particular, the seven new Reference Group members. He expressed the hope that everybody would feel at home and be able to contribute fully to the group and to the meeting: He urged participants to focus on the main purpose of the meeting, namely to produce a set of short, articulate, and practical recommendations to the incoming UNAIDS Executive Director, towards the strengthening of human rights in the work of UNAIDS and in national AIDS responses. In the current context of a global financial crisis, he warned that AIDS, health, and the needs of the poor and marginalized risked being eclipsed. UNAIDS, with the support of the Reference Group, had a responsibility to ensure that this would not happen. Doing this would mean that advocacy and guidance must become more practical, pragmatic and programmatic, and that those challenging the relevance of human rights should be responded to forcefully and convincingly. The ultimate goal is to ensure that programmes to support human rights are planned, budgeted and implemented parts of national AIDS plans. Heywood announced that he would not be able to stay until the end of the meeting, in light of urgent commitments in South Africa related to a national day of action on World AIDS Day. It was decided that Justice Michael Kirby would take over as chair of the meeting at the end of the first day.

2. Susan Timberlake (Senior Human Rights and Law Adviser, UNAIDS Secretariat) welcomed participants on behalf of UNAIDS. She explained that the UNAIDS Secretariat manages the group together with UNDP, and she welcomed Mandeep Dhaliwal, who would soon take up the position as Cluster Leader on Gender, Human Rights & Sexual Diversities at UNDP. Susan highlighted that in these times of political and economic change in the world, there was a unique opportunity to put human rights at the centre of the response to HIV. At the same time, however, there are still many active forces that want to exclude human rights. Barbara de Zalduno (Chief, Programmatic Priorities and Support Division, UNAIDS Secretariat) agreed with Mark Heywood that the by far most important outcome of the Reference Group’s meeting would be objective and practical advice to the incoming UNAIDS Executive Director about how the UNAIDS Programme “can make the biggest difference in the response to HIV”.

3. Timberlake briefed members about an emerging issue, the pending publication of an article in the *Lancet* by Kevin De Cock and colleagues at WHO regarding modelling a response to HIV that would involve universal and annual HIV testing in hyper-epidemic settings followed by the immediate provision of treatment to all those who test positive. There were a number of issues that merited the attention of the Reference Group, and De Cock offered to brief the Reference Group on the article. She expressed the hope that, though this was potentially an important development, it would not dominate either the meeting of the Reference Group or the event in honour of Jonathan Mann to be held in the evening following the first day of the meeting. Timberlake reiterated that the meeting’s objective was to come up with a list of recommendations for the incoming UNAIDS Executive Director. Members asked that the agenda be amended to allow the group to meet with De Cock before the event in honour of Jonathan Mann, and that they have an opportunity to review the article and develop a formal response to it.

---

Dialogue with UNAIDS Executive Director Peter Piot – human rights priorities for the response to HIV

4. Mark Heywood welcomed Peter Piot on behalf of the group. Piot greeted participants and said it was good to see many new members on the Reference Group, at a time when it was critical to get ready for a long-term response to HIV. He thanked Heywood for making time to chair the first day of the meeting, and for his work and leadership more generally, both as chair of the Reference Group and in South Africa.

5. Piot highlighted a number of challenges:
   - The push to medicalize the response to HIV (by “seeking technical solutions while failing to address critical issues such as gender and human rights”), coming not only from the medical establishment, but also at times from within international organizations. According to Piot, “this trend is extremely dangerous and an approach that fails to deal with the underlying issues will fail”.
   - The increasing trend to criminalize HIV transmission and/or exposure. Piot said we needed to understand why this was happening and craft responses that respond to those reasons.
   - The need to be far more efficient in times of economic and financial crisis. Piot welcomed this challenge, saying that it was a great opportunity to become more efficient, but warned that in times of crisis governments and people tend to become more conservative.
   - The need, as a human rights community, to come up with messages that are understandable and can be translated into practical and programmatic action.
   - The need to ensure that human rights issues penetrate the UN System. Piot noted that at country level, many UN Resident Coordinators are reluctant to take up human rights issues related to HIV, particularly when it comes to sexual minorities. In his view, human rights must be part of basic training and performance appraisals.

6. Piot concluded his opening remarks by saying that Reference Group members should continue the fight and not give up, and that they could continue to count on him after he left UNAIDS.

7. Heywood thanked Piot, noting that he has provided important human rights leadership throughout his tenure, including through setting up the Reference Group and providing space for it to make public statements. During the discussion that followed, Piot encouraged the Reference Group to continue to put pressure on UNAIDS and the UN System more broadly, but also to be even more practical and pragmatic, by flagging issues it feels that UNAIDS fails to address adequately, and focusing on a few key recommendations rather than coming up with long lists. The Reference Group must make human rights accessible, and talk differently about human rights, so that human rights are understood as a key element of the HIV response benefitting people everywhere. The importance of ensuring that human rights issues are on the agenda of the Executive Heads of UN organizations, and of building a strong alliance with the Office of the UN High Commissioner for Human Rights, was highlighted.

Discussion of recommendations to the incoming UNAIDS Executive Director

8. Ralf Jürgens and Susan Timberlake introduced the first draft of the recommendations to the incoming UNAIDS Executive Director and clarified that participants would have an opportunity to provide comments throughout the meeting. General comments from participants addressed the need to be more concise and focused in the next draft, with a goal of producing a set of very concrete recommendations about what the Executive
Director can do to increase commitment to, and programming on, human rights. Specific recommendations were discussed in more detail throughout the meeting under various agenda items.2

**Dialogue with the UN High Commissioner for Human Rights**

9. In her remarks, the High Commissioner for Human Rights, Ms. Navanethem Pillay, thanked UNAIDS and the Reference Group for extending an invitation to her, and welcomed the opportunity to engage in a dialogue on some of the most pertinent and emerging human rights issues in the context of HIV. She highlighted that the rhetoric of “universality of human rights” has not fully translated into tangible outcomes for people living with HIV. Some detractors to human rights and human rights-based approaches have suggested that human rights only bring an “ideological approach” or sentimental value to the discussion on how best to confront AIDS. Others have placed greater emphasis on a so-called “public health response” and have tried to draw attention to what they perceive as tension between public health and human rights. Pillay said she wished to add her voice to the many human rights defenders and AIDS activists across the globe in stating simply and clearly that human rights do matter and that it is because human rights are neglected that AIDS continues to cause significant human suffering and loss.

10. Pillay continued by saying that one of the most salient features of a human rights-based approach is the fact that it brings not only intrinsic value but also a framework of accountability. This attribute should be a key feature of national responses to HIV as it provides rights-holders living with or affected by HIV with the means to hold their governments responsible for protecting their human rights. Pillay then drew attention to five points:

1) We must recognize that the international human rights normative framework cannot develop a life of its own – it is not self-implementing and its benefits are often not immediate. Affected communities and individuals must participate in the decisions and policies that affect them and work collaboratively to maximize the potential for change. We must exhaust all our resources, measure the impact of our programmes and use the most appropriate human rights mechanisms that will achieve a positive outcome.

2) The law and enforcement of the law play an important symbiotic role in providing human rights protection. Law enforcement personnel and the justice sector need to work together to reduce repressive measures which fuel stigma and discrimination against marginalized groups and increase their vulnerability to HIV.

3) We must move beyond the rhetoric of a “rights-based approach to HIV” to implementation. This requires leadership not only at the institutional level but also at country level. It also requires greater investment in our best practices and a determination to replicate them where they are relevant.

4) We must ensure that the resources devoted to HIV prevention, treatment and care for marginalized groups are proportional to the HIV prevalence among them. A genuine rights-based response to HIV implies implementing, monitoring and financing programmes that work to mitigate the cycle of vulnerability among these groups.

---

5) We must recognize that the commitment Member States made in 2006 to universal access to HIV prevention, treatment, care and support is not just an aspiration – it is also a human right.

11. Pillay concluded by saying that her Office will remain true to its mandate in promoting and protecting human rights and will not waver in its commitment to a rights-based response to HIV.

12. Reference Group members thanked the High Commissioner for meeting with the Group and for discussing how her Office, UNAIDS, and the Reference Group can continue to work together to ensure greater attention to human rights in the response to AIDS. It was noted that HIV has in some way pushed the boundaries in the area of human rights, for example by extending the prohibited grounds of discrimination to include health status, including HIV. The challenges have the epidemic have brought to the forefront economic, social, and cultural rights, and furthered their justiciability, particularly the right to health through the right to effective HIV treatment for people in low-resource countries. The greater participation of people living with HIV and members of other vulnerable groups in all aspects of the response is also widely regarded as a practical, “human rights achievement” in the HIV response. While these have been important, members highlighted that many challenges remain, including the criminalization of many of the populations most at risk of HIV, resistance to gender equality which makes women more vulnerable to HIV, increased use of punitive laws against people living with HIV (rather than enactment of laws protecting them) and a trend to “medicalize the response” versus addressing the structural factors that drive vulnerability to HIV infection and impact. As a result, many people continue to face discrimination and other human rights abuses, and these abuses continue to be major obstacles to achieving universal access to HIV prevention and treatment, care and support.

13. Reference Group members emphasized that the response to HIV continues to need the High Commissioner’s help and that of her Office. They noted that there are many concrete ways in which the High Commissioner herself and OHCHR could assist UNAIDS and the Reference Group. In particular, they suggested:

- The High Commissioner should regularly speak out on the human rights of people living with HIV, the intersections between gender inequality and the vulnerability of women and girls to HIV infection and impact, and the human rights of members of marginalized and criminalized populations that are often left out of the response to HIV, such as men who have sex with men, people who use drugs, sex workers, and people in prisons and other closed settings. It would be particularly helpful if OHCHR could work to elaborate further applicable human rights standards regarding these issues and groups, as their human rights continue to be highly contested.

- The High Commissioner should meet with and speak out on behalf of people living with HIV and members of marginalized populations during her visits to countries, particularly in those countries where there is a high level of stigma, discrimination, and human rights abuses in the context of HIV.

- OHCHR should work to ensure that the human rights treaty monitoring bodies are much more proactive on HIV and human rights issues, including by making comments on issues like the overbroad criminalization of HIV transmission, social exclusion of marginalized groups, restrictions on sex education in schools, and the links between inequality of women and their greater vulnerability to HIV.
■ OHCHR should strengthen the ability of OHCHR country officers to address, together with UNAIDS, and in particular UNDP as lead on human rights and law within the UNAIDS family, the many HIV and human rights violations that occur in countries.

14. Members concluded by expressing the hope that the High Commissioner would have an opportunity to meet with the incoming UNAIDS Executive Director early in 2009 to further discuss these and other ways in which the UNAIDS programme and OHCHR can work together and strengthen their collaboration.

Universal HIV testing with immediate antiretroviral therapy: discussion of the mathematical model published in the Lancet

15. Kevin De Cock, Director of the WHO HIV Department, joined the meeting to present the mathematical model that was about to be published in the Lancet. He assured members that the purpose of the article was only to open discussion about a possible future approach to controlling HIV and even ending the epidemic, and to call for further research to test it. In this regard, he underlined that the article comprises theoretical mathematical modelling to stimulate debate and should not in any way be seen as policy or technical guidance from WHO. De Cock explained that the modelling suggests that a strategy of universal HIV testing with immediate antiretroviral therapy (ART) provision to those testing positive could lead to very good individual health and public health outcomes. He emphasized that there must be further research and that WHO would not embrace an approach unless it was based on evidence gained from such research. He also assured members that the article supports voluntary (not mandatory) testing, counselling and treatment and that it refers to various concerns that might arise during the implementation of the model, including human rights concerns.

16. Reference Group members thanked De Cock for taking the time to meet with them and discuss the article and the public health and human rights issues it raises. They welcomed the model inasmuch as it proposes the attainment of universal access to HIV treatment and HIV testing and counselling, and confirms the critical link between HIV prevention and HIV treatment, highlighting that these are essential components of the right to health, as well as the goal of universal access to HIV prevention, treatment, care and support. However, they expressed a number of concerns, including:
   ■ in the public eye, the model risks being seen as representing the thinking of WHO
   ■ the approach appears to reduce the response to HIV to two modalities: testing and treatment, excluding attention to the political, legal, social, economic forces that underpin much of the vulnerability to infection
   ■ the model appears to place nearly the entire burden of prevention on people living with HIV, to the detriment of empowering both the infected and non-infected to avoid HIV transmission and take mutual responsibility for their sexual health
   ■ the costing in the model does not include costs related to social protection, including programmes and services to address HIV-related discrimination and the other adverse consequences that may occur in relation to learning one’s HIV status
   ■ the modelling on uptake of testing and treatment does not address the vastly different social realities that people living with HIV face, including gender inequalities, criminalization, marginalization, poverty.

17. Other questions raised by the model include:
   ■ How and whether the model would be applicable in other settings besides hyperendemic settings?
Whether the model would result in disincentives to the funding, implementation, uptake and use of other HIV prevention modalities, as well as those relating to care and support?

How and whether the model would extend to (or leave out) various hard to reach and marginalized populations at risk, including people who use drugs, men who have sex with men, sex workers, migrants and mobile populations, and the poor?

Whether uptake of testing and treatment would be sufficient to achieve the results and whether voluntariness of testing and treatment could indeed be maintained in face of possible pressures. If so, how, and would necessary social protection and support measures be funded?

How confidentiality concerning status would be maintained and how people would be protected from stigma and discrimination attached to their HIV status and/or treatment?

Whether immediate treatment would in fact result in best possible health outcome for the individual whose immune system in not yet compromised, and whether such early treatment could result in toxicity, drug resistance and other forms of morbidity?

What are the ethical implications, based on the risks/benefits of such immediate treatment, of the proposed model – both for the individual and in terms of the individual’s possible exposure to risk for public health prevention benefits?

Whether the model is based on serious participation/engagement of people living with HIV in its development?

18. De Cock acknowledged that these are important issues and concerns, but concluded by saying that it was time to seriously discuss and possibly implement on a pilot basis the approach proposed in the paper, in order to become serious about saving lives.

19. Following the publishing of the article, members developed a statement in response, entitled “Time for action towards universal access to prevention, treatment, care and support: Beyond theory towards practice and protection.”

Special WHO/UNAIDS/OHCHR event in honour of Jonathan Mann & the 60th Anniversary of the Universal Declaration of Human Rights

20. Reference Group members participated in a special event hosted by UNAIDS, WHO, and OHCHR to commemorate the untimely death of Jonathan Mann in 1998 and to celebrate his legacy and the 60 year anniversary of the Universal Declaration of Human Rights. The event highlighted the ongoing relevance of human rights to HIV and to health, and considered some of the current key human rights and public health issues in the response to HIV.

21. The event was opened by Peter Piot who recalled Mann’s contributions to the response against HIV and credited Mann with creating the WHO Global AIDS Programme from a rights-based rather than a traditional public health perspective. According to Piot, if the Global Programme on AIDS had relied on measures such as quarantine and forced HIV testing, the response to HIV would have been catastrophic. Piot’s introduction was followed by the screening of a short film on Jonathan Mann and his legacy on human rights, HIV and health, and a keynote address delivered by Michael Kirby. A panel discussion moderated by Kevin de Cock elicited memories of Mann from peers who had worked very closely with him on AIDS in the early years of the epidemic, including Reference Group members Sofia Gruskin and Daniel Tarantola. Gruskin and Tarantola

---

highlighted that Mann did not come to human rights thinking as an ideologue but was interested in human rights because of its practical utility as a framework for analyzing and responding to AIDS. A second panel, moderated by Reference Group member Jonathan Cohen, sought to provide a critical review of the state of human rights in relation to HIV and broader health issues, and included four Reference Group members: Robert Carr, Michaela Clayton, Mark Heywood, and Anastasia Kamlyk. Hiro Nakatani (Assistant Director-General, HIV/AIDS, TB, Malaria and Neglected Tropical Diseases, WHO) closed the evening, which was attended by interested staff from UNAIDS, WHO, OHCHR and the Global Fund, key staff from other relevant international and civil society organizations, and government missions.4

**Update on recommendations raised at eighth meeting; developments in UNDP and in the UNAIDS Secretariat**

22. The Reference Group received a report from the UNAIDS Secretariat and UNDP on work undertaken in the area of human rights and law since the last meeting of the Reference Group, including with regard to implementation of the recommendations the Reference Group had made to the UNAIDS Secretariat and UNDP.

23. Susan Timberlake highlighted the work undertaken by the UNAIDS Secretariat in the following areas:

- **criminalization of HIV transmission** (including the publication, together with UNDP, of a policy brief prior to the International AIDS Conference in Mexico City)
- **universal access to HIV prevention, treatment, care and support** (including initiating a mapping of programmes to support human rights in national AIDS responses, producing technical guidance on human rights and law as part of a resource package to support country Global Fund applications; and briefing the Global Fund Technical Review Panel on key human rights and legal developments)
- **responding to human rights violations** (including providing training for UNAIDS Secretariat staff at the New Staff Orientation and at regional management meetings, providing strategic support to country/regional offices on individual cases, and supporting UNAIDS statements on human rights and sexual orientation)
- **protecting and promoting the rights of people who use drugs** (including by making a statement to the UN Commission on Narcotic Drugs)
- **HIV testing and counselling** (including by contributing to development of policy guidance on HIV testing and counselling in prisons and other closed settings and for refugee populations)
- **human rights-based approach to HIV and sex work** (including by supporting revision of the UNAIDS guidance note)
- **model legislation on HIV** (including by supporting/participating in regional stakeholder workshops for West and Central Africa; developing alternative language for problematic provisions of the N’Djamena law; supporting the development of official UNAIDS comments on draft HIV laws; with UNDP, supporting country support missions; and providing official comments to the Southern African Development Community draft model HIV law).

24. Timberlake highlighted the need for the UNAIDS Secretariat and UNDP to further strengthen capacity to be able to scale up action on human rights/legal issues at global,

---

4 For a detailed summary of the event, please see a special double issue of the “Epimonitor” (volume 30, numbers 1/2, January/February 2009). Available on-line at http://www.epimonitor.net/EpidemiologyMonitor/Index.htm.
regional, and national levels; and noted that while the Secretariat does its best to follow up on recommendations made by the Reference Group, other priorities sometimes take over and therefore reduce the amount of time available for follow up. For example, since the last meeting of the Reference Group, establishing and supporting the work of the International Task Team on HIV-related Travel Restrictions has taken a substantial commitment of time and resources.

25. Mandeep Dhaliwal noted that UNDP was increasing its capacity both at UNDP Headquarters and in regional offices, and reported about some of the recent activities undertaken by UNDP.

Programming to support human rights in national AIDS responses

26. Susan Timberlake presented work undertaken by the UNAIDS Secretariat aimed at ensuring that support for human rights forms an essential programmatic component of national HIV responses. She started by pointing out that, to be effective and rights-based, HIV responses should address human rights concerns in three ways:

(1) Human rights principles of participation and inclusion, non-discrimination, and accountability should guide the planning, implementation and monitoring and evaluation of all HIV programmes.

(2) Programmes must be directed to ensuring that the most marginalised and most at risk populations benefit from the national HIV response.

(3) Specific programmes to support human rights should be part of an effective HIV response regardless of (but based on) the epidemic type. Key programmes include:
   a. Legal support for people living with HIV and members of vulnerable groups (formal legal aid, community paralegals, dispute resolution, etc.)
   b. Legal audits/law reform that examine laws, law enforcement and access to justice
   c. “Know your rights/laws” campaigns
   d. Human rights training for key professionals (including health care professionals, police, judges and prison workers)
   e. Stigma and discrimination reduction programmes
   f. Programmes that address the intersection between violence against women and girls and HIV.

27. Timberlake briefly presented data from the 2008 National Composite Policy Index (NCPI), which forms part of countries’ UNGASS Progress Report, and from a 2007 survey of UNAIDS Country Coordinators (UCCs). These data suggest that efforts and specific programmes to promote and protect human rights are increasingly included in national HIV responses. However, Timberlake noted that the data shows that while such programmes may be mentioned in a plan or strategy, they may not be budgeted or implemented, and where they are, they may only reach a very small portion of those in need or be of substandard quality. There is a need to further explore content, scale, quality and impact of these programmes. Related to this work, there is also need to reach consensus about which programmes are most important depending on the nature of the epidemic and the cultural, social and legal context, continue building the evidence-base for these programmes and how they are best implemented, and strategise about how demand for such programming can be stimulated and financial resources mobilised for them.

---

5 See also the session on “Universal access to HIV prevention, treatment, care and support – two years to go”, where these issues were discussed in more detail.
28. Timberlake reported that in 2008, the UNAIDS Secretariat initiated a programme of work to map programmes to support human rights, and move towards clearer programming standards and guidance. The International HIV/AIDS Alliance has been contracted to begin the first phase of this work, the objectives of which are as follows:
   a. to map whether human rights issues are identified as obstacles to universal access or to effective national responses to HIV in selected documents setting out the national response to HIV;
   b. to track programmes to support human rights in key documents setting out the national response;
   c. to describe and cost essential programmatic components of these programmes;
   d. to define quality standards for these programmes;
   e. to identify and describe best practices in scaling up these programmes in national responses to HIV;
   f. to produce guidance on planning, costing, budgeting, implementing, monitoring and evaluation of these programmes.

29. The Reference Group congratulated the UNAIDS Secretariat for starting this important work and emphasized that it is extremely important to get to a place where we no longer talk about the need for rights-based responses to HIV in the abstract. Rather, we should be able to talk about a number of clearly defined programmes “so that everybody understands what they should do and how”. Reference Group members agreed that, to be effective and rights-based, HIV responses should address human rights concerns in the three ways outlined above; and agreed that the list of programmes to support human rights in national AIDS responses that was presented by Timberlake contains the most relevant programmes that every country should implement.

30. It was decided that a specific advisory group should be convened to help guide this work, consisting of some members of the Reference Group and some other experts; and that Timberlake and the chair of the advisory group should provide an update on work undertaken at the next Reference Group meeting, providing the Reference Group with another opportunity to provide feedback.

Focus on prevention and intersections with human rights

31. Susan Timberlake, Michael Bartos (Team Leader, Prevention, Care and Support, UNAIDS Secretariat) and Reference Group member Robert Carr introduced the session. Timberlake and Bartos reported about a meeting on HIV prevention held in Geneva in September 2008 to discuss a UNAIDS Secretariat-wide approach for re-intensifying HIV prevention. At the meeting, Peter Piot underlined that prevention needs to be a substantive priority for the UNAIDS Secretariat, for a number of reasons including: recognition that the development of effective microbicides and vaccines in the next 5 to 10 years is unlikely; concern about the fact that the number of new HIV infections remains unacceptably high and the ultimate cost and complexity of providing HIV treatment to an ever increasing number of people; high interest in “combination prevention” (comprising programmes to address the biomedical, social-behavioural and structural determinants of HIV risk and vulnerability) at the International AIDS Conference in Mexico; as well as recent critiques and commentaries on prevention in medical and social science literature. As part of UNAIDS’ expanded work on prevention, the meeting identified the critical role of human rights and law in shifting political and programmatic commitment to address the prevention needs of vulnerable populations and populations at risk, and to empower communities to demand HIV prevention as a part of the right to health.
32. Timberlake and Bartos clarified that, broadly speaking, UNAIDS promotes two sets of rights in the context of HIV: those rights necessary to enable a person to avoid HIV infection; and those necessary to enable a person living with HIV to live successfully. They further clarified that UNAIDS’ essential prevention and human rights responsibilities are threefold:

(1) As part of the human rights function of the United Nations, UNAIDS staff have an obligation to support national responses towards ensuring that all people, including the most affected, the most marginalized and the criminalized, have access to the information, means and services to avoid HIV infection. UNAIDS’ role therefore is to shift/increase, as needed, prevention programming to the most affected through “know your epidemic and response analyses” coupled with the “UN challenge function” – challenging, encouraging and supporting governments to overcome discrimination/denial/punitive policies to address populations that, to date, have not received sufficient or equitable prevention resources and programming.

(2) UNAIDS staff have an obligation to ensure that HIV prevention programmes respect human rights principles. This means promoting more resources and programming for the mobilization and empowerment of people living with HIV, women, young people and marginalized groups in prevention.

(3) UNAIDS staff have an obligation to help address the social and legal barriers to the uptake of prevention through the promotion of sufficient and concrete programmes that support human rights, as an integral part of funding proposals and national AIDS responses.

33. At the meeting on HIV prevention, it was agreed that a campaign would be rolled out to re-energize coordinated prevention action throughout the UNAIDS Secretariat and Joint Programme. Meeting participants underlined the need for UN staff to stand firm and united with vulnerable communities. Programmatically, they highlighted that UN staff must work to shift the prevention response to ensure full coverage of most-at-risk and vulnerable populations, and in doing so challenge unfavourable political, legal and social environments that block equitable and effective prevention responses. They agreed that combination prevention should be promoted, requiring programmatic action in disparate domains, supporting social change as well as individual behaviour change; and that supporting the use of a human rights-based approach is a critical part of intensifying prevention. They recognized that this will require moving a fairly “entrenched industry” that sees prevention as primarily biomedical and individual behaviour change; and that, with regards to the UNAIDS role, this will require two fundamental changes in approach:

(1) Providing much greater leadership to address the political challenges involved in shifting the prevention response to populations hitherto largely neglected: sex workers, men who have sex with men, and people who use drugs and people in prisons and other closed settings, among others;

(2) Being able to shift the prevention response towards new types of prevention programmes that (1) address intersections of HIV and structural factors and (2) empower communities to demand prevention.

34. Robert Carr then presented work undertaken in Jamaica, using social communication to address structural vulnerabilities of men who have sex with men.

35. The Reference Group agreed that, while maintaining the full commitment to achieving universal and sustainable access to HIV treatment, care and support, the UNAIDS Secretariat should aggressively expand the promotion and support of evidence-informed and rights-based combination HIV prevention, ensuring the appropriate balance among
biomedical, behavioural and structural prevention programmes. The Group emphasized that all those engaged in the response to HIV have to do a much better job on prevention, and that this is particularly important in a time when some focus nearly exclusively on HIV testing and treatment. In particular, the human rights community has an obligation to articulate the human rights issues in prevention, addressing the fact that people do not perceive prevention as their right and “we have not generated demand for prevention” in the same way that demand has been generated for treatment. The Group appreciated the emphasis on structural interventions and noted that this approach needs to be taken up and supported by all UNAIDS Co-sponsors. It agreed that the incoming UNAIDS Executive Director should:

a. call for enhanced focus and articulation of prevention programmes to address structural vulnerabilities of HIV, necessitating the engagement of the entire UN system, in particular the Co-sponsors of UNAIDS
b. call on the UNAIDS programme to develop modalities by which to ensure that all groups that need access to HIV prevention measures and services receive them
c. ensure that “combination prevention” is promoted and that it includes greater attention to the legal, social and political barriers to the roll out of HIV prevention, in particular, the criminalised or highly marginalised status of most at risk populations and the high levels of stigma and discrimination against people living with HIV
d. ensure that “combination prevention” also includes sufficient attention to effective social mobilisation and social change communications strategies to create demand for prevention, including a call for the “right to prevention”
e. ensure that prevention efforts include a greater focus on people living with HIV, providing them with programmes that protect their human rights and empower them to avoid passing on the virus.

Expanding availability of HIV testing and counselling

36. The Reference Group heard from Donna Higgins, WHO HIV Department, about activities undertaken by WHO to expand the scale-up of HIV testing and counselling. She mentioned that WHO, jointly with other UN organizations, developed specific guidance on scaling up HIV testing and counselling for prisoners (which the Reference Group commented on) and for refugees; that guidelines for counselling of children also have been developed; and that funding has been obtained for the development of specific guidance for people who use drugs, men who have sex with men, people at risk of being trafficked, and sex workers. She noted that all guidance documents WHO produces now have to go through a “Guidelines Review Committee”, which is responsible for ensuring that WHO guidance is consistent with internationally accepted best practices, including the appropriate use of evidence.

37. As at its previous meeting, the Reference Group expressed concern about how the 2007 WHO/UNAIDS guidance on provider-initiated testing and counselling in health-care settings (PITC guidance) is being rolled out, and about follow-up action on the guidance. Specifically, the Group expressed concern about the gap between policy and practice. While the guidance calls for establishment of supportive social, policy and legal environments, in practice HIV testing is often being scaled up without much, if any, attention to the programmatic elements required to establish such supportive environments. Referring specifically to a recent Human Rights Watch and AIDS and Rights Alliance of Southern Africa (ARASA) report on the experience of Lesotho’s
universal HIV counselling and testing campaign, Joe Amon highlighted the need for
countries and UN agencies to learn important lessons from current efforts to scale up
access to HIV testing and counselling. If there is failure to secure necessary resources to
ensure oversight and quality, it will be impossible to implement HIV testing and
counselling in a way that respects rights, reduces the vulnerability of those who test
negative and protects the rights of those testing positive, most importantly by linking them
to treatment, care and support, and protecting from any discrimination, violence or any
other adverse consequences.

38. Concern was also voiced that the guidance documents for HIV testing and counselling for
vulnerable populations, which were supposed to come out quickly after the PITC
Guidance, now look like a call for testing, rather than a call for adequate protection to
ensure the general PITC Guidance is not misused or misunderstood as authorizing testing
without fully informed consent. The Group recommended that all the documents, whether
they are currently in draft form or in earlier stages of planning, be looked at again to
ensure that they adequately address this issue. Finally, concern was voiced about the
draft “Guidance on Provider-initiated Routine Medical Examination, Testing and
Counselling for Infectious Diseases in Injecting Drug Users” prepared by the European
Monitoring Centre for Drugs and Drug Addiction. The Group recommended that WHO and
UNAIDS provide detailed comments to ensure the document will undergo necessary
changes before it is released.

39. The Group recalled a number of recommendations it made at its last meeting, asking that:
(1) senior management of the UNAIDS Secretariat and UNDP meet with WHO to develop
a plan to ensure that all elements of the PITC Guidance are implemented, and to
agree on mutual responsibilities;
(2) WHO, UNAIDS Secretariat, and UNDP appeal to donors to fund all elements of the
PITC Guidance, ensuring that support to expanding HIV testing and counselling is
accompanied by funding that enables communities and national AIDS programmes to
put the other essential elements in place;
(3) WHO, UNAIDS Secretariat and UNDP make the issuing of guidance on legal and
social protection a priority.

40. In addition to these recommendations, which it felt remain relevant, the Group
recommended that the UNAIDS Secretariat and WHO look at the pipeline of all
documents related to HIV testing and counselling that are in preparation and ensure that
the Reference Group can provide input into all documents, including a “testing strategy”
document Higgins referred to, that is more technical in nature but may still benefit from a
review by human rights and HIV experts.

41. WHO also agreed to share additional information about Lesotho’s universal counselling
and testing campaign with the Group, including the WHO/CDC review and the costing of
the plan; and send Group members a study of testing and counselling by the WHO
Regional Office for the Americas (PAHO) which suggested that “a lot of mandatory testing
is taking place”.

42. Finally, in response to the Group’s concern that WHO’s new guidance review process
ignores the place of human rights standards in the elaboration of guidance and “will err on

---

6 Human Rights Watch and AIDS and Rights Alliance for Southern Africa (2008), A Testing
Challenge. The Experience of Lesotho’s Universal HIV Counseling and Testing Campaign.
the side of evidence-based as opposed to evidence-informed”, WHO agreed to discuss with the UNAIDS Secretariat and others (e.g. UNODC) how they can participate in the review process. It was urged that, for documents jointly released by WHO and UNAIDS, the UNAIDS Secretariat should always be part of the process.

Promoting gender equality
43. Kristan Schoultz (Director of the Global Coalition on Women and AIDS and responsible for gender within the UNAIDS Secretariat) and Susana Fried (Gender/HIV Advisor, UNDP) provided an update on activities undertaken within the UNAIDS Secretariat and UNDP to promote gender equality in the context of national responses to HIV. Both noted that, while there is wide acknowledgment that countries’ AIDS strategic plans need to address gender issues, countries continue having a difficult time moving beyond a rhetorical commitment to implementation of programmatic responses.

44. The Reference Group commended the work that has been undertaken. It urged that the gender and human rights and law teams work together more closely and share resources and approaches, noting that for both gender and human rights the challenge is to move from rhetoric to real action and programmes on the ground. It recognized that efforts to include specific gender programmes in funding proposal and implement in practice tend to be further advanced than corresponding efforts on human rights programmes; that gender programming tends to be more politically acceptable than human rights programming; and that gender programming “is taking off” while resistance to including human rights programmes in national responses is more widespread. However, the Reference Group noted that there are many synergies and overlaps between gender and human rights programmes and approaches, and that those working on gender and those working on human rights need to work in collaboration to ensure their common goals are reached. In particular, the Group suggested that UN staff training on gender and human rights be combined, and that the gender and human rights teams within the UNAIDS Secretariat and UNDP work together to inform the “know your epidemic and response” methodology, which currently focuses on modes of transmission rather than on barriers to access and ways to overcome these barriers. Generally, it was agreed that more needed to be done to ensure that gender and human rights initiatives and programmes stay connected and mutually reinforce each other. Specifically, Schoultz agreed to share with the Reference Group a draft report on "where the world is at with regard to women and HIV” and other forthcoming documents on gender and HIV so that the Group can provide input and help ensure that human rights issues are adequately addressed.

Universal access to HIV prevention, treatment, care and support – two years to go
45. Susan Timberlake, Rebekah Thomas (National Capacity Support Unit, UNAIDS Secretariat) and Igor Toskin,(Monitoring and Evaluation, UNAIDS Secretariat) and Reference Group member Sofia Gruskin introduced the discussion on universal access. Susan reminded the Reference Group that, at its eighth meeting in December 2007, the Group discussed both

- the need to clarify and articulate what processes, programmes and outcomes are required from a human rights perspective as part of governments’ commitment to universal access; and
- the need to continue work to ensure that indicators of universal access are both qualitative as well as quantitative; that a human rights analysis of UNAIDS’ main indicators is undertaken; and that stand alone human rights indicators are established.
46. The Reference Group then heard about a number of important developments since that meeting:

(1) In June 2008, global progress towards the implementation of the Declaration of Commitment on HIV/AIDS was assessed at a High-level Meeting on AIDS in New York. In the Country Progress Reports that were submitted prior to the meeting, many countries reported having made significant progress in responding to the HIV epidemic, especially in providing anti-retroviral treatment, prevention of mother-to-child transmission and access to HIV testing and counselling. However, targets have been set unevenly on prevention, treatment, care and support, and most countries are still far from reaching all their universal access targets. In particular, they report significantly less progress on HIV prevention efforts. Progress towards ensuring the care of orphans and vulnerable children also remains poor in many countries. Particularly worrying from a human rights perspective is that key vulnerable and marginalized populations are barely being reached in many countries.

(2) In the National Composite Policy Index (NCPI), governments reported increased attention to policies, laws and plans to address human rights issues in national responses. A 2007 survey of UNAIDS Country Coordinators (UCCs), which like the NCPI reports has not been independently verified, also seems to suggest increased attention to programmes to support human rights. However, there are many limitations to the data provided by countries. In particular, there is little if any information about the number of human rights policies or programmes, their size and coverage, their quality, or whether they have in fact been costed, budgeted, implemented or evaluated. In addition, while a majority of countries report that laws and regulations are in place to protect people living with HIV from discrimination, only few countries report protections for specific vulnerable groups including men who have sex with men, sex workers, and people who inject drugs. Quite usefully, 57% of countries report the existence of laws and policies that present obstacles to their ability to provide effective prevention, treatment, care and support for most at risk populations. Finally, only 22 percent of countries report using performance indicators or benchmarks to measure compliance with human rights standards in the context of their HIV efforts. Despite their limitations, these signal important areas for advocacy and potential intervention.

(3) In addition to the data provided in country reports, work undertaken by civil society organizations underscored some of the human rights concerns. 7

47. Before the discussion started, Ralf Jürgens reminded the Group that, in June 2008, it had written a letter to Peter Piot and made a public statement on universal access. The Reference Group highlighted that the goal of universal access to HIV prevention, treatment, care and support is a human rights imperative in every respect, and that countries and the international community need to dramatically scale up efforts to make good on their commitments. In particular, the Reference Group urged action in the following areas: setting ambitious targets and including all populations at risk; ensuring meaningful civil society participation; and scaling up programmatic responses promoting human rights and gender. The Reference Group concluded its statement by saying that “monitoring and evaluation of universal access targets and country plans should include a detailed assessment of how well country processes, programmes, and policies adhere to human rights”.

7 ICASO (2008), Declaration of Commitment on HIV/AIDS and Political Declaration on HIV/AIDS: A review on progress from the community sector. amfAR (2008), MSM, HIV and the Road to Universal Access – How Far Have We Come?
48. In its discussion, the Reference Group noted that, although the existing information is limited and there is an urgent need to improve monitoring of universal access, particularly as it concerns its human rights aspects, existing processes do provide important and compelling information, and promote dialogue that supports increased accountability. Case studies presented highlighted the fact that in some countries, an over-riding benefit appears to be the way in which the NCPI brings together, in one place, a wide range of stakeholders and information. By illustrating how the legal and policy components of the national response affect people living with and affected by HIV, as well as their access to programmes and services, the report and the process by which it is developed helps a wider range of stakeholders understand the role of law and policy in efforts to address the epidemic. It can also set the stage for further discussion on how different actors – government, civil society, networks of people living with HIV, academic, private sector – can work together to positively influence law and policy to better support the national response. In all countries, the NCPI reporting process should play an important role in strengthening civil society engagement with HIV-related data.

49. NCPI data, although presenting a rather simplistic snapshot of the national response, does suggest a need to increase focus on HIV prevention and, in particular, programmes and services for populations most at risk of HIV. It also suggests an urgent need to address the legal and policy barriers to delivering comprehensive prevention, treatment, care and support to key populations. Reference Group members agreed that the data should be used much more actively at national, regional, and global level for advocacy and law reform, and to strengthen human rights programming efforts. The Group also noted that continuing work was needed to: (1) strengthen monitoring efforts for the next reporting round; and revise the NCPI questionnaire with a view to adding components such as quality, content and implementation of laws and policies. Given some of the acknowledged weaknesses of the data, the group felt it important that additional attention be given to strengthening validation activities.

50. The Group also noted the importance of devoting attention to the period following the 2010 Universal Access target, when Declaration of Commitment reporting obligations end. Many countries will likely remain far from achieving universal access to HIV prevention, treatment, care and support, and the UNGASS monitoring framework can remain a relevant accountability framework in the context of advancing towards the realisation of the Millennium Development Goals. Additionally, the Group noted that NCPI questions, as is being done with other UNGASS indicators, should be incorporated into national monitoring and evaluation frameworks.

51. The Group made a number of recommendations towards intensifying the commitment of the UNAIDS Programme to universal access to HIV prevention, treatment, care and support. In particular, it recommended that the incoming UNAIDS Executive Director make universal access the primary and explicit objective of the Joint Programme. As part of supporting increased commitment, the Executive Director should:
   a. ensure that the UNAIDS Secretariat more clearly articulates what is meant by “universal” and “access”, takes a rights-based approach to universal access, and speaks out about the need for countries to achieve appropriately ambitious targets;
   b. push for equitable access to prevention, treatment, care and support by marginalised communities (including sex workers, men who have sex with men, people who use drugs and prisoners);
   c. call for a fourth pillar on which universal access must rest – “non-discrimination” (in particular, non-discrimination against people living with HIV, against women and
against marginalised populations) making this area also one of programmatic obligation comparable to prevention, treatment, care and support;

d. ensure that sufficient political, funding and programmatic attention is devoted to the realization of non-discrimination, highlighting that – as is the case with universal access to HIV prevention, treatment, care and support more generally – it will never be achieved without such attention; and

e. call for the development of recommended indicators in the context of achieving universal access by which to measure such issues as whether: people affected by HIV are aware of their rights and have access to remedies; sufficient programmes to address both sexual violence and gender inequality in the context of HIV are in place, as well as their content and quality; children affected by HIV are receiving protection and support; caregivers are benefiting from economic empowerment programmes and social support; laws and policies protecting people living with HIV and marginalised populations are in place and adequately enforced; laws and law enforcement practices that create barriers to HIV prevention, treatment, care and support have been removed.

HIV legislation

52. After its eighth meeting and a telephone conference in January 2008 on legislative developments in West and Central Africa concerning the problematic “N’Djamena law”, the Reference Group established a sub-committee on legislation, including criminalization of HIV exposure and transmission. Ralf Jürgens and Jonathan Cohen provided a short summary of the activities of the subcommittee, which drafted two letters to Peter Piot asking for greater leadership from the UNAIDS Secretariat and UNDP specifically related to the developments in West Africa; and urging the UNAIDS Secretariat and UNDP to be more proactive in monitoring the legal environment and offering technical assistance early on in HIV law reform processes. The letters pointed out that urgent action was required not only because of the implications for West and Central Africa, but also because of the possible influence these law reform processes could have elsewhere on the continent, notably a “model” legislation initiative underway in Southern Africa, and national processes in Malawi, Uganda and Mozambique.

53. Susan Timberlake and Bechir N’Daw (Human Rights Adviser, HIV Practice, UNDP) reported on work undertaken by the UNAIDS Secretariat and UNDP to try counter the recent epidemic of “bad” HIV laws.

- In order to respond to the problematic N’Djamena law, the UNAIDS Secretariat, with partners, including UNDP, held consultations in Dakar in July 2007 and April 2008, bringing together parliamentarians, government officials, civil society and concerned international organisations to discuss the N’Djamena law and national laws; provided official UNAIDS alternative language to the problematic aspects of the N’Djamena law; provided official UNAIDS comments to pending law in some 8 countries; developed road maps for change for all countries affected by the N’Djamena law; and undertook technical visits to four countries who either had pending laws or had indicated they were wishing to reconsider their laws.

- The UNAIDS Secretariat sent a briefing e-mail to all staff, providing an overview of what had happened in West and Central Africa as well as the multisectoral engagement processes organized in response, and encouraging staff to support other efforts to positively influence the legal environment in-country. The briefing included powerpoint presentations on the role of law, law enforcement and access to justice in an effective and rights-based response to AIDS, a short legislation checklist and a briefing guidance note on addressing the legal challenges relevant to national
responses to HIV. The e-mail encouraged staff to go beyond formal law and address access to justice and law enforcement, which can often lead to more immediate and tangible positive impacts for people living with and affected by HIV.

- The UNAIDS Secretariat and UNDP continued working with parliamentarians, promoting the Inter-parliamentary Union (IPU), UNAIDS, and UNDP Handbook for Parliamentarians, Taking Action against HIV, which is now available also in French and Spanish; co-organizing an IPU session for parliamentarians at AIDS 2008; and co-organizing an IPU consultation in Uganda in October 2008.

- To response to the creation in many countries of new HIV-specific offences criminalizing the act of transmitting HIV or exposing another person to HIV, UNAIDS and UNDP issued a policy brief at AIDS 2008 and participated in other initiatives to raise awareness about the problem of overly broad criminalisation.

54. Timberlake highlighted that while UNAIDS promotes the “know your epidemic and response” approach, many countries rush to legislate on HIV without doing any groundwork to understand how law and policy can positively affect the response and empower people to access HIV prevention, treatment, care and support. It was underlined that legal audits should address not only formal law, but also traditional law, law enforcement, the role of the judiciary, the role of parliament and access to justice issues, and should be participatory and involve civil society and parliamentarians. Timberlake noted that there is no single methodology in wide use for such an audit. Developing such a tool, which would support civil society and parliamentarians’ engagement, should be a priority.

55. The Reference Group congratulated the UNAIDS Secretariat and UNDP for their many activities aimed at addressing legal challenges in the response to HIV. It highlighted that, while a lot had been done, capacity to deal with legal developments remains limited, often leading to a reactive rather than proactive response to the legal environment. It recommended that the UNAIDS Secretariat, UNDP, and OHCHR strengthen their capacity in this area. In particular, training for staff of UNAIDS Secretariat and staff of the Co-sponsors working on HIV should include training on effective strategies to support an enabling legal environment. Staff throughout the Joint Programme should understand that work with parliaments, Ministries of Justice, Interior and Migration, the police, and the judiciary is essential to ensure that the legal environment is one that enables an effective, rights-based and equitable response to HIV at the national level, particularly for all those most vulnerable to infection and most affected by HIV. In addition, efforts are needed to strengthen civil society capacity, as well as the capacity of national human rights institutions, towards greater access to justice, and capacity for advocacy that is based on human rights.

56. The Reference Group discussed and provided comments on a draft of a guidance note on addressing HIV-related law at national level. It generally agreed with the approach taken in the guidance note that suggests that, in light of limited financial and human capacity, efforts by national stakeholders, the UN System and donors focus on four areas of legal challenge in the response to HIV, in the following order of priority:

- first, community empowerment and mobilization to know the law and to access justice;
- second, monitoring and assessment of the law’s impacts;
- third, human rights training for key service providers and those responsible for law enforcement; and
- fourth, legislation and law reform.
57. It noted, however, that in some cases, legislation and law reform may have to be the priority. In particular, in some legal systems, enabling legislation is needed in order to be able to introduce certain HIV programmes (for example, opioid substitution therapy) in a country. In other countries, reforming laws and policies that create barriers to HIV treatment and care (such as reforming national intellectual property legislation to ensure that TRIPS flexibilities are incorporated into national laws and regulations without delay; or reforming national patent laws in least developed countries to allow national authorities the option of not providing any patent protection in the pharmaceutical sector until 2016, as provided in the WTO Doha Declaration) would be an obvious priority.

58. The Reference Group suggested that the guidance note, which was originally drafted for UNAIDS Secretariat staff, should be revised and that possibly three versions should be issued: one for staff of the UNAIDS Programme, one for civil society, and one for governments and parliamentarians. The Group agreed to provide additional, more detailed comments in writing after the meeting.

59. The Reference Group briefly discussed a draft of a public statement, prepared by the subcommittee on legislation, to support the UNAIDS/UNDP policy on criminalization of HIV transmission, while at the same time calling on countries to change laws and policies that stand in the way of effective HIV prevention and treatment. The Group agreed with the statement in principle, but decided that members should be able to provide additional written comments on the draft within two weeks. After the meeting, the statement was revised based on a few comments received and disseminated. Upon suggestion by Michael Kirby, the group endorsed the document entitled, “10 reasons to oppose the criminalization of HIV exposure or transmission”, produced by the Open Society Institute on behalf of civil society organizations from many countries around the world.

Key developments since last meeting

60. Reference Group members reported about a number of key events and developments since the last meeting. Mary Ann Torres reported about the High-level Meeting on HIV/AIDS in June 2008. While the meeting did not include a specific panel on human rights, Mark Heywood delivered a video address and most civil society and a number of governments made reference to critical human rights issues. Jonathan Cohen reported about the World AIDS Campaign’s recent decision to make human rights the main theme of the Campaign for the next two years, which provides a great opportunity for advocacy and awareness-raising, but there will have to be care taken to avoid the risk that human rights becomes an empty slogan. The campaign will need to be backed up by serious content that creates clarity about what a rights-based approach to HIV demands. Susan Timberlake reported about the work of the International Task Team on HIV-related Travel Restrictions, which was established to galvanize attention around HIV-related restrictions on entry, stay and residence, and generate support for much greater action against such restrictions. Ralf Jürgens reported about efforts to highlight human rights at AIDS 2008 and plans for even greater focus on human rights at AIDS 2010.

---

Reference Group issues

61. The Reference Group briefly discussed several issues related to the Group’s composition and working methods. However, members had limited time for this discussion and provided written input in follow up to the meeting. The following text summarizes both the discussion at the meeting and the written input received.

62. With regard to membership, members felt that the Reference Group had been strengthened and reinvigorated by the addition of the seven new members who joined in July 2008. While recognizing the contributions of departing members and the need to address some gaps in representation, they also felt that there should now be a period for consolidation and building cohesion within the membership, with a small number of members rotated on and off each of the next two years. Specific suggestions to support the diversity of the Group and its expertise included: increased participation from Eastern Europe and Central Asia; expertise on issues related to injecting drug use and prisons; adding a youth representative, recognizing the energy and vision of young people at AIDS 2008, including on human rights issues; increased representation of people living with HIV; and expertise on public health programming.

63. Reference Group members sought feedback from the UNAIDS Secretariat about the Reference Group’s use of its capacity to speak and act publicly and independently, what impact it has had, and how the Reference Group is perceived within UNAIDS. Timberlake said she felt that the Group and its statements have had an impact, conveying the expert views of a diverse human rights constituency, and focusing attention on critical issues that need greater attention by the UNAIDS Secretariat and the Co-sponsors. However, she emphasized that it will remain a constant challenge for the Reference Group to choose its battles and issues carefully, being selective enough that its voice retains power and impact, and further developing its capacity for follow up when the Group does speak up. Members discussed how dissemination of Reference Group statements could be further improved, and agreed that Reference Group statements, if they relate to issues under consideration by the UNAIDS Programme Coordinating Board, should be sent to all “UNAIDS Global Coordinators”, who represent UNAIDS Co-sponsors and are part of the UNAIDS Board.

64. Reference Group members made a plea for greater engagement with UNAIDS Co-sponsors in the work of the Reference Group, covering human rights issues across a wider range of technical areas, and building on the engagement to date with WHO, UNDP, UNFPA and UNODC. One member noted the example of drug use, harm reduction, and human rights, an area in which the Reference Group has done some work and involved UNODC at one of its meetings, but where a lot of work remains to be done. Members also recognized that many of the UNAIDS Co-sponsors have never participated in a meeting (UNHCR, UNICEF, WFP, ILO, UNESCO, World Bank), although some of them have expressed an interest in discussing issues of concern to them with the Reference Group. Members made several suggestions about how, in practice, interaction with other Co-sponsors can be increased without overwhelming Reference Group meetings with heavy meeting agendas or more “external” participants than actual Reference Group members. Generally, they felt that there should be prioritization based on the timeliness and urgency of the issues for consideration, not just engagement for the sake of engagement. The guiding questions therefore should be: (1) What issues does the Group see as needing greater attention? (2) Who needs to be around the table to have a meaningful discussion about these issues? Members suggested a number of
priority issues, including refugees and migrant populations, institutionalized populations, and TB and Hepatitis C virus (HCV) in the context of HIV.

65. Members did not resolve the issue of whether the Reference Group should recommend to the incoming Executive Director that its work be evaluated by an independent expert, so that its work and its impact can be further strengthened. Generally there was agreement that the work of the Reference Group should be monitored and evaluated. However, before making a decision, members felt they needed to know whether any of the other UNAIDS Reference Groups has been evaluated. In the absence of a broader initiative to evaluate reference groups, they wondered how an evaluation of the Human Rights Reference Group would be perceived. One member suggested that asking for an independent evaluation by external experts may not be required, but that it would be good to undertake a process of reflection about when the Reference Group has been most effective, and why. Such a process would be led by an external facilitator and support the Reference Group to make more informed decisions about which issues to prioritize in its future work. Another member suggested that it would be appropriate for the UNAIDS Secretariat to conduct an external review of all its Reference Groups. This would be preceded and informed by individual Reference Group internal reviews, based on a common framework to be suggested by an external review panel in consultation with the Reference Groups.

66. Ralf Jürgens reported that the Reference Group had been able to follow up on most of the commitments it made at its eighth meeting, but failed to follow up on issues that had not been assigned to any of the three subcommittees (gender, legislation, and universal access) established at that meeting. He reminded members that, according to the Terms of Reference of the sub-committees, rather than starting new work on issues the Reference Group has not considered before, the committees are meant to “follow up on commitments made by the Reference Group on specific issues discussed at a Reference Group meeting by providing input into documents or processes, drafting letters or Reference Group statements, or undertaking other activities decided upon at a Reference Group meeting, as reflected in the summary of recommendations of the meeting”. He further reminded members that it was intended that sub-committees may finish their work before the next meeting of the Reference Group. However, a sub-committee “may propose at the next meeting of the Reference Group to continue its work, or the Reference Group as a whole may suggest to the sub-committee that it continue its work and suggest additional activities the sub-committee should undertake”.

67. Earlier in the meeting, members had suggested that a number of additional sub-committees be created. However, during the session on Reference Group issues, members recognized that it may be better to limit the number of sub-committees and, instead of creating new committees, assign additional tasks to each of the sub-committees. In particular, it was suggested that: (1) the universal access sub-committee should (a) continue working on monitoring and evaluation of universal access; and (b) add consideration of issues related to HIV testing and counselling to its mandate; (2) the legislation (including criminalization) committee could be asked to add consideration to issues related to drug use to its mandate; and (3) rather than creating a formal sub-committee on reproductive health and rights, a small group of members could undertake the background work and prepare a session (including an issue paper) on reproductive health and rights at the next meeting of the Reference Group. Following the meeting, these suggestions were approved. New Reference Group members were encouraged to join the work of any of the three sub-committees, according to their expertise and interest.
68. In addition to discussing the work of the sub-committees, members raised the need to increase participation in other aspects of the work of the Reference Group in-between meetings. In particular, it was pointed out that some members are not consistently providing comments on documents sent to them for input. It was suggested that the Reference Group should be clear about what minimum level of participation it expects from its members. One member proposed that members self-evaluate their participation each year, and that members who are unable to attend -- in person or through electronic communication -- more than two consecutive meetings should resign.

69. With regard to the Chair, members agreed that the Reference Group needed a person with the expertise, perspectives and skills that Mark Heywood brings to the Group. Members expressed their hope, however, that Heywood could be more visible as Chair in 2009. It was suggested that, in addition to considering what level of engagement the Reference Group expects from its members, the Group should also look at what it expects from its Chair.

70. The Group briefly considered the issue of translating Reference Group documents to other UN languages to make them more widely available. Generally, members were supportive of the idea that at least some of the more important public documents produced by the Reference Group, such as its statements, should be available in other languages, resources permitting.

Presentation of Reference Group conclusions/recommendations to the UNAIDS Deputy Executive Director

71. Michael Kirby thanked UNAIDS for its continued support of the Reference Group and Michel Sidibe, UNAIDS Deputy Executive Director, for his leadership on human rights. He reported on the outcomes of the Reference Group’s deliberations and noted that the Reference Group had focused on producing a recommendations brief to the incoming UNAIDS Executive Director, which would be finalized as a priority after the meeting.

72. Sidibe thanked Reference Group members for their hard work, underlining that, in his view, we cannot make any difference in the response to HIV if we do not put human rights at the centre. Medicalizing the response would not allow us to solve the serious issues underlying the epidemic. He added that AIDS represents a crisis of inequity, and that lack of social justice and of opportunities for people to have access to the services they need drives the epidemic. He emphasized that all UNAIDS staff need to become more competent on human rights issues, and that the priority must be to move from human rights rhetoric to human rights programming.

73. Reference Group members thanked Sidibe and discussed several pressing issues with him, including the status of the UNAIDS guidance on sex work and problematic HIV legislation in Africa.