



UNAIDS Global Reference Group on HIV/AIDS and Human Rights

Third Meeting, January 28-30, 2004, Geneva

Public Report

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I. Introduction

The third meeting of the UNAIDS Reference Group on HIV/AIDS and Human Rights was held in Geneva on 28 – 30 January 2004, with the primary focus of the meeting being to revisit HIV testing and counseling, address scaling up of HIV treatment, and the scaling up of HIV testing in the context of the 3by5 initiative.

The discussions and recommendations of the meeting are summarized in the following sections of the report.

II. Opening Remarks

The third meeting of the Reference Group was opened by Marika Fahlen, Director of the Social Mobilization and Information Department, UNAIDS, who expressed the importance of the work of the group at this crucial time in the push to scale up HIV/AIDS efforts. She added that this meeting follows another consultation by WHO on the equitable access of treatment and the principles of equity in resource-poor settings and that linkages with the outcomes in that meeting would be necessary to offer proper guidance to UNAIDS/WHO on this topic. Fahlen welcomed Maria Luisa Silva, representative from OHCHR, who will serve as the permanent observer at Reference Group meetings to ensure continuous engagement between the work of OHCHR and UNAIDS at all levels.

Sofia Gruskin then welcomed participants and gave an overview of the agenda for the three days. She reiterated the significance of this meeting as expressed by UNAIDS in continuing to focus on the scaling up of HIV testing particularly in light of the resources and attention focused on achieving the targets of the “3 by 5” Initiative.

III. Focus Sessions

The substantive sessions of the third meeting of the Reference Group were organized around three broad categories: HIV Testing, chaired by Daniel Tarantola; scaling up of access to HIV treatment (the 3by5 initiative), chaired by Michael Kirby; and scaling up of HIV testing in the context of the 3by5 initiative, chaired by Anand Grover.

1) HIV Testing

Updates on work done around HIV testing

This session involved discussion and review of two documents: the Technical Update produced by the WHO and UNAIDS; and the Guidance Note drafted by the Reference Group.

Technical Update: Marika Fahlen and Anindya Chatterjee presented a draft of the “Technical Update: Scaling up Voluntary HIV Counselling and Testing (VCT) - The Right to Know.” This document was previously called the “Q and A on scaling up of HIV testing” and was drafted in consultation with WHO. The Reference Group members raised a number of issues and concerns about the current draft. There was consensus among members that including the “Right to Know” in the title was inappropriate in its misuse of human rights terminology. Recognizing that the term was a slogan for the campaign, members nonetheless felt strongly that any document produced by intergovernmental organizations, such as UNAIDS and WHO, needed to be technically accurate. It was suggested that reference be made instead to the rights to access and to choose to be tested.

Other suggestions were discussed which include:

- Members noted the importance of framing issues in the document with reference to populations affected and infected.

- Furthermore, clarity was needed on who was being addressed by the document. The tone and approach would shift depending on whether addressed to policy makers, providers, NGOs, or some other group, and the current draft seemed an unhappy mix of all of the above.
- The Members advised that language should move out of the passive voice and identify who the actors and players were for each section in the document. In particular, members expressed strong concern about use of the language of “routine”. It was stressed that the document should distinguish between routinely offered and routinely imposed testing. To avoid ambiguities, the language of the testing process should be made clear and much more descriptive. For example, if using “opt-out”, then this should be followed by a description of the process involved and clarification of the ways this did or did not involve decision-making by individuals.
- It was also noted that pre-test counseling was not sufficiently addressed and that minimum requirements of pretest counseling, with a focus on informed decision-making, should be incorporated.
- Some human rights principles were misused and/or incompletely addressed in the document, and the key factors identified in the Reference Group’s guidance to UNAIDS should be included to ensure a more comprehensive approach.

UNAIDS Secretariat explained that they appreciated the comments and were aware of gaps in the document. They further explained that the text of the document was established through an intensive negotiated process between partners, and therefore the process in putting together the draft had been very challenging. It was agreed that the Reference Group would coordinate detailed input on the document and would submit this to UNAIDS the week immediately following the meeting in the hopes that the Reference Groups input could help to strengthen the document and the guidance given.

Guidance Note¹: Sofia Gruskin presented this document to the participants, which was a summarized version of the guidance prepared shortly after the second meeting of the Reference Group. Although the original longer version of the Guidance Note drafted from the second meeting discussions was useful to UNAIDS in several ways, the Executive Director had requested a shorter version be put together for discussions and distribution – in particular to country staff.

Members provided several important recommendations on how to revise the document. They agreed that the document should present the crucial factors necessary for the scale up of HIV testing as “an equation”: scaling up of the routine offer of testing has to be harmonized with the availability of benefits and protection from stigma and discrimination. In addition, the document should highlight the synergy between the public health and human rights benefits of scaling up of testing, recognizing that human rights effectiveness has to be supported by evidence. Additional suggestions included ensuring explicit attention to the definition of “routine”, the implications of a positive test result, and the framework of progressive realization for the achievement of scale up efforts. The Reference Group Secretariat agreed to further shorten the Guidance note based upon this input and submit the revised version to UNAIDS in the weeks following the meeting.

HIV testing of specific populations: recruits of the armed forces

This session was presented by Ralf Jürgens². The presentation reviewed several court cases in which questions were addressed of whether mandatory testing in the military was a useful strategy and whether the HIV status of an individual in any way impacts on their ability to perform their duties. In 2001, the UN established an Expert Panel to study the issue of whether to support HIV testing of peacekeeping personnel. In the end, the Expert Panel unanimously rejected mandatory testing and instead reiterated their endorsement of voluntary HIV counseling and testing for UN peacekeeping personnel. Nonetheless, evidence seemed to indicate that a majority of governments undertake mandatory testing of their own peacekeeping and military forces and most of these were also rejecting applicants or limiting their duties based on their HIV status. Mandatory testing practices seemed to be the norm even though the UN has produced explicit guidance to the contrary.

¹ See the *Guidance Note on Scaling Up of HIV Testing*

² See Issue Paper “HIV Testing of Specific Populations: Recruits of the Armed Forces.”

Discussion centered on why these policy directives have failed to sufficiently influence government policies on this issue, and how this can best be addressed. The group recommended that current UNAIDS documents be disseminated more effectively. There was consensus that the recommendations of the Expert Panel needed to be endorsed, and that the concept of confidentiality must be stressed in all circumstances. Members expressed concern that this issue was being revived and suggested a follow-up be conducted on the recommendations of the Expert Panel report. They however noted that the Expert Panel report had been drafted for peacekeeping forces, and the issues raised by HIV testing within national militaries may be different. Members agreed that of utmost importance in all future work was to make clear distinctions between UN Peacekeeping Forces, peacekeeping forces generally, and national military and security forces. UNAIDS should make these distinctions in all its documents so as to avoid ambiguity in its guidance, even as in all cases the concept of confidentiality should be stressed. As the request to review HIV testing in the military came from the UNAIDS Secretariat, members agreed that they would need guidance from UNAIDS on whether they think it would be useful for the group to address separately the issues raised with testing in the military and security forces.

The need to further explore how the scale up and availability of treatment impacted on this discussion was expressed, recognizing the importance of the distinction between peacekeeping forces and the military in this respect. For example, a useful strategy would be to document the rationales and experiences of countries that have chosen not to institute mandatory testing of peacekeepers or armed forces, as this may prove the most effective information to persuade governments wishing to institute mandatory testing of their populations on why they should not do so.

UNAIDS Secretariat also suggested that the Reference Group provide input in the report being prepared by UNAIDS for the upcoming Security Council meeting. Members agreed that if Peter Piot would find this useful they would be happy to do so. Finally, the group suggested that members with expertise in this topic, namely, Michael Kirby, Ralf Jürgens, and Mark Heywood, can work with UNAIDS on this topic as necessary. It may also be useful to bring in senior military personnel in future discussions.

HIV testing of specific populations: children and adolescents

This session was presented by Sofia Gruskin³. The presentation highlighted the complex balance of rights and responsibilities among the State, parents, and children that framed and cut across the human rights considerations of HIV testing for children and adolescents. She stressed the need to distinguish children from adolescents in these discussions and in recommendations because each raised different issues of law, policy, and practice. Any guidance must not only consider laws, policies, and practices separately but also the interactions between them. The extent of the State's duty to ensure the conditions under which children/adolescents might decide to voluntarily get tested, recognizing their evolving capacities, gender and other differences, and the content of what those conditions might be, remained an open question.

The discussion raised several points. Recommendations should be grounded in the principles of the Convention on the Rights of the Child (CRC) with explicit attention to the language of "evolving capacity," and serving the best interests of the child. Of utmost importance was attention to the legal role of parents and guardians in facilitating or impeding the access of adolescents to HIV testing. While the Reference Group strongly supported the engagement of parents in providing support to adolescents wishing to be tested, they explicitly and unanimously agreed that in no case should parental consent block access to testing. In fact, the Reference Group drafted language to present to UNAIDS as suggested guidance in this regard. Any guidance statement should begin by stating that "Parents of children should be encouraged to be aware of the risk of exposure to HIV faced by their children and to take part in educating their children about HIV and the means of avoiding exposure to it. Children who have been exposed (or who themselves consider they may have been exposed) to HIV should have access to HIV testing with or without parental consent."

³ See Issue Paper "HIV Testing of Specific Populations: Children and Adolescents."

Also discussed were inconsistent laws and policies which impeded access for adolescents to HIV testing, treatment, and care. For example, a law may prohibit access to health services for adolescents without parental consent, while the HIV policy may state that voluntary HIV testing is available to all who come forward (the reversal also exists). It was suggested that it would be useful to document these variations and their impact on the HIV testing practices to highlight differences and produce effective recommendations.

While discussion focused primarily on access to HIV testing for adolescents, it was agreed that further attention is needed also to the specific issues that exist in relation to HIV testing of infants and children under 12. It was recognized that further extensive discussion was needed on the implications of availability of treatment on issues raised around HIV testing of adolescents.

Implications of a positive test result

This session was presented by Sofia Gruskin⁴. The presentation elaborated on how, as policies were being adopted in order to scale up HIV testing because of the promising access to treatment, there was insufficient attention to the lessons learned over the past 20 years as to how positive test results were conveyed, to whom and for what reasons, areas which must not be ignored in the rush to scale up. Dr Gruskin pointed out that when testing policies are silent on this matter, this leaves this area to be dealt with at the health providers own discretion. On the other hand, some policies call for information regarding the result of the test remaining strictly confidential and only disclosed for an *overriding legal or ethical duty* with the individual's informed consent. In neither case is the guidance sufficient to help ensure that abuses will not occur in the rush to scale up.

There was a large amount of evidence in relation to HIV and STDs that established the ineffectiveness of these discussed forms of disclosure in improving access to testing, treatment, and care. Therefore onus should be on public health professionals that push for these practices to provide evidence on effectiveness. It was suggested that issues of named reporting, disclosure, and partner notification should be addressed further by the group. Members agreed that the concept of confidentiality remained key and must be stressed.

It was agreed that the concerns raised in this discussion would be included in the Reference Group's Guidance Note and a request made to the UNAIDS Secretariat that these issues be integrated into the documents produced by UNAIDS in relation to testing, including the Technical Update on Scaling Up of Voluntary HIV Counseling and Testing.

Summary of Recommendations of Focus Sessions on HIV Testing

1. With the current push to scale up, UNAIDS should ensure that all technical guidance, policies and guidelines on HIV testing continue to be explicitly based on human rights norms and standards. Any deviations from key human rights principles must be stated clearly as such and justified.
2. In regards to **recruits of the armed forces**,
 - i. There is already clear guidance from UNAIDS on this topic but current documents should be disseminated more effectively.
 - ii. Documents produced by UNAIDS should clearly define UN peacekeeping forces, peacekeeping forces generally, and military and security forces to ensure there is no ambiguity on who is affected by policies and how to apply policies.
 - iii. Follow up on the Expert Panel report (Bangkok, November 2001) could be produced which highlights actions taken since this 2001 document was published.

⁴ See Issue Paper "The policy and programmatic implications of a positive test result: preliminary considerations."

3. In regards to **children and adolescents**,
 - i. UNAIDS documents on HIV testing should, when addressing children and/or adolescents, distinguish between these two groups and consequently the implications of these differences on policies and programs.
 - ii. Governments should be encouraged to recognize discrepancies in laws and policies which may impede adolescents' access to HIV testing, treatment, and care (for example, parental consent, age of consent, and gender).
 - iii. The harmonization of evidence, law, policies and practices is a dynamic process. UNAIDS can use any of these entry-points to define optimal ways in which HIV testing can be made available to adolescents but attention should be given to each in the guidance offered to countries.
4. In regards the **implications of a positive test result**, the concerns raised in this discussion (and as addressed in the Reference Group's Guidance Note to UNAIDS, final submitted on 5 March 2004) should be integrated into the documents produced by UNAIDS in relation to testing, including the Technical Update on Scaling Up of Voluntary HIV Counseling and Testing.
5. The discussion also highlighted the growing need to collect evidence on the effectiveness of human rights approaches to HIV testing and more broadly. This evidence is needed for several reasons including to dispel the notion that it is a failure of human rights approaches that has impeded access to testing and services. This must be countered, as the Reference Group believes a main issue has been the failure of governments to fully and effectively implement human rights approaches in their work. UNAIDS Secretariat agreed that this recommendation is crucial for their work. It was suggested to UNAIDS that this be the topic of the next Reference Group meeting. A sub-group was formed including Ralf Jürgens (who will facilitate this sub-group), Anand Grover, Mark Heywood, Daniel Tarantola, and Mary Ann Torres to support work on the first phase of this effort. Work will begin by framing of research issues and pinpointing priority areas – the sub-group will review efforts within their organizations and brainstorm research questions and gaps that need to be addressed. These would then be provided to the Chair who, and then in conjunction with UNAIDS, would assess how best to plan the next meeting of the Reference Group.

2) Scaling up of Access to HIV Treatment – the “3 by 5” Initiative

Risks, challenges, and opportunities of 3by5

This session was presented by Badara Samb, HIV/AIDS Department, WHO⁵. He explained how the 3by5 initiative represented a change in culture and approach to HIV/AIDS. The presentation provided an overview of the approaches, milestones, processes, and expected outputs for the initiative. The new approach was based on two main objectives: simplification of methodologies to scale up treatment particularly in resource-poor settings; and country support to leverage necessary resources and respond to gaps in treatment services. The WHO budget for 3by5 was estimated to be \$220 million and would require 480 additional WHO staff. The target, in order to put 3 million on ARV treatment by 2005, was to have 20,000 service outlets providing VCT, 10,000 service outlets providing ART, 100,000 health providers and community treatment supporters, and 30,000 partnerships between formal ARV therapy outlets and community-based groups.

Members of the Reference Group voiced full support for the initiative but nonetheless raised several concerns. In particular, the need for caution to ensure that human rights were not intentionally or inadvertently abused as a result of simplification in the guidance given in relation to services offered or as a result of the use of the language of “emergency” which was used to draw attention to the 3by5 initiative.

⁵ Please see PowerPoint presentation “Treat 3 million people living with HIV/AIDS by 2005 – 3by5.”

Concerns were also raised to the risks in setting targets for the number of people who would be on treatment and what actions governments may take in pursuit of these targets. For example, mandatory testing of certain populations could be implemented or key parts of the HIV testing process such as pre-test counseling and confidentiality could be sidelined. Questions were also raised on how a “person on treatment” was going to be defined and counted and what criteria will be used to determine who will access treatment, initially and over time.

The Members stressed that prevention efforts, including vaccines and microbicides, must also not be sidelined and the opportunities that the availability of treatment may raise to work on these areas must be taken advantage of. There was also consensus on the necessity of better community involvement in all aspects of planning and implementation. Employing communities, including business owners, to take part for example in following up with patients taking treatment, could be vital. The implications of gender for sustained access to treatment must be given more serious consideration.

The group suggested that it would be interested in reviewing training packages to be used by the 3by5 Initiative to help ensure proper emphasis on fundamental human rights principles in critical aspects such as VCT. Finally, it was agreed that 3by5 should be carefully monitored by an independent external group, and concerns were raised that no such group seems as yet to have come forward. Criteria for determining failure (or indicators) that would trigger exit strategies by governments and/or international organizations with minimal damage to clients and patients must be considered and made publicly known.

Human Rights and HIV/AIDS in the Context of 3by5: Time for New Directions? A Perspective from Southern Africa

This session was presented by Mark Heywood⁶. Although the 3by5 campaign needed the active support of human rights activists of all hues, he stressed that it was important to be sober and realize that it also presented major risks. Just as it could raise global expectations, it could also dash them. In regards to the 3by5 initiative, the concerns raised in the previous presentation were again stressed, but in addition, he suggested that UNAIDS and WHO must deal with the crisis in governance (and failure of governments to take responsibilities seriously) at the international level, national level (ensuring commitment of governments to implement national policies), and at local level (services in schools, clinics, etc.), as well as implications of these crises for ensuring access to treatment for all who need it. Heywood described how the use of international legal human rights norms and standards were well established and have been used successfully for instituting national legislation and holding governments accountable. However, he suggested human rights offer other possibilities which have not been sufficiently addressed and this should be further explored to bring human rights more effectively to the community level.

Members reiterated here that although they were raising a number of concerns around 3by5, this should not in any way be interpreted as undermining the importance of the initiative. 3by5 was recognized as a victory for human rights and was established through sound human rights advocacy. To ensure success of the initiative, fair criteria must be established, and efforts must be made to ensure that stigma, discrimination and criminalization are not increased as a result of the initiative.

⁶ See Issue Paper “Human Rights and HIV/AIDS in the Context of ‘3 by 5’: Time for New Directions? A Perspective from Southern Africa.”

Ethics and Equity in the Context of 3by5

This session was presented by Ruth Macklin⁷. The Issue Paper for this session was a summary of a longer version Dr. Macklin prepared for the WHO consultation entitled “Ethics and Equity in Access to HIV Treatment: 3by5 Initiative.” She explained that WHO does not want to impose a single way to ensure access but to put forth different alternatives governments can choose from. By following key ethical principles relevant to fair distribution of ART, and mechanisms for procedural fairness, she suggested three steps should be followed in any policy process to ensure equitable access to ART: specifying necessary conditions for individuals to receive ART; identifying locations and institutions where treatment is to be offered first; and setting priorities for who shall be the first to receive ART.

For the 3by5 initiative, ethical and human rights frameworks must be applied in all aspects: currently human rights exist only in the rhetoric and ethics appears in only one of the pillars of the strategy. Discussion centered on how human rights norms and standards and ethical principles provide different and complementary guidance as to how to ensure access to treatment. It was agreed that key in both human rights and ethical terms was ensuring a process that would lead to fair outcomes. Using the two frameworks, a plan could be put together to progressively realize equitable access to treatment. The Reference Group felt that human rights and ethics should be introduced in the tool kits being produced.

Summary of Recommendations of Focus Sessions on Scaling up Access to HIV Treatment

1. It was considered imperative that simplification of HIV strategies to meet established targets does not impact the quality of services, nor violate human rights or established ethical standards. Restrictions on rights that may occur because of rush to implement strategies and in order to meet benchmarks and targets need careful consideration. The language of emergency should be used with caution and after implications have been weighed carefully. Criteria for failure must be established that can support execution of exit strategies to minimize negative consequences.
2. Public disclosure is needed as to how an individual on treatment is counted, this includes clarifying who will be considered as "on treatment" and ensuring that individuals are not double-counted. This is not clear from current documents.
3. Ensure all communications from UNAIDS in the context of 3x5 are explicit in their articulation of established human rights norms and standards. This is critical to ensure work at national level – whether governments or NGOs continue to draw on these standards and ensures accountability for their responsibilities in providing services.
4. Ensure there is clarity on the linkages between 3by5, existing national level plans, and existing UNAIDS/WHO efforts, in regards to resource allocation, priority setting, etc, and address the implications of differences between policies.
5. Ensure prevention efforts, including vaccines and microbicides, are not sidelined in rush to scale up treatment. A clear process should be put together to identify the most effective entry points for working on these efforts as they connect to the 3by5 initiative.
6. Ensure engagement of community representatives in all phases of implementation strategies, and not only in drafting of the initial policy or program.
7. Ensure issues of gender and women’s rights are systematically addressed in all scale up efforts.
8. UNAIDS should ensure ethical frameworks are emphasized in relation to the international human rights obligations of governments engaged in this work and not presented as a substitute. Reference Group suggests that human rights and ethics be discussed jointly in the context of 3by5.

⁷ See Issue Paper “Ethics and Equity in Access to HIV Treatment in the Context of ‘3 by 5’”

9. Ethics is critical to decision-making but, in particular given the legal obligations of policy-makers under the human rights framework, the value of human rights for addressing issues of fair processes and accountability, etc., within decision-making deserves further exploration. Current attention to ethics and human rights in the context of 3x5 seems to be focused only on equity and non-discrimination.
10. UNAIDS has a critical role to play in planning and implementation of 3by5 to ensure sustainability of efforts and programs connected to 3by5 beyond 2005.

3) Scaling up of HIV Testing in the Context of the “3 by 5” Initiative

National level testing and treatment plans

This session was presented by David Miller, Prevention Team of WHO’s HIV/AIDS department, and Kwame Ampomah, UNAIDS Country Coordinator from Botswana. Miller⁸ began by giving an overview of developments in HIV testing and counseling since his presentation at the Reference Group’s second meeting (August 2003). He stressed several criteria as crucial for implementing the testing and counseling process itself, which included: promoting routinely offered testing and counseling; linking services to care and treatment; acting on community denial, stigma, discrimination, and gender inequality; and increasing competence of health care workers. He believed human rights guidance was needed on issues such as testing and counseling which include testing and counseling for youth; “perpetrators” refusing consent; testing in “gray” settings (e.g. post-injury; counseling boundaries and responsibilities; and practical responses to mandatory testing (e.g., military, prisoners, marriage). Ampomah⁹ presented the efforts of scaling up testing in Botswana, and among other things, described the human rights challenges involved in the implementation of such scaling up, including the importance of clear guidance. He indicated that it appeared that the language of “routine” was being used by some providers to ensure the routine *offer* of the test in facilities, and by others to impose testing without consent.

There was consensus among members that UNAIDS/WHO must take a firm stand on any situation where testing is being imposed without consent. The Reference Group stressed the need for clear guidance from UNAIDS/WHO on the language of “voluntary” and “routine” in regards HIV testing and counseling. If the ambiguity of what is being done is not challenged and clarified, this may be taken as an endorsement of routine *imposition* of HIV testing. The Members asked that UNAIDS/WHO better disseminate policies and guidance on voluntary HIV testing and counseling to ensure correct interpretation at the national level. It could also be useful for UNAIDS to set some rules of engagement with countries that would ensure governments’ commitment to basic human rights principles in their HIV/AIDS efforts if UNAIDS was to work actively with them. In addition, within the UNAIDS and UN system more generally, there should be ongoing training of staff at all levels to unify and clarify the policies and principles followed by the organization.

Involvement of Civil Society

This session included presentations by Mary Ann Torres and Jim Welsh. Mary Ann Torres presented the role of NGOs and other civil society groups in HIV testing scale up efforts¹⁰. She stressed that these groups were critical in the scale up of HIV testing efforts within the context of the “3 by 5” initiative, particularly since most social and health services were not delivered through government structures in developing countries but through them. Jim Welsh presented the issues raised in ensuring the involvement of marginalized communities in HIV testing scale up efforts¹¹. An important issue arising from

⁸ See power point presentation for this session “Developments in Testing and Counseling (Since August last year..)”

⁹ See PowerPoint presentation for this session “Routine HIV Testing – Efforts in Botswana.”

¹⁰ See Issue Paper “Strategies for involvement of civil society in HIV testing within context of ‘3 by 5’: Involvement of NGOs.”

¹¹ See Issue Paper “Strategies for involvement of civil society in HIV testing within context of ‘3 by 5’: Focus on marginalized communities.”

the 3by5 initiative would be maximizing the potential benefit to marginalized communities from expanded testing while minimizing the potential negative outcomes including stigmatization and discrimination.

The discussion that ensued raised several issues and concerns. One concern was how to define which NGOs and other organizations are understood to represent civil society. The question was raised as to which groups UNAIDS engaged with within countries and if there were guidelines they followed in choosing their partners. These distinctions between NGOs and other civil society groups and organizations, and whether these organizations were service providers, whether they took service fees, or whether they sub-contracted with governments, etc, were discussed as all relevant criterion in forming the perceptions by communities and governments as to the independence and objectivity of these groups in HIV efforts. The Reference Group agreed that the accountability, transparency in what they do, and adherence to human rights principles in their work should be key criteria for UNAIDS in choosing partner NGO organizations.

Members also noted that with scale up efforts underway, the responsibilities placed on NGOs were huge, and putting more pressures on them, without sufficient support and resources, may lead to the collapse of these organizations. Furthermore, scale-up efforts which introduced unbalanced funding and power to certain groups could fragment work already underway. Conversely, in some countries where the epidemic was worst, and where advocacy was most needed, there seemed to be no organized civil society, and challenges were raised as to how to create and engage groups and individuals.

Members proposed a broader discussion at a later time on the interface between the efforts of UNAIDS/WHO and other international efforts such as the Global Fund and its impact on the sustainability of NGOs engaged in HIV/AIDS work at the community level.

There was also discussion on the increasing role being played by private organizations in providing HIV/AIDS treatment and care services. Concerns were raised as to the proper role for governments in monitoring the work of public-private partnerships, noting in this regard the fact that the private sector fall outside the established legal human rights frameworks. It was suggested that it would be useful to invite a representative from the ILO to one of the Reference Group's meetings to discuss the accountability of the private sector for its HIV/AIDS efforts.

Summary of Recommendations of Focus Sessions on Scaling up of HIV Testing in the Context of 3by5

1. UNAIDS/ WHO should take a firm position against the routine imposition of testing without consent, since remaining quiet may be taken as endorsement of such testing. Governments should be made aware of UNAIDS/WHO recent recommendations and guidelines on HIV testing and counseling and should ensure that *offers* of HIV testing are routinely made where appropriate, but testing is not routinely imposed. Government should be explicit in their guidance to implementers in regard to the routine offers of tests.
2. UNAIDS/WHO must make efforts to better disseminate their VCT policies and guidelines as they are not sufficiently known in places where abuses are taking place.
3. Ensure that a central message around HIV testing is clarified, which indicates that the failure in the uptake of testing in developing countries has not been the failure of human rights as a concept or a process, but the failure to properly implement human rights principles.
4. In working with NGOs/civil society groups in other areas and efforts, UNAIDS could begin to include attention to HIV testing in such a way as not to disassociate HIV testing from other efforts. Integration into a holistic approach will help to support uptake of HIV testing more generally.
5. There is concern that engagement with 3by5 may fragment NGO/civil society work on HIV/AIDS. There is also concern that 3x5 will overburden already over- committed and under-resourced NGOs, particularly in places where resources are scarce and NGOs feel they must

respond to the latest global initiatives presented in order to stay viable. UNAIDS/WHO are being asked to be aware of this as they engage with NGOs in this area in the future.

6. Difficulties arise for NGOs at national level when there is no legal system in place to address abuses they may experience in their engagement with national level governments. UNAIDS is asked to consider this constraint in their dealings with national level NGOs and to consider approaches for helping to strengthen the NGOs through their engagement with them.
7. UNAIDS is asked to distinguish in its work with “civil society” between NGOs, service providers, government sub-contractors (including whether they take fees for services), community groups, private business etc., and to draw attention to distinctions in roles of different sorts of civil society actors in work done by UNAIDS, in relation to 3by5 and more generally. There is much confusion as to what organizations are included under the rubric of “civil society” with potential damage to the viability of NGOs (in particular those that speak out against their government’s actions) and to the success of HIV/AIDS efforts that rely on NGO actions.

IV. Future Directions

Global Coalition on Women and AIDS: UNAIDS campaign theme for 2004

This session was presented by Gillian Holmes, Chief, Programme Development Unit, UNAIDS. This session was organized to present the efforts of the Coalition and introduce the work of the Coalition to the Reference Group so as to open up pathways for future engagement if needed¹².

Members were pleased to hear about the objectives of the Coalition and were supportive of its goals. They raised several points for consideration which included how the Coalition was ensuring attention to women beyond their engagement in antenatal clinics. Questions were also raised as to how the role of men was being addressed. There was also concern that reproductive and sexual health was not being adequately addressed by the Coalition. Recognizing that human rights were firmly on the Coalition’s agenda, members expressed their willingness to engage in the future with the Coalition in whatever ways would be most useful to their efforts.

Determination of Action Items for the Future Work of the Reference Group

Outcomes of the meeting would be presented to UNAIDS which detail products to be delivered by the Reference Group, the Reference Group’s recommendations to the ongoing work of UNAIDS, and the decisions to be taken by UNAIDS. The Reference Group would wait for guidance on these matters from the UNAIDS Secretariat.

¹² See the website: http://www.unaids.org/Unaid/EN/Events/Coalition_Women_and_AIDS.asp

V Closing Remarks

Sofia Gruskin welcomed Peter Piot to the meeting and gave a summary of the discussions and outcomes of the meeting. Peter Piot then provided closing remarks. Dr. Piot expressed the importance of scaling-up HIV/AIDS treatment in a holistic manner. He noted that debates about “routine” testing should not be a “debate on words,” since there was a lot of confusion on language, but should be based more importantly on how national plans were implemented and policies played in practice. He reiterated UNAIDS’ commitment to VCT and the position that mandatory testing was not acceptable. With the advent of treatment, prevention efforts, campaigns against stigma, and other proven effective strategies have to be sustained and strengthened. Dr. Piot therefore stressed the need to work on several fronts simultaneously. He noted some of the challenges in sustaining efforts and attention on stigma, discrimination and human rights. The meeting was concluded with an open discussion between Dr. Piot and Reference Group members on the important issues and concerns raised during the three days and a commitment to work together to address these concerns effectively.