

UNAIDS Reference Group on HIV and Human Rights

CLOSING THE GAPS AND FAST-TRACKING PROGRESS: HUMAN RIGHTS IN 2015

Sixteenth Meeting: 10–12 December 2014 Summary and Recommendations

This summary and recommendations was prepared by the Secretariat of the UNAIDS Reference Group on HIV and Human Rights after its sixteenth meeting (December 2014). The views contained herein are the views of the members of the Reference Group and do not necessarily reflect the views of the UNAIDS Secretariat or the Co-sponsors of the Joint Programme.

The sixteenth meeting of the UNAIDS Reference Group on HIV and Human Rights (“Reference Group”) took place in Geneva, from December 10–12, 2014. Over the course of three days, Reference Group members engaged with various UNAIDS staff, discussed persistent human rights challenges in the global HIV response, attended sessions of the 35th meeting of Programme Coordinating Board (PCB), and strategized about effective interventions to protect the rights of key populations and people living with HIV. The report that follows presents a summary of those discussions.

In the course of its deliberations, the Reference Group formulated twelve key recommendations. The Reference Group looks forward to opportunities to engage with the UNAIDS Secretariat and others regarding the implementation of these recommendations.

UNAIDS REFERENCE GROUP ON HIV AND HUMAN RIGHTS’ SIXTEENTH MEETING RECOMMENDATIONS

1. The UNAIDS strategy update

The Reference Group recognizes the importance of the 2016–2021 strategy update process to the future of the global HIV response. The Reference Group offers its expertise and support through this process, and encourages the UNAIDS Secretariat to involve the Reference Group in a meaningful way throughout the process to help ensure the prominence of human rights-centered strategies in the update.

2. The “Fast-Track” strategy

The Reference Group is concerned that the Fast-Track strategy is rolling out without a clear roadmap or a proper consideration of human rights. Furthermore, the Reference Group believes that the objectives of the Fast-Track cannot possibly be achieved unless respecting, protecting and fulfilling human rights are at the centre of the strategy. As such, the Reference Group welcomes the invitation to have a Reference Group member on the Scientific and Technical Advisory Committee (STAC) and requests that a formal process be established without delay to elaborate a human rights-informed Fast-Track guidance note.

3. Key populations

The Reference Group recommends that a critical element of the strategy update process be a substantive focus on the idea of “key populations” and their critical role in an effective response. The definition of key populations in the updated strategy should reflect the stigma, discrimination, social exclusion and criminalization experienced by these groups, as well as the necessity of their meaningful involvement in prevention, care, treatment and support policies and programming. The operating definition of “key populations” must appropriately capture the most at-risk groups and the social circumstances that make them more vulnerable to infection. That definition must apply to all countries.

Moreover, the Reference Group recommends that a specific human rights-based key population strategy be tied to each of the three targets (i.e., treatment, prevention and discrimination) so that country-gap analyses can reveal the key population-related gaps. This way, “no one gets left behind.”

4. Human rights-compliant HIV testing

The Reference Group recommends that its forthcoming statement on HIV testing — which emphasizes that human rights, including the right to informed consent and confidentiality, not be sacrificed in the pursuit of high coverage — be used to inform strategies to attain the first “90” in the treatment target. (The target is that, by 2020, 90% of all people living with HIV will know their status; 90% of all people diagnosed with HIV will receive sustained antiretroviral therapy; and 90% of all people receiving antiretroviral therapy will reach viral suppression.)¹ To this end, the Reference Group invites the treatment team to initiate a dialogue with representatives of the Reference Group and WHO to ensure UNAIDS-recommended approaches are optimal from a human rights perspective.

5. Intellectual property and access to medications

The Reference Group is extremely concerned that reaching the 90-90-90 treatment target will not be possible without addressing the challenges currently posed by intellectual property enforcement. As such, the Reference Group recommends the following:

- The UNAIDS Secretariat should openly acknowledge that the reconciliation of intellectual property law with human rights law is essential to the success of the 90-90-90 treatment target;
- The UNAIDS Secretariat should significantly increase in-house resources for promoting approaches to intellectual property that facilitate access to medications, including alternatives to the traditional patent regime;
- The UNAIDS Secretariat should support civil society to build up advocacy related to medications;
- The UNAIDS Secretariat should participate actively in the Equitable Access Initiative (EAI), and promote transparency and accountability in all activities of the EAI; and
- The UNAIDS Secretariat should continue to support Recommendation 6.1 of the Global Commission on HIV and the Law, which calls on the UN Secretary General to convene a neutral, high-level body to recommend a new intellectual property regime for pharmaceutical products that would be consistent with international law and public health requirements, while safeguarding the justifiable rights of inventors.

Furthermore, the Reference Group notes its disappointment that reference to the Global Commission on HIV and the Law was removed from the final intellectual property decision points of the 35th PCB. The Reference Group expresses its endorsement of the original decision points.

¹ UNAIDS, *90-90-90: An ambitious treatment target to help end the AIDS epidemic*, 2014.

6. Zero discrimination

The Reference Group recommends that the UNAIDS Secretariat adopt no targets that might reasonably be interpreted as accepting any level of discrimination against “key populations.” With respect to the forthcoming discrimination target, the commitment of UNAIDS should, as a matter of principle, continue to be zero — as are the goals of zero new infections and zero AIDS-related deaths. Targets that indicate progress towards the ultimate goal of zero discrimination must be presented as benchmarks only, not end goals.

Furthermore, the Reference Group recommends that the treatment, prevention and non-discrimination targets be presented as a package and explicitly linked. It should be clear in all UNAIDS messaging and interventions that reducing discrimination and protecting human rights are essential for success across the targets and throughout the Fast-Track strategy.

7. 2016 UNGASS on drugs

The Reference Group recognizes that the 2016 United Nations General Assembly Special Session (UNGASS) on drugs represents a critical moment and recalls recommendations made at its fifteenth meeting. In particular, the Reference Group reiterates its Recommendation 5.6 from that meeting, namely that the UNAIDS Secretariat should seek support from the co-sponsors for a common United Nations position based on the following principles:

- People who are dependent on drugs should be subject to public health, not criminal, measures;
- All harm reduction measures should be legal and available;
- Possession for personal use should not be criminalized; and
- Drug use is a human rights issue, not just a health issue. The human rights of people who use drugs must be respected and protected.

Furthermore, the Reference Group offers its expertise and support to the UNAIDS Secretariat in preparing for the UNGASS.

8. HIV and disability

The Reference Group commends the UNAIDS Secretariat for initiating an informal working group on HIV and disability. Moreover, the Reference Group calls on the UNAIDS Secretariat and co-sponsors to include people with disabilities in their meetings, reference groups and advisory committees. The Reference Group also encourages the UNAIDS Secretariat and co-sponsors to encourage and support governments to collect data on HIV regarding individuals with disabilities, and to promote accessible HIV prevention, treatment and support programs.

9. Civil society funding

Recognizing the importance of civil society in the HIV response, the Reference Group is concerned that funding for civil society action on rights-based responses to HIV remains dismally low. The Reference Group recommends that the UNAIDS Secretariat address this matter urgently, and advocate with governments and other funders for rapid increases in the funding available to civil society organizations for HIV-related work. Moreover, the Reference Group requests that UNAIDS advocates for civil society funding to be distributed effectively and equitably.

10. Crisis response

The Reference Group commends the UNAIDS Secretariat for its rapid response to recent human rights crisis situations and commends senior management for communicating that it is every staff member's responsibility to take action in response to human rights violations. The Reference Group encourages UNAIDS to continue to intervene when human rights are being violated, and to respond to situations involving all key populations and groups identified in UNAIDS' *The Gap Report* (2014).

11. Faith Ambassadors

The Reference Group endorses the initiative of appointing UNAIDS Faith Ambassadors and offers its expertise in identifying appropriate persons to take forward the mandate from a collaborative interfaith approach.

12. Ongoing engagement

The Reference Group is keen to support UNAIDS in all endeavours to keep human rights at the centre of the HIV response. To that end, the Reference Group is open to exploring different ways to engage and communicate in the coming year. Furthermore, the Reference Group asks that UNAIDS provide a progress report at the next full Reference Group meeting with respect to each of the foregoing recommendations.

Closing the gaps and fast-tracking progress: Human rights in 2015

UNAIDS Reference Group on HIV and Human Rights
Sixteenth Meeting Summary

TAKING STOCK OF THE CURRENT MOMENT

The sixteenth meeting of the UNAIDS Reference Group on HIV and Human Rights (“Reference Group”) began by recognizing new and departing Reference Group members and UNAIDS Secretariat staff. The Reference Group formally acknowledged the exceptional work of Susan Timberlake, former Chief of UNAIDS Human Rights and Law Division, and Jason Sigurdson, who has worked with the Reference Group for many years and has now taken the position of Senior Policy and Strategy Advisor with UNAIDS in Washington, D.C. In addition, the group warmly welcomed Luisa Cabal, who in January 2015 filled the Chief of UNAIDS Human Rights and Law Division post. Finally, the Reference Group welcomed Joe Amon to the role of Reference Group co-chair, alongside Michaela Clayton.

Mariangela Simão, Director of Rights, Gender, Prevention and Community Mobilization, formally opened the Reference Group meeting. On behalf of the UNAIDS Secretariat, Helena Nygren-Krug, Senior Human Rights Advisor, provided the Reference Group with an overview of the Human Rights and Law Division’s work over the past year.² Her presentation underlined the centrality of stigma- and discrimination-related issues throughout a range of activities, particularly through UNAIDS’ *The Gap Report* (2014), the elaboration of targets, and the tools and capacity-building activities of the department. The Reference Group noted the UNAIDS Secretariat’s leadership in responding to human rights crises and punitive laws, and the leadership and advocacy work being done through interventions as *amicus curiae* in strategic litigation, as well as around the funding crisis for HIV-related human rights work.

The overview of UNDP’s activities was provided by Clif Cortez, Deputy Director of the HIV, Health and Development Group, Bureau for Policy and Programme Support of UNDP.³ Cortez explained how UNDP’s role in the global HIV response has taken shape around the report of the Global Commission on HIV and the Law (“Global Commission”).⁴ He indicated that UNDP is collecting information regarding Commission follow-up activities undertaken by civil society and UN organizations. Cortez also described UNDP’s work on access to treatment and UNDP’s support for the continued focus on human rights in the strategy of the Global Fund to Fight AIDS, Tuberculosis and Malaria (“Global Fund”). This presentation catalyzed further discussion on how to continue leveraging the work of the Global Commission, even though the Global Commission’s formal mandate has now concluded.

Members of the Reference Group expressed a desire to be as engaged as possible in providing advice to UNAIDS, and encouraged more frequent communication between the UNAIDS Secretariat and the Reference Group. It was also suggested that revisiting the terms of reference and work processes of the Reference Group should be prioritized in the coming year in order to ensure clarity, effectiveness and optimal collaboration. Looking ahead to 2015, several critical opportunities for engagement between the Reference Group and UNAIDS were highlighted, including: defining the prevention and discrimination targets, updating UNAIDS’ Strategy, working with the UNAIDS 90-90-90 Scientific and Technical HIV Treatment Advisory Committee (STAC), and preparing for the 2016 UN General Assembly High-Level Meeting on HIV and AIDS and the 2016 UN General Assembly Special Session on Drugs.⁵

² Slide deck on file with Reference Group Secretariat.

³ Slide deck on file with Reference Group Secretariat.

⁴ Global Commission on HIV and the Law, *HIV and the Law: Risks, Rights & Health*, UNDP, July 2012.

⁵ See discussion on each of these initiatives below.

THE ROLE OF HUMAN RIGHTS IN ENDING THE AIDS EPIDEMIC AS A PUBLIC HEALTH THREAT BY 2030

Discussions on “the role of human rights in ending the AIDS epidemic as a public health threat by 2030” were introduced by Jason Sigurdson, UNAIDS Senior Strategy and Policy Advisor, who provided some historical perspective on the Reference Group’s role to date in advising UNAIDS on how human rights is integral to ending the AIDS epidemic. Sigurdson identified three statements/processes that he thought were particularly influential in elevating human rights. They are:

- The Reference Group’s *Recommendations Brief to Michel Sidibé, Executive Director* (January 2009), and the participation of the Reference Group co-chairs through UNAIDS’ Strategy development process in 2010;⁶
- *Stay the Rights Course: Statement to the 2011 United Nations High-Level Meeting on AIDS* (April 2011), with its strong focus on human rights programming;⁷ and
- *Human rights defined the AIDS response. They should define the “End of AIDS” and the global health response beyond.* (December 2013), and the Reference Group’s other input into the UNAIDS-Lancet Commission process.⁸

Over the course of the meeting, various presentations were made and background papers presented⁹ to help the Reference Group understand the multiple processes and initiatives that are converging around the theme of ending AIDS as a global health threat. Under the “ending AIDS” theme, the following initiatives were discussed:

A) Elaboration of the post-2015 development goals: This process began in 2012 and will culminate in an intergovernmental summit in September 2015. Ruth Blackshaw, Policy Officer, presented on UNAIDS’ engagement, which she described as “connecting, convening and mobilizing” — towards maintaining a specific focus on HIV in the development agenda. The Open Working Group on Sustainable Development Goals has proposed 17 themes and 169 goals in total. Goal 3, to “ensure healthy lives and promote well-being for all at all ages,” aims to “by 2030 end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases.”¹⁰

B) Development of targets under each pillar of UNAIDS’ vision: “Zero new HIV infections. Zero discrimination. Zero AIDS-related deaths.” In July 2014, UNAIDS released its new treatment target, “90-90-90.” The target is that, by 2020, 90% of all people living with HIV will know their status; 90% of all people diagnosed with HIV will receive sustained antiretroviral therapy; and 90% of all people receiving antiretroviral therapy will reach viral suppression.¹¹ A draft global non-discrimination target and global prevention target were shared for civil society consultation in the final months of 2014. These targets will be finalized in 2015 so that the three targets together constitute a framework through which collective efforts can be galvanized and monitored.

C) Fast-Track: Ending the AIDS Epidemic by 2030: In 2014, UNAIDS released its Fast-Track Strategy, using modelling to demonstrate that an ambitious acceleration in the next five years could end the AIDS epidemic by 2030.¹² The crux of the strategy is rapid progress towards the targets through front-loading investment.

⁶ Available at <http://www.hivhumanrights.org/statements/recommendations-brief-to-michel-sidibe-unaidsexecutive-director/>.

⁷ Available at <http://www.hivhumanrights.org/statements/stay-the-rights-course/>.

⁸ Available at <http://www.hivhumanrights.org/statements/human-rights-defined-the-aids-response-they-should-define-the-end-of-aids-and-the-global-health-response-beyond/>.

⁹ See UNAIDS Reference Group on HIV and Human Rights, Sixteenth Meeting Provisional Agenda. Available at <http://www.hivhumanrights.org/meetings/sixteenth-meeting/>.

¹⁰ Goal 3.3. Available at <https://sustainabledevelopment.un.org/focussdgs.html>. Note that the report of *The UNAIDS and Lancet Commission: Defeating AIDS — Advancing global health* was intended to be an input into the process, but the final report has been delayed. See report of the Reference Group’s Fifteenth Meeting, available at http://www.hivhumanrights.org/commitmenttohumanrights/wp-content/uploads/downloads/2014/05/HRRefGrp-15thMtg_Rec-ENG.pdf.

¹¹ UNAIDS, *90-90-90: An ambitious treatment target to help end the AIDS epidemic*, 2014.

¹² UNAIDS, *Fast-Track: Ending the AIDS epidemic by 2030*, 2014.

According to this approach, success requires focusing on the locations and populations where risk is greatest.

D) Renewal of the UNAIDS strategy: Building on its current strategy and UNAIDS' vision of "the three zeros" (i.e., "Zero new HIV infections. Zero discrimination. Zero AIDS-related deaths."), UNAIDS will update its current strategy in 2015 for the 2016–2021 period.¹³ This planning and visioning process will begin imminently and continue through most of 2015, setting the future direction for the Joint Programme.

E) Working towards the 2016 UN General Assembly High-Level Meeting on HIV and AIDS: As the next intergovernmental process focuses specifically on the HIV response, this High-Level Meeting is a critical moment for advancing international support for human rights-based interventions and attention to key populations in the global HIV response.

Much of the Reference Group's discussion of these various processes emphasized the belief that ending AIDS is not possible without concerted attention to human rights issues and key populations. The three processes that garnered the most attention were the zero discrimination target, proposed task force and "fast-tracking" the AIDS response, and a focus on key populations in the strategy update.

Zero discrimination target and proposed zero discrimination task force

With respect to target development, the Reference Group agreed that ambitious targets are necessary to drive the HIV response. Members noted their appreciation of the work to date that has gone into defining the targets and recognized that measuring concepts such as justice, equality and health is extremely difficult.

As one Reference Group member noted, however, it is important to emphasize that UNAIDS' vision has not changed and must not be confused with programmatic targets and accountability measures along the way. No degree of discrimination can ever be defined as "acceptable." Different disciplines use different terminology and have distinct objectives; as such, careful communication is essential.

Another concern raised by several Reference Group members was the practicality of the modelling as presented. As one Reference Group member noted, a necessary precondition is that the targets be based on reliable data and be realistically attainable. In terms of the draft discrimination target in particular, many questions were raised regarding the specific indicators proposed, both in terms of whether they are realistic (e.g., training of judges, repealing laws, etc.) and in terms of the actual meaning assigned to the results (e.g., percentage of people seeking redress for rights violations, etc.). Similar concerns were raised regarding the 90-90-90 treatment target.

A significant challenge mentioned by several Reference Group members was respecting the reliability of available data, the gaps in data, and the lack of baseline data. For example, one member pointed out that country reporting can be flawed and incomplete; government statistics do not match community monitoring and methodologies can vary greatly from place to place. Baseline data will be critical, and thus a sophisticated strategy is required to generate baselines over the next year.

Chris Collins, Chief, Community Mobilization Division at UNAIDS, acknowledged that equity and key populations are essential to all three targets. The ensuing discussion highlighted the risk that key populations are seen as a prevention issue, while treatment effectiveness and health systems issues are seen as the primary focus of the treatment agenda. Reference Group members reiterated that the treatment targets will only be met if the barriers to testing and retention in care are addressed, which necessarily includes confronting criminalization, stigma and discrimination, and ensuring access to justice to overcome human rights barriers.

Another concern raised by some Reference Group members was that because the treatment target has been released in advance of the discrimination and prevention targets, treatment has a "head start" and appears to be a stand-alone agenda item. The Reference Group agreed that the three targets must work together towards the 2030 goal of ending AIDS as a public health threat, as put forth by Alexandrina Iovita, UNAIDS Human Rights and Law Programme Officer.

¹³ 35th Meeting of the UNAIDS Programme Coordinating Board, 9–11 December 2014, Decisions, 3.5.

The Reference Group discussed some of the particular challenges in developing a meaningful discrimination target. One member noted that customary laws are a huge driver of the epidemic in many parts of the world which are often insulated from international laws and scrutiny; this should be considered in the development of anti-discrimination interventions. The issue of access to justice and legal services was also discussed, as many people do not even understand that they could get a lawyer and challenge a discriminatory action. Providing legal services can be quite complicated, however, and we need to ensure that the funds get to the right organizations. Another suggestion was for caution when developing targets related to law reform because these can wrongly imply that nothing can be done until the law is changed, when there are actually some very effective programs for key populations in places where the legal environment is unfavourable. The targets need to signal that there are ways to work even if the laws remain bad, and that there are things that can be done to work towards ultimately changing the law, thereby making the response more effective. It was also observed that defining social science indicators is a specific body of expertise; experts should be consulted in drafting the targets.

Another suggestion was to specifically name key populations such as sex workers, people who use drugs, men who have sex with men, and transgender people in the targets. Reference to the Global Commission on HIV and the Law's recommendations was also suggested as a good way to advance the anti-discrimination targets. One Reference Group member underlined the importance of thinking about discrimination beyond impacts on health. Many Reference Group members endorsed the suggestion of a brainstorming-type consultation with key populations and experts in discrimination indicators.

Discussion of the non-discrimination target segued into a discussion of a proposed task force on zero discrimination, perhaps similar to the task force on HIV-related travel restrictions convened in 2008.¹⁴ It was noted that the task-force model is powerful as it involves setting a standard, galvanizing momentum and action by various constituencies, and tracking changes. It was also noted that task forces should be specific, time-bound and focused on a specific goal. Concern was expressed that unlike travel restrictions, discrimination is extremely broad and implicates many more difficult, controversial issues — not necessarily well addressed through the task-force model.

One suggestion was that perhaps energizing people around the goal of “zero discrimination” could be tied into the process of updating the UNAIDS strategy, rather than requiring a separate task force. Another Reference Group member raised the issue that human rights are about more than just issues of discrimination; by investing so heavily in anti-discrimination work, there is a question about whether UNAIDS may be inadvertently disregarding other key issues such as intellectual property, confidentiality, consent and others — all of which are HIV-related human rights issues.

If the task-force model is to be pursued, the Reference Group generally felt that a well-defined focus and objective were necessary. Some ideas for focus included: criminalization of HIV non-disclosure, exposure and transmission; discrimination in the health sector; criminal laws and key populations; achieving the specific discrimination targets; and the place of key populations across UNAIDS initiatives. The Reference Group did not reach a consensus on a recommendation to UNAIDS; however, the group did agree that a specific, strategic anti-discrimination initiative is needed in some form.

Fast-tracking the AIDS response

Mbulawa Mugabe, Director of Country Impact and Sustainability at UNAIDS, and Badara Samb and Martina Brostrum, Office of Special Initiatives at UNAIDS, presented to the Reference Group on the theme of supporting country action to attain the Fast-Track targets. They emphasized that the Fast-Track approach is a “new way to do business” and requires significant shifts at the country level. They expressed their belief that meeting the targets is possible; however, many questions remain about how to achieve success. They requested the Reference Group's advice regarding the inherent ethical challenges in this strategy and what safeguards to put in place.

The Reference Group's discussion on this theme was a challenging one, highlighting both positive aspects related to the ambitiousness and boldness of the program, and significant concern that it was insufficiently addressing

¹⁴ UNAIDS, *Report of the International Task Team on HIV-related Travel Restrictions*, 2008. Available at http://www.unaids.org/sites/default/files/media_asset/jc1715_report_inter_task_team_hiv_en_0.pdf.

human rights issues. Reference Group members felt that from a human rights perspective, the concept is exciting, but the strategy is incomplete. Much of the advice that the Reference Group has provided over the years could be used to inform the development of a response to the full scope of the epidemic. Human rights expertise will be critical to success.

There was specific concern about the proposed emphasis on the ethics of HIV testing (and plans for a consultation on this), which seemed to overlook the frequent contributions by the Reference Group on HIV testing in the past. As a way forward, it was agreed that a representative of the Reference Group should be added to the Scientific and Technical Advisory Committee (STAC) which will next meet in March 2015. Invitations to the co-chairs to join the meeting were subsequently offered.

Another specific concern was that the elements of the strategy aimed at women and girls relied on circumcision and cash transfers, and were lacking in strategic depth and empowering, evidence-based interventions.

A focus on key populations in the strategy update

The Reference Group identified the UNAIDS Strategy renewal process as a key moment to re-examine the definition of “key populations” used by UNAIDS. Reference Group members noted that currently the key population definition can be used by some countries to avoid accountability to certain standards. This definition should therefore be rethought and strengthened. One member suggested that perhaps UNAIDS should add a fourth zero in the strategy of “zero people left behind.” None of the prevention, treatment or non-discrimination targets will be met without addressing barriers facing key populations, and these are the most complicated pieces to address.

A NEW FOCUS ON DISABILITY ISSUES

The Reference Group heard from Helena Nygren-Krug, UNAIDS Senior Human Rights Advisor, about opportunities to promote a disability-inclusive HIV response. Nygren-Krug noted that although there is little data on HIV and individuals with disabilities, disability is mentioned at least four times in the *UNAIDS 2011 Political Declaration on HIV/AIDS* and that persons with disabilities were included on the list of vulnerable populations in the *UNAIDS Gap Report*.¹⁵

The Reference Group was happy to learn that an informal working group had been established at UNAIDS to consider work on HIV and disability. It agreed that there is a shocking lack of data on this community, and that strategies must be found to increase attention to disability within UNAIDS activities (including prevention and treatment) and to integrate data collection regarding prevalence and access to treatment and care for people with disabilities into ongoing data processes.

The group also discussed HIV-related disabilities (that is, disabilities caused by HIV infection). One Reference Group member noted that defining HIV status as a disability often affords people living with HIV access to necessary grants and services in some settings. Simultaneously, however, defining HIV as a disability can create further stigma.

Reference Group members noted that there are groups around the world that have been doing this work for a long time, particularly at the local level. Much can be learnt from organizations that have worked in contexts where disability enjoys little support; voices from developing countries will be particularly important.

¹⁵ UNAIDS, *The Gap Report*, 2014.

DRUG POLICY AND THE RIGHTS OF PEOPLE WHO USE DRUGS ARE CRITICAL IN THE HIV RESPONSE

Alison Crocket, UNAIDS Senior Prevention Expert, joined the Reference Group meeting for the session on drug policy. She noted that there is currently no natural place to focus on public health and human rights under UNODC's three pillars (i.e., demand reduction, supply reduction and international co-operation). She therefore suggested that a separate pillar on health is needed.

Reference Group members expressed dismay at the continuing failure of approaches rooted in punitive laws and policies for both HIV prevention and the rights of people who use drugs. It was noted that UNAIDS' goal to reduce HIV transmission by 50% among people use inject drugs by 2015 will not be met,¹⁶ and the new targets now being set (e.g., respecting treatment, prevention and discrimination) will be "pure rhetoric" if the approach to people who use drugs does not fundamentally change.

In the ensuing discussion, amongst other points, the emerging evidence on the high costs of prohibition (i.e., financial and human) was noted. It was suggested that sharing the experiences of countries that have decriminalized drug use and minor possession can also be helpful to advocacy efforts (i.e., rates of problematic drug use did not skyrocket, etc.). Another member suggested that it is important to directly address the concerns people have regarding young people and drug use, offering health system alternatives.

With respect to the upcoming 2016 UN General Assembly Special Session on Drugs (2016 UNGASS), Reference Group members emphasized the importance of evidence-informed interventions. Vigilance is needed with respect to any "re-packaging" of the drug-control story under the guise of drug treatment courts or unscientific rehabilitation programs. These so-called "alternatives" do little for people who need treatment and often facilitate human rights abuses. Moreover, the place of harm reduction in effective HIV-prevention programming must not be downplayed.

Clif Cortez noted that UNDP has started a new initiative on drug policy and will be developing a discussion paper for the Commission on Narcotic Drugs (CND). It was suggested that there should be a time at CND for all UN agencies to share their discussion papers. The Reference Group is keen to be involved in developing messaging and supporting UNAIDS and UNDP in developing their approaches to the CND and the 2016 UNGASS on drugs.

This meeting of the Reference Group deliberately coincided with the 35th UNAIDS Programme Coordinating Board (PCB) meeting so that the Reference Group could participate in the thematic segment on "Halving HIV transmission among people who use drugs." Crocket explained to the Reference Group how the PCB thematic segment would be structured.¹⁷ Raminta Stuiyte gave further insight into the organization of the segment, as she had represented the Reference Group on the working group planning the thematic session. It was agreed by the Reference Group that Joanne Csete, chair of the Reference Group sub-committee on drug policy, would make a statement on behalf of the group during the thematic session.¹⁸

Following the thematic meeting, the Reference Group noted with appreciation the excellent statements made by Michel Sidibé, UNAIDS Executive Director, and Luiz Loures, UNAIDS Deputy Executive Director, at the thematic session, emphasizing the importance of harm reduction and advocating for a health and human rights approach (rather than a criminal justice response) to drug possession for personal use. Furthermore, the Reference Group commended UNODC and the other UN agencies for their progressive messaging during their presentations as well. It was noted that the PCB thematic segment focused mostly on harm reduction, paying less attention to decriminalization and with no mention of drug detention centres. Reference Group members suggested that in the period leading up to the 2016 UNGASS, the full scope of drug policy issues and the rights of people who use drugs need to be part of the discussion. UNAIDS' mandate to address HIV among people who use drugs is also affected by these broader issues. Therefore, UNAIDS should not limit itself to a narrow focus on harm reduction or other health services for people who use drugs.

¹⁶ See <http://www.unaids.org/en/targetsandcommitments>.

¹⁷ See Agenda Item 11: Halving HIV transmission among people who use drugs, *Background Note*. Available at http://www.unaids.org/sites/default/files/media_asset/20141125_Background_Note_Thematic_Segment_35PCB.pdf.

¹⁸ See appendices below.

INTELLECTUAL PROPERTY AND ACCESS TO MEDICATIONS REQUIRE URGENT ACTION

The Reference Group heard presentations by Carlos Passarelli, Senior Treatment Expert at UNAIDS, and Clifton Cortez, Deputy Director, UNDP HIV, Health and Development Group, regarding intellectual property (IP) challenges to expanding and sustaining treatment access and UN agencies' related activities.¹⁹ One issue they spoke about was the implementation of the Global Commission on HIV and the Law's Recommendation 6.1 regarding a UN Secretary-General's high-level panel on a new IP regime for pharmaceuticals.²⁰ UNDP and the UNAIDS Secretariat have been working jointly to urge the Secretary-General to convene a panel, and Cortez indicated that a decision on this matter was expected soon.

Another issue addressed was the precarious position of middle-income countries (MICs), where the majority of people eligible for treatment will be living by 2020. India will not be able to supply generic versions of new ARVs under patent as easily as before, and new approaches such as "test and treat" and "treatment as prevention" will increase demand. With decreased funding, availability of treatment in MICs is an urgent challenge. UNDP and UNAIDS will be hosting a meeting of MICs on this issue in 2015.

Finally, they discussed the need to step up IP programming across the UNAIDS Joint Programme. In particular, within the UNAIDS Secretariat the profile of IP needs to be increased as a key determinant of the 90-90-90 treatment target.

In response to the presentation, the Reference Group urged UNAIDS to increase its engagement on IP and access to medications. Members of the Reference Group expressed the opinion that self-regulation of the pharmaceutical industry was not working, and neither are public-private partnerships. Members of the Reference Group felt that civil society involvement is necessary to ensure accountability of the Equitable Access Initiative (EAI) and other related processes. The processes need to be transparent, with clear objectives.

The Reference Group was concerned that the international IP framework discussion and the EAI have not been linked with UNAIDS' 90-90-90 treatment targets and its Fast-Track strategy. The Reference Group felt it would be beneficial for UNAIDS to seek clarity on the composition and objectives of the EAI and determine the best intervention points. Members of the Reference Group felt that a public health and human rights lens on IP policy is critical at this juncture, as this is clearly a right-to-health issue and various processes are underway (including the negotiation of potentially more restrictive IP standards in various trade agreements) that could further impede access to medications.

REFERENCE GROUP ENGAGEMENT WITH MICHEL SIDIBÉ, UNAIDS EXECUTIVE DIRECTOR

The Reference Group met with Michel Sidibé, UNAIDS Executive Director, on December 11, 2015. Sidibé emphasized that this is a defining moment in the HIV response. He indicated that he values the input and commitment of the Reference Group and will look to the Reference Group for guidance in the coming year.

The Reference Group invited Sidibé to identify several areas where it could be most helpful. He set out the

¹⁹ Slide decks and handouts on file with Reference Group Secretariat.

²⁰ Recommendation 6.1: "The UN Secretary-General must convene a neutral, high-level body to review and assess proposals and recommend a new intellectual property regime for pharmaceutical products. Such a regime should be consistent with international human rights law and public health requirements, while safeguarding the justifiable rights of inventors. Such a body should include representation from the High Commissioner on Human Rights, WHO, WTO, UNDP, UNAIDS and WIPO, as well as the Special Rapporteur on the Right to Health, key technical agencies and experts, and private sector and civil society representatives, including people living with HIV. This re-evaluation, based on human rights, should take into account and build on efforts underway at WHO, such as its Global Strategy and Plan of Action on Public Health, Innovation, and Intellectual Property and the work of its Consultative Expert Working Group. Pending this review, the WTO Members must suspend TRIPS as it relates to essential pharmaceutical products for low- and middle-income countries." Global Commission on HIV and the Law, *HIV and the Law: Risks, Rights & Health*, UNDP, July 2012.

following priorities:

- **Helping UNAIDS develop a measurement tool on discrimination:** Sidibé said that he is looking for a practical approach to link normative work on human rights to achievable, measurable actions.
- **Providing a human rights lens for UNAIDS’ official documents:** Sidibé acknowledged that, at times, documents produced by UNAIDS insufficiently incorporate human rights considerations. He welcomed the Reference Group’s contributions reviewing key draft documents.
- **Contributing to preparations for the 2016 UNGASS on Drugs and the 2016 High-Level Meeting on HIV:** Sidibé said that UNAIDS must quickly define a clear roadmap to the two meetings and think differently about these events. Proposals to weaken or impede ambitious action, including on human rights, must be resisted.
- **Identifying issues and opportunities for his advocacy:** Sidibé invited suggestions by Reference Group members of on-the-ground situations involving HIV-related human rights violations where he could intervene, and suggestions of workable solutions.

Reference Group members took this opportunity to draw Sidibé’s attention to several priority issues. First, one member highlighted that the changes to the Global Fund’s model could undermine the rights of many people, particularly in MICs’ becoming ineligible, and where there is inadequate potential of financial commitment at the country level to sustain or enhance programs that have historically been implemented with considerable (or exclusive) reliance on Global Fund or other international donor support. Another member inquired about how the Reference Group might contribute to the Equitable Access Initiative. Another member suggested that it is timely to take an overarching look at IP as a human rights issue. With respect to the crisis in Gambia regarding government attacks on men who have sex with men, another Reference Group member asked Sidibé to consider different forms of non-confrontational diplomacy that could be used, including the engagement of faith leaders.

Another topic that was raised was the issue of sexual rights and trade-offs being made in the Sustainable Development Goal negotiations. Sidibé responded that bringing the different movements together would be critical, particularly in a combined front to combat the potential “fragmentation” of the human rights agenda across a wide spectrum of potential subjects. Another Reference Group member broached the topic of faith communities and the potential role of Faith Ambassadors; he explained that an interfaith approach works well with respect to HIV and offered to help advance this area of work. Finally, a Reference Group member expressed concern that the enthusiasm related to UNAIDS’ treatment target is not matched when it comes to human rights issues and key populations.

Sidibé committed to looking into each of these issues, and agreed that Reference Group members should be brought into the debates and discussions concerned.

DISCUSSION WITH LUIZ LOURES, UNAIDS DEPUTY EXECUTIVE DIRECTOR, PROGRAMME BRANCH

In accordance with Reference Group tradition, on the final afternoon of the meeting the Reference Group met with a senior UNAIDS management representative to provide an overview of the meeting deliberations. The Hon. Michael Kirby, Reference Group member, provided the overview.

In response, Loures thanked the Reference Group for its work. He acknowledged the recommendation to increase leadership on the intellectual property issue; he also confirmed that Reference Group representation will be added to the STAC.

Loures explained that his immediate priority is to devise a roadmap for the Fast-Track strategy. This process would involve “optimizing everything UNAIDS is doing,” enhancing existing relationships, and restoring power to the treatment agenda. Treatment, prevention and anti-discrimination work need to come together in a comprehensive package. He also indicated that a new methodology would be used to identify gaps on a country-by-country basis, identifying what is needed to achieve the targets. The identification and measurement of human rights gaps is therefore a priority.

Loures encouraged the Reference Group to issue pointed, specific recommendations. He stated that the anti-discrimination agenda is his priority and he committed to ensuring that everyone within UNAIDS aligns to support it. As the UNAIDS Joint Programme moves towards its most ambitious targets ever, it needs to do business in a radically different way.

CLOSING

The meeting was closed by the co-chairs, Luisa Cabal and Mariangela Simão.

The Reference Group thanks all those who presented to or engaged with the Reference Group during its sixteenth meeting, including: Ambassador Deborah Bix, Ruth Blackshaw, Martina Brostrom, Richard Burzynski, Luisa Cabal, Chris Collins, Clif Cortez, Alison Crocket, Shona Dalal, Patrick Eba, Alexandrina Iovita, Luiz Loures, Mbulawa Mugabe, Helena Nygren-Krug, Carlos Passarelli, Badara Samb, Michel Sidibé, Jason Sigurdson, Mariangela Simão and Nina Sun.

APPENDIX 1

Statement by Joanne Csete (representing the UNAIDS Reference Group on HIV and Human Rights) to the PCB, 11 December 2014

The challenge of stopping AIDS linked to drug use is one of those remarkable opportunities — in life and in the UN — where a vexing problem can be solved by enhancing justice and human dignity. As we have seen, what it takes to meet this challenge, happily, is abundantly clear. Now, in 2014 and through to the 2016 UNGASS and beyond, what the world seeks is leadership committed to doing what is right and what is effective to meet this challenge, leadership that will not allow propaganda or facile moral judgments to trump empirical evidence and human rights. What the world seeks is *your* leadership around AIDS — your voice that says we do not control AIDS without respecting, protecting and fulfilling the rights of people who use drugs.

Every person is entitled to respectfully-offered harm reduction services as a matter of human rights, as UN member states asserted unanimously in the Declaration of Commitment on HIV/AIDS in 2001. It takes special leadership to go beyond just ensuring services are available and to come to the realization that to thrive and succeed, those services must have an amenable policy, legislative and law enforcement environment. High-quality harm reduction services must be available in prisons and pretrial detention, for example, but it will ultimately be very difficult to sustain those services unless prison populations are reduced, as happens when societies have something better than imprisonment to offer in the case of drug use and minor infractions. Custodial sentences cannot be used just to keep out of public view what Efi [Efi Kokkini, co-founder and chairwoman of the Greek Drug and Substitute Users Union] called the dirty stain of drug use.

We need leadership to make up for decades of what Ruth Dreifuss [Commissioner, Global Commission on Drug Policy] called policies that are not only ineffective but harmful. The easy tolerance by societies of policing that treats people who use drugs as not quite fully human must end. The fact that extortion of people who use drugs is an important part of the compensation of police in many countries is something that begs reform and redress. That people who are dependent on drugs frequently undergo a form of torture unique to them — being interrogated by police when they are in a state of withdrawal or otherwise ill — must be stopped, as noted by two UN Special Rapporteurs on Torture. We need leaders who know it is simply wrong to allow police to fill arrest quotas and the courts to over-fill prisons by targeting small-scale offences.

We know that even if it is politically challenging, it is right and urgent to remove drug consumption and minor drug offences from the purview of criminal law. This conclusion was stated by country after country across the political spectrum in the high-level session of the Commission on Narcotic Drugs in March of 2014 as well as by UNODC. So now the world seeks leaders ready to take the next step, to work with people who use drugs and with health care and social service providers to create the alternatives to incarceration. Who are ready to claim the opportunity presented by the UN General Assembly Special Session to produce a declaration for the world that is bold about the human rights commitment that is harm reduction and is bold about removing ill-conceived applications of criminal sanctions to behaviours that do not by any reasonable definition meet the standard of

criminal offence.

There is a thirst for the leadership that recognizes that AIDS will not be stopped until people at risk of it enjoy all their rights — the whole range of human rights. The very right to assemble and organize is crucial to the meaningful participation of drug users in society and in the AIDS response, but in so many countries drug-user organizations cannot register or operate as NGOs and cannot receive funding like other NGOs. Continuing to tolerate the denial of these rights belies all of our pronouncements about rights-based approaches.

There cannot be another global reflection on the world drug problem that does not put harm reduction and the lessons of fighting AIDS at the centre of the discussion. Those lessons, well known to this body, include the idea that without meaningful participation of those most affected in decision-making on policies and programs, there is no hope for success. They include the idea that human rights-centred mean setting examples of respect for the humanity, the intelligence, the capacities of people who use drugs and their organizations. They mean recognizing that access to justice is every bit as important as access to health services and must be prominent in HIV funding. They mean seeing how very urgent it is to make up for decades of failing to fund harm reduction and centuries of disparaging the humanity of people who use drugs.

The world seeks *your* indispensable leadership on these points at the 2016 UNGASS and before it and beyond it. Please do not disappoint us.

APPENDIX 2

Statement by Rev. Fr. JP Heath (representing the UNAIDS Reference Group on HIV and Human Rights) to the PCB, 11 December 2014

The ongoing stigma and discrimination in all its forms remains the single biggest obstacle to the efficacy of all our interventions to overcome HIV. It is an affront to the inherent God-given human dignity with which every person is born, and as the Reference Group we promote human rights to protect this.

Stigma and discrimination negatively affect testing, uptake of treatment, prevention, access to all services, and of course the mental, spiritual, emotional and physical health of all persons living with HIV (PLHIV). Criminalization further exacerbates stigma in social environments which create vulnerabilities and even funding levels and areas in which the needed resources are or are not applied.

Stigma and discrimination as experienced by PLHIV and those especially vulnerable to HIV must be overcome if we are to achieve our targets.

Current funding models in this regard are not useful: Firstly, very little money goes to addressing stigma and discrimination and, secondly, most funds are going to governments, with less than 1% of funding going to civil society and faith-based organizations that are most equipped to challenge this.

Clear indicators must be developed to plot stigma and discrimination in all its manifestations.

As the Reference Group, we will continue to keep a close eye on this, constantly raising the issue until zero stigma and discrimination is a reality for all people.