UNAIDS Reference Group on HIV and Human Rights

AT A CROSSROADS: UNAIDS AND HUMAN RIGHTS IN THE HIV RESPONSE

Eighteenth Meeting: Geneva, 7–8 December 2016 Meeting report and recommendations

This report was prepared by the Secretariat of the UNAIDS Reference Group on HIV and Human Rights after its eighteenth meeting (December 2016). 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.

SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

1. UN Women and the health and human rights of sex workers

It is important that UN Women take a firm stand supporting the human rights of sex workers and the settled Joint Programme position regarding HIV and sex work, including supporting the repeal of all laws criminalizing or penalizing consensual sex work and recognizing sex work as a form of labour, with full protection for the rights of sex workers, as well as dedicated funding and other concrete support for programmes and services by and for sex workers to protect their health and human rights. The Reference Group will communicate these views to UN Women

2. Global Review Panel on future of UNAIDS

The UNAIDS Programme Coordinating Board has decided to establish a review panel to examine and make recommendations regarding the Joint Programme model by the time of its next meeting (June 2017). The Reference Group is keen to ensure that in any restructuring or redefinition of the UNAIDS Joint Programme, the human rights lessons from the HIV response, as well as the important work done by the Secretariat and co-sponsors on advancing human rights, is not lost. The Reference Group co-chairs will seek additional information regarding the panel and its process, and will prepare a submission to the Review Panel.

3. Human rights in the fast-tracking of the HIV response

The Reference Group is pleased that UNAIDS Secretariat is preparing guidance on how to ensure attention to human rights in efforts to fast-track the achievement of HIV prevention, testing and treatment targets. The Reference Group will be pleased to review a further draft of the guidance document being prepared before it is finalized. The Reference Group identified a number of recommendations to UNAIDS Secretariat to ensure that this practical guidance is in fact translated into programs and approaches at country level, including public support from the highest level within UNAIDS upon release and roll-out of the guidance and direction from senior management to UNAIDS staff to use the resource in their fast-track efforts at country level. More generally, the Reference Group would be pleased to discuss with UNAIDS senior management other measures to ensure attention to human rights is more routinely integrated into the work of UNAIDS, such as representatives of the Reference Group engaging more regularly with senior managers (including regional managers) to discuss human rights challenges, as well as taking steps to reflect the expectation to advance human rights as part of the job of UNAIDS country representatives in the performance reviews of UNAIDS personnel.

4. Access to medicines

The Reference Group is concerned about how the repositioning within UNAIDS will affect the capacity within the UNAIDS Secretariat to address policy issues affecting access to medicines, including matters of intellectual property and related questions. These issues require continued attention, particularly given that half the world's people with HIV still lack access to treatment; the fast-track treatment targets will not be achievable without increasing access to affordable medicines; and recent initiatives such as the Global Commission on HIV and the Law and the UN Secretary General's High-Level Panel on Access to Medicines have underscored the need for substantial revisiting of current approaches. The Reference Group has made a number of recommendations in the course of this meeting to the UNAIDS Programme Coordinating Board and urges the UNAIDS Executive Director to have regard to that submission, including the request to ensure that the Secretariat and Joint Programme co-sponsors have the necessary resources to implement the recommendations in the synthesis report prepared for the PCB, which are in keeping with the core actions in the 2016–2021 UNAIDS Strategy to address barriers to access to health technologies.

5. Drug policy, HIV and human rights

The Reference Group welcomed the project supported by UNDP to develop international guidelines on drug policy and human rights. The Reference Group would be pleased to provide input into those guidelines as they are being drafted, and to communicate its support as appropriate to the leadership of UNAIDS and co-sponsors, as well as urging the leadership of UNAIDS and co-sponsors to support this initiative.

The Reference Group expressed its interest in providing comment on the "model legislation" on drugs being developed by co-sponsor UNODC, and noted its view — as shared with senior representatives of UNODC during the meeting — that it is important for any such model legislation to reflect a human rights approach, ensuring that legislative provisions for states are consistent with human rights standards and principles, in keeping with states' own repeated declarations that responses to drugs must be consistent with human right obligations

6. Stigma and discrimination in health-care settings

The Reference Group welcomes the "Agenda for zero discrimination in health-care settings." This work must be incorporated into fast-track efforts and into UNAIDS support at the country level. The Reference Group noted with appreciation the update provided by UNAIDS in relation to its work in this area including the development of a reference document on "Eliminating Discrimination in Health Care. Stepping Stone towards Ending the AIDS Epidemic," the finalization and launch of a repository of tools to tackle HIV-related discrimination in health care, and the finalization of a Joint UN Statement on Discrimination in Health Care Settings. It urged UNAIDS to ensure that the imperative to address discrimination in health settings is integrated into the different areas of work at the global and country levels.

AT A CROSSROADS: UNAIDS AND HUMAN RIGHTS IN THE HIV RESPONSE

UNAIDS Reference Group on HIV and Human Rights
Eighteenth Meeting, December 2016
Meeting Report

The eighteenth meeting of the UNAIDS Reference Group on HIV and Human Rights ("Reference Group") took place in Geneva, 7–8 December 2016. Over the course of two days, the Reference Group engaged with various staff members of the UNAIDS Secretariat, representatives from the Joint Programme co-sponsors, the UN Development Programme (UNDP) and the UN Office on Drugs and Crime (UNODC), and a representative from the Office of the UN High Commissioner for Human Rights (OHCHR). The Reference Group also met with the UNAIDS Executive Director and Deputy Executive Director to discuss a number of issues related to advancing human rights in the HIV response.

The report that follows presents a summary of those discussions. In the course of its deliberations, the Reference Group formulated several conclusions and recommendations, a summary of which is attached to this report. The Reference Group looks forward to opportunities to engage with the UNAIDS Secretariat and others regarding the implementation of these recommendations.

WELCOME AND INTRODUCTIONS

The Reference Group co-chairs, Michaela Clayton and Joe Amon, and Dr. Mariangela Simão (Director, Rights, Gender, Prevention and Community Mobilization Department, UNAIDS Secretariat) welcomed members of the Reference Group. The group reviewed the agenda, and noted the regrets received from members Joanne Csete and Rodrigo Uprimny, who were unable to attend in person but would be joining certain sessions by phone. In reviewing the agenda, the group agreed that it would be sure to discuss, before meeting with UNAIDS Executive Director Michel Sidibé the following day, the ongoing internal changes within UNAIDS (both the Secretariat and the Joint Programme as a whole), and the potential implications for human rights work within the Joint Programme and for the Reference Group itself.

THE CURRENT POLITICAL CONTEXT AND IMPLICATIONS FOR WORK ON HUMAN RIGHTS AND GLOBAL HEALTH

The co-chairs welcomed to the meeting Ms. Kate Gilmore, UN Deputy High Commissioner for Human Rights. On behalf of UNAIDS, and by way of introduction, Luisa Cabal thanked Ms. Gilmore for coming to meet with the Reference Group and noted a number of examples of partnership between the offices, including in advancing HIV-related human rights concerns at the Human Rights Council and acting on the results of a dialogue on these issues with the African Commission on Human Rights.

Ms. Gilmore expressed her appreciation for the opportunity to discuss with the Reference Group the current landscape for advancing human rights concerns related to HIV, and to share some information on how OHCHR is attempting to address these issues in light of that context. In her view, with the elevation of human dignity and the alleviation of preventable human suffering as our overarching goals, we must think of how we can collectively use various tools — including the OHCHR, the special procedures, the treaty bodies and the Human Rights Council — to advance these goals.

She noted that OHCHR is undertaking a joint project with the World Health Organization (WHO) to explore ways in which health and health-related rights can be strengthened via both the World Health Assembly (WHA) and the Human Rights Council (HRC). The two agencies have jointly established a high-level working group and

technical advisory panel for said group, which is preparing a discussion paper for presentation at the next WHA and HRC on the intersection between health and human rights and how these two inter-state bodies should work together. There will be a first in-person meeting of the working group in early 2017, and UNAIDS will explore opportunities for collaborating with and supporting this initiative, including for members of the Reference Group.

Ms. Gilmore offered some reflections regarding the current climate for health and human rights. First, she underscored that we must celebrate the extraordinary achievements in global health in pursuit of the Millennium Development Goals (MDGs), including on TB, malaria, access to antiretrovirals (ARVs) for HIV treatment, and maternal, newborn and child health. But equally, she noted that the aggregate of these gains in health outcomes globally has masked a deep failure of differentiated outcomes that both create and reinforce inequalities — inequality that has deepened and broadened under the MDGs. We should be troubled by the international community's difficulty in confronting failure, noting the example of an implicit censorship in addressing the lives of young people, including their sexuality. For all the consultation leading to the new Sustainable Development Goals (SDGs), we still have not faced up to the areas in which we have failed with respect to the MDGs and are not addressing the reality of emerging demographics. Globally, poverty is young and privilege is old; and privilege is locking up its doors, barring its windows, drawing up the bridge and barring access, to the point that conflict has become a viable, rational choice made by some communities.

So many lessons can be learned from the struggle in responding to HIV. It represents one of the greatest success stories in recalibrating political interest, in seeing synergies between issues rather than just a single, specialist issue. This has been achieved primarily by creating dialogue with affected populations, without which no change would have been possible. Civil society activism has led to extraordinary shifts quickly; we must embrace this example and take it to a new scale, applying it elsewhere on a much broader set of issues.

In some concluding observations, Ms. Gilmore stressed that every UN agency needs to move beyond defining its projects within its specific niche, focusing on its "brand" in the contest for resources; rather, we need to focus on the collaborative advantage in advancing the welfare of "we the peoples" of the United Nations. This includes looking beyond just disease-specific outcomes, for example. As for strategies to engage states, she observed that human rights standards (including those in international law) and evidence are all necessary elements of the task of engaging states, but are not sufficient on their own. Rather than a trickle-down approach to human rights, we need a stream of demand for them; the greatest hope lies in building up civil society. She concluded by reiterating that the OHCHR is at the disposal of the Reference Group and UNAIDS, and looks forward to support the Reference Group's work as another voice for human rights in the UN system.

UNAIDS HUMAN RIGHTS WORK AND PRIORITIES: UNAIDS SECRETARIAT AND UNDP

UN Development Programme

Mr. Tenu Avafia, Policy Advisor (Human Rights, Law and Treatment Access), presented an update on UNDP's work related to HIV and human rights since the last Reference Group meeting, and identified a number of developments and questions facing the Joint Programme as a whole and UNDP as a co-sponsor:

- While the Joint Programme has adopted the UNAIDS Strategy 2016–2021, there are serious concerns regarding the funding situation for the Joint Programme generally, for the work on human rights of a cosponsor such as UNDP (which has a lead on human rights issues among the co-sponsors), for the UNAIDS Secretariat and for other co-sponsors. There have been some substantial reductions in funding and staff.
- UNDP has continued its extensive work in following up on various recommendations of the Global Commission on HIV and the Law, which has been a key reference point for its work on human rights and legal dimensions of HIV. This work consists of advancing human rights through legal environment assessments (LEAs); national dialogues and actions plans; judicial dialogues and capacity-strengthening; work with parliamentarians; activities aimed at improving access to justice; guidance documents; and capacity-building manuals.
- Avafia noted several examples of LEAs in which UNDP had been engaged, continuing to use the

2014 resource produced by UNDP.¹ These processes capture important data and produce important recommendations for legislative reform and other means of advancing human rights to strengthen the HIV response; they also increase the awareness of policy-makers regarding human rights and create opportunities to engage with them.

- UNDP and UNAIDS Secretariat have been and are actively involved in discussions regarding the formulation and implementation of the new strategy of the Global Fund, that includes as a key priority area a focus on human rights and gender. It will be important in the years ahead to show results from human rights programmes at the country level where these have been incorporated into Global Fund grants.
- UNDP is involved in an ongoing project, with a number of civil society organizations, to develop international guidelines on human rights and drug policy. The purpose of such a project is two-fold: first, to better define for states (and others) what "rights-based approaches to drug policy" consist of, and second, to create a tool to increase accountability of states for complying with human rights obligations in their drug policy, as repeatedly committed in various resolutions and declarations.
- With respect to the question of access to medicines, UNDP has multiple areas of work, including policy and technical support on reforming medicines, competition and patent laws; technical support for government procurement of health technologies; and capacity strengthening on competition law, patent examination (prevention is better than cure). UNDP has also been intensely involved in supporting the work of the UN Secretary General's High-Level Panel on Access to Medicines, which released its report in mid-September 2016,² and which will be discussed in further detail at a later point in the Reference Group's meeting.³
- With respect to addressing HIV and the human rights of sex workers, Avafia noted that UNDP and UNAIDS Secretariat have shared the existing Joint Programme position on sex work with new co-sponsor UN Women, which is undertaking a process of consultation to inform its position on the matter.

The Reference Group thanked UNDP for its work to advance human rights related to HIV over the previous year. With respect to the matter of UN Women's consultation on sex work, a number of Reference Group members expressed concerns, based on their experience and that of organizations and human rights advocates with whom they work, that UN Women appears reluctant to engage sex workers. It was noted that, in response to requests, UN Women had committed to posting online all the submissions it received through the consultation process. Reference Group members also noted and appreciated that part of the value of having a Joint Programme responding to HIV, involving multiple UN agencies, is that at the country level, even where one UN agency may, for various reasons, be or feel constrained in defending or advancing human rights concerns, it may then be possible for other UN co-sponsors that also have a local presence to engage on this. It was agreed that this was an important point to highlight as the Joint Programme undergoes a review.

¹ Practical manual: Legal environment assessment for HIV: An operational guide to conducting national legal, regulatory and policy assessments for HIV (UNDP, 2014). Available at www.undp.org/content/undp/en/home/librarypage/hiv-aids/practical-manual--legal-environment-assessment-for-hiv--an-opera.html.

² Report of the United Nations Secretary-General's High-Level Panel on Access to Medicines: Promoting Innovation and Access to Health Technologies, 2016. Available via www.unsgaccessmeds.org.

³ It was noted that the PCB has before its current meeting, overlapping with the meeting of the Reference Group, a synthesis report on the issue of access to medicines and various factors affecting it, including matters related to intellectual property, prepared by the UNAIDS Secretariat at the request of the PCB. Reference Group member Dr. Michael Kirby is participating in that discussion at the PCB, in his capacity as a member of the High-Level Panel and Chair of the panel's Expert Advisory Group. The Reference Group's sub-committee on intellectual property and access to medicines had prepared a draft submission, approved by the co-chairs, to the PCB with a number of recommendations. The submission includes continued support for action by UNAIDS and others to follow-up on the recommendations of the High-Level Panel. See UNAIDS Reference Group on HIV and Human Rights, "Access to medicines: human rights and intellectual property-related factors," Statement to the UNAIDS Programme Coordinating Board (December 7, 2016). Available at www.hivhumanrights.org/statements/access-to-medicines-human-rights-and-intellectual-property-related-factors.

UNAIDS Secretariat

The Reference Group was pleased to receive an update on the work of the UNAIDS Secretariat from Dr. Mariangela Simão (Director of Rights, Gender, Prevention and Community Mobilization) and Ms. Luisa Cabal (Chief of Human Rights, Law and Gender).

Simão noted that the heads from each of the Joint Programme co-sponsors had met in November 2016 to work out an agreement on certain aspects of the Joint Programme's functioning. UNAIDS Executive Director Michel Sidibé has proposed that, within the Unified Budgeting, Reporting and Accountability Framework (UBRAF), funding allocations among co-sponsors and the Secretariat be kept the same in 2017 as had been the case in 2016. Simão reported that this proposal had just been approved by the UNAIDS Programme Coordinating Board the day before (on December 6, 2017).⁴ She noted that there are some encouraging signs from some Member States that they will maintain funding levels for the Joint Programme; in the short term, the focus is on retaining current levels of support, and working to possibly restore funding from some donor governments that have made significant reductions in the past two years.

Simão also addressed what the current constrained funding environment means at the programme level. There is a decreased number of staff within the UNAIDS Secretariat, and the Executive Director has decided to focus Secretariat staff capacity on supporting efforts in fast-track priority countries. Work on a number of human rights issues of concern to the Reference Group is affected. For example, the position focused on intellectual property issues and access to medicines is being discontinued. Work on gender issues is now folded into the Human Rights, Law and Gender team (under Luisa Cabal's leadership). Two positions in this unit that were previously eliminated are not being restored.

The UNAIDS Executive Director has proposed, and the Programme Coordinating Board is expected to approve, a high-level panel to review the working model of the Joint Programme, which he and the UNDP Administrator, Helen Clark, will co-chair. This is occasioned in part by the funding situation; some agencies have mainstreamed HIV into other, broader areas of work, raising some concern that the specificity of the HIV response and attention to it may be lost. It was also noted that very few of the co-sponsors (other than UNDP and WHO) have core funds dedicated to HIV work other than what they receive as their allocation under the UBRAF. There is a need to revisit how the different elements of the Joint Programme do their work, how it is financed, and how the joint programme is governed. The Reference Group should consider what contributions it wants to make to this review with respect to human rights.

Cabal presented an overview of some of the work of the Human Rights, Law and Gender team at the UNAIDS Secretariat, including the following:

- The Secretariat was actively engaged in several political processes and forums in 2016 with a view to ensuring attention to, and inclusion of, human rights dimensions, including a panel on human rights and HIV at the Human Rights Council session in February–March 2016; a report on human rights issues submitted to the process leading up to the High-Level Meeting on HIV in June 2016; and a panel event on "leaving no one behind" at the High-Level Meeting.
- Working with the African Commission on Human and Peoples' Rights, UNAIDS has also jointly produced the first-ever Commission report on HIV and human rights in Africa; released a report of the UNAIDS/OHCHR-hosted dialogue between OHCHR, the Inter-American Human Rights Commission and the African Commission on the protection of the rights of LGBTI people; and organised the visit of the Committee on the Rights of People Living with or vulnerable to HIV of the African Commission on Human and People's Rights to Côte d'Ivoire. In addition, UNAIDS is working with the African Commission on its report on HIV and human rights, to be launched in 2017.
- UNAIDS also has a programme of work aimed at integrating human rights into policy and monitoring frameworks. This includes strengthening the human rights elements of the National Composite Policy Index (NCPI), which is currently undergoing revisions as part of regular country reporting to UNAIDS

⁴ See Decision Point 6.3 adopted by the UNAIDS Programme Coordinating Board at its 39th meeting: www.unaids.org/sites/default/files/media_asset/20161208_UNAIDS_PCB39_Decisions_EN.pdf.

on implementation of key commitments in the UN General Assembly's Political Declaration(s) on HIV; providing input into the development of the UN Women policy on sex work (e.g., via a joint submission with UNDP, already noted above, to which several other UN agencies also contributed informally); and the preparation of the "Do No Harm" report as a UNAIDS contribution to the UN General Assembly Special Session on drugs (that took place in April 2016). In addition, the UNAIDS Secretariat is working to finalize the forthcoming guidance on human rights in the fast-track approach and is looking for (further) input from the Reference Group on not only the content of that guidance, but also how to roll it out and operationalize it.

- UNAIDS has also obtained amicus curiae status, and submitted briefs as such, in a number of legal proceedings aimed at defending or promoting human rights, including on the issues of mandatory HIV testing (before the UN Human Rights Committee on a case relating to South Korea), the criminalisation of same-sex conduct (before the East African Court of Justice on a case relating to Uganda), and coercive sterilisation of women living with HIV (before the High Court of Kenya).
- Another significant piece of work by the Human Rights, Law and Gender team has been advancing the "Agenda for zero discrimination in health-care settings." On March 1, 2016 (Zero Discrimination Day), UNAIDS jointly launched this agenda with WHO and the Global Health Workforce Alliance (GWHA). There will be ongoing work by UNAIDS to raise the visibility of this issue and convening stakeholders to build stronger joint UN action to address discrimination in health care.
- UNAIDS is also supporting the Global Fund initiative to scale-up of human rights programmes in 20 priority countries, including partnering in convening key partners and on the Technical Working Group on Monitoring and Evaluation; supporting the methodology of baseline assessments in each country; and getting buy-in at the level of UNAIDS headquarters and in regional and country offices, so that these human rights programmes are seen as part of the fast-track approach.
- UNAIDS has been collaborating with PEPFAR to integrate human rights into its most recent guidance on developing country operational plans (COP); promoting the scale-up of human rights programmes; and supporting the development of PEPFAR's framework for work on stigma and discrimination.
- At the country level, UNAIDS has been working in more than 20 countries to prevent and respond to human rights crises, and has also been seeking to insert human rights considerations into the WHO tool to be used to validate the elimination of vertical transmission of HIV in countries such as Armenia, Belarus and Thailand.

Finally, Cabal flagged for the Reference Group some upcoming potential areas of work in 2017 for the Human Rights, Law and Gender team, and matters on which guidance from the Reference Group would be useful in setting priorities.

- With respect to working at the global and regional levels to build political support for human rights—based HIV responses:
 - The Social Forum of the UN Human Rights Council on 2–4 October 2017 will focus on health and HIV. It will provide a critical platform for reflecting on the progress, challenges and opportunities relating to health and HIV.
 - The African Commission on Human and Peoples' Rights will be presenting its forthcoming report on HIV and human rights at the African Union.
 - Building on the workshop at AIDS 2016 in Durban on intersections between different key populations and communities affected by HIV and subject to criminalisation, UNAIDS is seeking to further develop these connections between advocacy constituencies including through the upcoming multistakeholder meeting on criminalisation to take place in Bellagio, Italy, in February 2017.
- With respect to strengthening human rights at country level, UNAIDS will
 - Finalize, launch and roll out the guidance for integrating human rights principles, standards and

⁵UNAIDS, *Agenda for zero discrimination in health-care settings*, 15 February 2017. Available at www.unaids.org/en/resources/documents/2017/2017-agenda-zero-discrimination-health-care.

approaches into the fast-track approach for scaling up HIV services

- Continue providing assistance in responding to human rights emergencies
- Support efforts (e.g., by the Global Fund) to scale up investments in key human rights programmes
- Work with countries on validating the elimination of vertical transmission, including certifying achievement of human rights indicators for this certification
- There will be extensive work to continue supporting the advancement of the "Agenda for zero discrimination in health-care settings." One specific target is to secure a resolution at the World Health Assembly (by 2018) with commitments and action items for achieving zero discrimination in health-care settings.
- Finally, with respect to specific areas of legal advocacy, UNAIDS will
 - Partner with several organizations to develop a global scientific statement on HIV, with a view to informing law reform and other advocacy efforts to limit overly broad HIV criminalisation
 - Respond to various requests to secure amicus curiae status in support of legal proceedings, including leveraging support from law firms for this work
 - Undertake further work on eliminating HIV-related travel restrictions
 - Contribute to and support a study on how shrinking space for civil society is affecting the HIV epidemic and response with a focus on three countries in sub-Saharan Africa (Kenya, Uganda and Ethiopia)

Cabal indicated the UNAIDS Secretariat and her team would welcome the input of the Reference Group on any of the above activities, as well as some specific additional issues:

- Identifying criteria for defining priority areas of work for the UNAIDS Secretariat on human rights issues, given constrained capacity
- How to ensure gender and human rights issues and work remain central within the work of UNAIDS in light of the "repositioning" underway
- Recommendations on how best to advance human rights at the country level, again particularly in the context of this "repositioning" and what it means for country-level presence and capacity of UNAIDS

The Reference Group members thanked UNAIDS Secretariat for their work over the past year and raised a number of points for consideration:

- It is unfortunate that OHCHR has, as of a few years ago, eliminated a position dedicated to HIV and human rights and reduced approval of expenditures on such work, including no longer having ongoing, regular representation at the Reference Group meetings. Given the stated desire by Deputy High Commissioner Gilmore for greater collaboration and coordination, UNAIDS might consider exploring with the OHCHR the possibility of restoring this link. Simão noted that UNAIDS does collaborate regularly with OHCHR, which is engaged despite not being a co-sponsor and not receiving any funds allocated under the UBRAF; often, OHCHR is the biggest partner at the country level when there is a human rights crisis that UNAIDS is responding to.
- Given the epidemiological data, addressing adolescents' HIV risk and access to services should be a priority for UNAIDS. Simão noted that UNAIDS would seek to feed into the upcoming ECOSOC forum on young people in January 2017 and the subsequent high-level forum in July 2017 (that will include discussion of both SDG3 on health and SDG5 on gender equality). In numerous countries, there is a need to address legal and other barriers to young people in gaining access to services, including unnecessarily restrictive requirements for parental consent up to certain ages.
- The cross-population work on criminalisation and other punitive laws is welcome. In pursuing this work, consider incorporating the issues of criminalisation and denial of access to sexual and reproductive health services of women and girls, including abortion and post-abortion care. Similarly, it was suggested that attention to gender issues and to the rights of women and girls is one important aspect of keeping HIV on the political and donor agenda.
- Given the shrinking space for civil society in many settings, and the constrained funding environment facing

civil society and UN agencies particularly for human rights work, do we need to radically rethink how we address HIV-related human rights issues within the UN system? At times, it seems there is more of a focus on competition across UN agencies (e.g., for funds and space) than a focus on collaboration with civil society. Simão noted that UNAIDS is estimating the funding needs for supporting civil society engagement in the HIV response; this exercise should be useful as part of the resource mobilization effort that is needed.

- There is both a necessity and an opportunity to reflect on how best to use the constrained resources UNAIDS has. From the perspective of West Africa, it is clear that most of the barriers to reaching prevention, testing and treatment targets are related to stigma, discrimination and other human rights concerns. People are avoiding HIV testing and health centres, even if treatment is available, because of these concerns. There needs to be more, not less, work on reducing stigma and addressing legal and human rights issues. Support has been received from UNAIDS from its headquarters in Geneva but not necessarily from UNAIDS at the country level. There is also a need to prepare for attacks on human rights that can be anticipated, rather than being in crisis response mode: for example, elections are coming in several countries in West Africa, and it is certainly to be anticipated that some politicians will seek attention and to gain support by proposing punitive laws against men who have sex with men, people living with HIV and other key populations.
- There remains the ongoing concern, particularly in the context of "fast-track" and the singular focus on the "90-90-90" targets, about the heavy emphasis on the biomedical dimensions of the HIV response, often at the expense of attention to the human rights barriers. Failing to attend to the human rights barriers will mean the 90-90-90 targets cannot be achieved, and yet the resources are not being mobilized to finance this part of the response. For example, stigma remains a huge barrier, including to treatment. Paradoxically, even as the efficacy of treatment can lessen stigma by radically changing the medical prognosis for those living with HIV, it has also allowed stigma and discrimination to intensify because it renders HIV less visible.
- In challenging stigma and discrimination, there is an ongoing need for work with and within faith communities. There are positive examples of work by faith communities in encouraging testing and providing care. But there also needs to be more support for work challenging stigma and discrimination that is being presented or justified in the name of religious tenets. Efforts to address stigma and discrimination in the health sector are needed, but the effort must be substantially broader as well, including engaging faith leaders and communities to create more enabling social (and also legal) environments. The Reference Group was reminded of the earlier proposal to have UNAIDS designate a faith ambassador on HIV, which to date has not yet been taken up. UNAIDS Secretariat noted that UNAIDS is undertaking some engagement with faith communities regarding stigma and discrimination despite the lack of a faith ambassador.
- The Reference Group is concerned at the apparently further reduced capacity within the UNAIDS Secretariat to address policy issues affecting access to medicines, including matters of intellectual property and related questions. These issues require continued attention, particularly given that half of the people living with HIV worldwide still lack access to treatment; the fast-track treatment targets will not be achievable without increasing access to affordable medicines; and recent initiatives such as the Global Commission on HIV and the Law and the UN Secretary General's High-Level Panel on Access to Medicines have underscored the need for substantial revisiting of current approaches. The Reference Group has previously supported the work of those bodies and continues to believe it is important that UNAIDS, both the Secretariat and relevant co-sponsors (such as UNDP), have the capacity to continue engagement on this front. This approach is in keeping with recognition of this issue in the UNAIDS Strategy 2016–2021. The Reference Group will take up this concern with the UNAIDS Executive Director.
- Given the restructuring within UNAIDS, it is important that there be a vocal commitment to human rights as part of the work of UNAIDS from the Executive Director, externally but also internally to staff. It was noted that the Executive Director reaffirmed the centrality of human rights in his opening remarks to the PCB the day before. It was agreed that the Reference Group would, in its upcoming meeting with Sidibé, raise this concern, including the need to ensure that the human rights work of the UNAIDS Secretariat and UNDP is seen as complementary and collaborative, not in competition. Finally it was noted that part of the value of having a Joint Programme, including a Secretariat with dedicated human rights staff, is that it allows the agency to take on issues that other agencies, for various reasons, cannot or will not.

FAST-TRACK AND HUMAN RIGHTS

To initiate a discussion about integrating human rights considerations into UNAIDS' work on the push to "fast-track" the achievement of agreed-upon prevention and treatment targets, the Reference Group welcomed Dr. Mbulawa Mugabe (Director, Country Impact and Sustainability Department) from the UNAIDS Secretariat.

Dr. Mugabe shared with the Reference Group some updates about the work of his department in line with the internal restructuring of the Secretariat. The plan is for his department to combine within UNAIDS the agency's country support functions and its programmatic support functions; e.g., not only scaling up prevention, testing and treatment services, but also dealing with stigma and discrimination. Before the 2016 High-Level Meeting on HIV, UNAIDS had been working with countries to identify needs and bottlenecks in fast-tracking the response to achieve the agreed-upon prevention and treatment targets. The Political Declaration that was adopted at the High-Level Meeting is a mechanism for accountability of Member States regarding those commitments, and the Country Impact and Sustainability Department is working to build capacity at country-level to fast-track the achievement of those targets. UNAIDS is seeking to ensure greater connection and coordination between headquarters in Geneva and staff at the country level to provide guidance on programming to countries.

Therefore, the conversation with the Reference Group is timely, as it is important to receive guidance on human rights that can assist programme officers at the country level responsible for working with countries to achieve the fast-track targets. Dr. Mugabe indicated four areas in particular where the Reference Group's input would be valuable for the work of his department:

- 1. In many settings, the **political environment** is making access to services more difficult. Some of these dynamics can be anticipated; we know certain countries face challenges in the political environment to fast-tracking the HIV response. Perhaps the Reference Group can provide guidance on how to proactively address these challenges.
- 2. In many instances, there is a need to **remove policy barriers** that impede access to services. This includes access to not only treatment, but also prevention, which is often underdeveloped.
- 3. With respect to **service delivery**, what are the major human rights barriers or concerns, and how can these be addressed? For example, in some settings (e.g., West and Central Africa), the lack of resources for services is not necessarily the primary barrier; rather, the concerns are human rights barriers such as stigma and discrimination, user fees making services inaccessible, and a lack of human rights protection. What can and should UNAIDS be doing to address these and build a culture of respect for rights?
- 4. Finally, what are **innovations** that countries can introduce, including in health-care settings, to quicken the pace of the response, while respecting and protecting human rights? For example, there may be innovative ways to gather and use **data** that can improve services, and assist in correcting course with efforts in order to maximize impact. But we need to be careful in such efforts to respect human rights and ensure practices do not keep people away from services, which would defeat the purpose.

With regard specifically to the forthcoming guidance on fast-track and human rights, Dr. Mugabe suggested to the Reference Group that it would best be presented as helping remove barriers to HIV services and thereby achieve the fast-track targets.

Patrick Eba (Senior Human Rights and Law Advisor, UNAIDS) provided the Reference Group with some background and an update on the work to develop guidance on fast-track and human rights. The fast-track targets were developed and proposed by UNAIDS in 2014, have informed the new UNAIDS 2016–2021 Strategy approved by the PCB, and have been endorsed by the UN General Assembly at the High-Level Meeting in June earlier this year. Given the centrality of human rights to an effective HIV response, there is a need to ensure that human rights considerations are part of the work by UNAIDS and countries as they seek to scale up HIV prevention, testing and treatment to reach the agreed-upon fast-track targets. As the Reference Group is well aware and has repeatedly advised UNAIDS (and others), respecting, protecting and fulfilling human rights is essential to achieving those targets. There is also the reality that the push to scale up services rapidly to achieve those targets carries with it inherent risks that human rights will be infringed in the delivery of services, which is a matter of human rights concern and would ultimately undermine the success of the effort.

UNAIDS has therefore commissioned assistance (from the Canadian HIV/AIDS Legal Network, which is also serving as secretariat to the Reference Group) to develop a guidance document that addresses both why human

rights principles and standards should be integrated into fast-track efforts and how this integration can be done—including through some checklists translating the most HIV-relevant human rights principles into concrete factors that can be applied and monitored in scaling up and delivering HIV prevention, testing and treatment services. The guidance also touches on the need to scale up human rights programmes alongside prevention, testing and treatment services. UNAIDS would welcome input on the draft guidance document from the members of the Reference Group. A key question to consider is how this guidance document can be most helpful for programme implementers.⁶

Richard Elliott (Executive Director, Canadian HIV/AIDS Legal Network) has taken the lead on drafting the guidance note for UNAIDS. He noted that in discussions with UNAIDS it has been agreed that 5 core human rights principles will be applied in each of the three programmatic areas (HIV prevention, testing and treatment) to identify specific considerations and measures reflecting a human rights—based approach to HIV. He noted that of course measures to address stigma and discrimination are an essential part of the guidance, reflecting the fundamental human rights principle of non-discrimination, but the remit of the guidance is to address human rights considerations for programme implementers (and policy-makers) more broadly, including as well the key elements of realizing the right to health (availability, accessibility, acceptability and quality of services), the right to privacy and corresponding obligations of confidentiality, respect for personal dignity and autonomy, and meaningful participation and accountability in the design, delivery and evaluation of HIV services.

Beyond providing input into the content and format of the draft guidance note, Elliott suggested the Reference Group also recommend some form of dedicated follow-up by UNAIDS, including the Executive Director and including with UNAIDS representatives at the country level, to make the guidance "stick." Similarly, the Reference Group might usefully consider possible mechanisms for reviewing and reporting against the measures recommended in the guidance note. For example:

- Is there a way incorporate some elements into the regular Global AIDS Monitoring reporting (GAM) indicators?
- Could UNAIDS work with the OHCHR to incorporate some of this guidance into its work, and use the guidance note in putting issues before human rights treaty bodies or the Human Rights Council's Universal Periodic Review (UPR) of countries' progress in addressing HIV-related human rights challenges?
- Can the guidance be incorporated and used in some way in the work on advancing the "Agenda for zero discrimination in health-care settings"? Could it be taken up in some way in a resolution at the World Health Assembly?
- What opportunities might the Reference Group and UNAIDS (including Dr. Mugabe's department) be able to identify to popularize and apply the guidance with programme implementers? Policy-makers? Donors? Civil society at the country level?

Reference Group members welcomed the opportunity to provide input to Dr. Mugabe's department as it implements the fast-track approach and to UNAIDS more generally in maximizing the impact of the forthcoming guidance on fast-track and human rights:

- Reference Group members noted for Mugabe that there is a need to be more assertive in "de-medicalizing" HIV testing and treatment in order to scale up and increase access. In many countries, funds are there, but governments need to be encouraged to loosen some control over that money and support civil society organizations' involvement in efforts to scale up, including delivery of HIV services for key populations. Mugabe agreed that this was a valid point and noted many countries do not currently have an enabling environment for services such as community-based testing, and this gap needs to be addressed as part of a fast-track approach.
- Reference Group members welcomed Dr. Mugabe's suggestion to plan proactive efforts to defend human rights, and to identify countries (e.g., in West Africa) where there are opportunities to advance human rights as an integral part of the fast-track approach. If this integration can be implemented in one or two countries

⁶ For the final document, launched jointly with the Global Fund to Fight AIDS, Tuberculosis and Malaria, see UNAIDS, *UNAIDS Guidance: Fast-Track and human rights: Advancing human rights in efforts to accelerate the response to HIV*, 27 May 2017. Available at www.unaids.org/en/resources/documents/2017/Fast-Track_human%20rights.

in the region, it can then be used as a model to bring others on board with a human rights—based approach to fast-track. Dr. Mugabe mentioned plans to develop and launch an emergency plan for West Africa.

- There is ample evidence of stigma and discrimination as barriers to HIV prevention, testing and treatment, and we have evidence of the benefits of programmes addressing stigma and discrimination. The question is how to fund such work. Indications are that PEPFAR is "ready to move" with an agenda of addressing stigma and discrimination, including support to take such efforts to scale. UNAIDS could be useful here, working with PEPFAR to use the forthcoming guidance to integrate these factors into national strategies/plans and also at the level of programmes.
- The guidance document is too lengthy in its current draft form; ways to make it more digestible and accessible will need to be found. It was suggested that the checklists could be a stand-alone document, perhaps accompanied by some additional explanatory material on how to apply these standards at the programme level (e.g., link to the legal environment assessments by UNDP) and how to use the tool to monitor services (e.g., gathering data from in-depth interviews with service users, as well as with others to identify reasons for not using services).
- Civil society organizations have a key role in monitoring the implementation of HIV services, so it will be important for them to be made aware of this guidance note and its checklists to assist them in ensuring that services are reflecting human rights principles and standards. It was also suggested the document could make a stronger case about the crisis in HIV prevention — apart from the important successes in reducing vertical transmission, overall it appears that HIV incidence has only declined marginally otherwise, and HIV prevention efforts are stalled.
- Some Reference Group members suggested the possibility of disseminating the guidance in the guidance note in some other formats (e.g., video) and, of course, noted the need for such a resource to be available in languages other than English.
- The guidance note is a good document and will be useful, but, as previously mentioned, providing this kind of programmatic advice on integrating human rights into HIV services cannot mean losing sight of the larger ongoing assault on the very concept of human rights that is undermining the response. In some ways, this approach is akin trying to plug holes in a dam while the dam as a whole is being eroded. For example, in the Caribbean, conservative religious groups from outside the country are decrying the very notion of human rights for various key populations; this is a big-picture barrier to HIV services delivery that needs to be addressed — including, for example, by engaging with faith communities and leaders to challenge stigma and discrimination, and to build a human rights culture. Eba agreed that this higher-order issue needs to be addressed, but in a different manner; the guidance document is focused on integrating human rights principles and standards at the level of programmes. The idea of using various sections of the guidance, produced in different formats, was welcome.
- The question was also raised as to how the current funding constraints faced by UNAIDS may affect the ability to implement the guidance in the guidance note at the country level. This underscored an ongoing concern of the Reference Group, already identified again at this meeting, about strengthening the human rights literacy of UNAIDS staff, including country directors. Based on their own experience working the field, Reference Group members alluded to the reality that in some countries this capacity (or possibly willingness) to defend and advance human rights is certainly missing, with the result that some work that is needed has not advanced.
- Mugabe agreed that the question of UNAIDS' in-house capacity is a real one; there is little in the way of funds for new positions and how staff do their work in the field is evolving, so we need to ensure that UNAIDS staff on the ground in country have the capacity to deal with human rights issues. He suggested an initiative whereby members of the Reference Group and Secretariat staff of the Human Rights and Law team could participate periodically in UNAIDS' regional management meetings to discuss human rights issues; this participation would help keep these considerations on the agenda as UNAIDS supports "fast-track" efforts, and would reinforce the message that UNAIDS staff must take up this issue at country level. He also suggested that some discussion of human rights with all new staff in his department is required, so they understand that meeting fast-track targets necessarily requires attention to human rights challenges.

• There was agreement by all participants, from the Reference Group and the UNAIDS Secretariat departments present, that the guidance document should be launched with high-profile support from the UNAIDS Executive Director, and that it should be included, with his endorsement, in the package of materials for implementers and UNAIDS country-level staff. This will create expectations for action and reporting on the use of the guidance note. The Reference Group also welcomes Mugabe's suggestions for incorporating human rights issues in a more ongoing, systematic way into UNAIDS' work on fast-track and agreed to explore those ideas with UNAIDS senior management.

HUMAN RIGHTS AND THE GLOBAL FUND TO FIGHT AIDS, TUBERCULOSIS AND MALARIA

The Reference Group welcomed Ms. Debra Von Zinkernagel (Director, Global Fund and Global Plan), UNAIDS Secretariat, and Ms. Hyeyoung Lim (Human Rights Advisor) of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Von Zinkernagel summarized UNAIDS' engagement in the past year with the Global Fund on addressing human rights barriers to an effective HIV response. As the Global Fund's Executive Director, Mark Dybul, noted in his remarks to the Programme Coordinating Board earlier in the day, the Global Fund and UNAIDS need to be "linked at the hip" to do their respective jobs. Human rights constitute a key, top-level component of the new Global Fund strategy, elevated as never before. Now there is a requirement that all concept notes submitted to the Global Fund must include some allocation for work on human rights programmes. UNAIDS helps create the conditions for implementation of Global Fund-supported programmes and is a key technical partner to the Global Fund in strengthening the HIV response. Both UNAIDS and the Global Fund are committed to importance of community engagement in the development of concept notes for securing Global Fund grants. UNAIDS is very pleased to see that a substantial body of funding will be available via the Global Fund for human rights programmes, and was able to provide input on how the USD 45 million for catalytic funding to scale up human rights programmes should be implemented. There is also a role for UNAIDS on Country Coordinating Mechanisms (CCMs) as they develop concept notes, including ensuring inclusion of human rights work. UNAIDS would welcome input from the Reference Group on how to communicate the importance and necessity of human rights programmes to country-level actors, and on building country ownership and understanding of why such initiatives are important — as this is a challenge in many settings. UNAIDS also welcomes input from the Reference Group about priority human rights activities that need to be scaled up, including in the context of the Global Fund grant-making.

Ms. Lim thanked UNAIDS and the Reference Group for the opportunity to present. She recalled that the Global Fund strategy adopted in 2012 included some human rights objectives, but that the focus on human rights has been strengthened in the new, current strategy, in which promoting and protecting human rights and gender equity constitute one of the four key strategic objectives of the Global Fund. That strategy strengthens the Global Fund's commitment to invest in programmes addressing human rights—and gender-related barriers, and to integrating human rights principles—participation, equity, accountability and transparency—throughout the grant cycle.

Lim provided an update on recent work at the Global Fund regarding human rights, particularly the plan for an intensified effort in 20 priority countries selected for intensive support. In these eligible countries, catalytic human rights funding will be offered in the form of a matching grant; i.e., in order to secure this additional catalytic funding for human rights programmes, the applicant country will have to commit some portion of funds in its main Global Fund grant or from other sources for human rights programmes. The Global Fund has commissioned in-depth baseline assessments in each of the 20 countries that will identify the nature and extent

⁷ The Global Fund, *The Global Fund Strategy 2017-2022: Investing to End Epidemics*, 1 May 2017. Available at www. theglobalfund.org/en/strategy.

⁸ For additional information about this intensified effort, see "Scaling up Programs to Remove Human Rights Barriers to Health Services: A Strategic Objective and Major Initiative Q&A" and "Scaling up Programs to Remove Human Rights Barriers to Health Services: Intensified Efforts in 20 Countries Q&A."Available via www.theglobalfund.org/en/human-rights (under "Related Resources"). The 20 countries are: Benin, Botswana, Cameroon, Democratic Republic of

of the human rights barriers to health services; the populations and locales most affected by these barriers; and the current status and scope of programmes being implemented to address those barriers. This catalytic funding is intended to be part of the 5-year planning cycle for each country, which should also include bringing in other donors to support and sustain these human rights programmes. The goal is to move beyond the current Global Fund module of "removing legal barriers" to support countries in implementing more comprehensive human rights programming, aligned with UNAIDS' seven key programme areas to reduce stigma and discrimination and increase access to justice. The goal is to include rigorous monitoring and evaluation of these programmes, helping to build the evidence base for such interventions. The Global Fund is looking to UNAIDS for support in achieving the inclusion and scaling up of human rights programmes in countries' concept notes. This includes mobilizing political support for such initiatives; providing technical support in the elaboration of programmes and costing of programmes; including such programmes in national plans and strategies; and providing support at the country level in the implementation of programmes (or regional level in the case of regional grants).

Dr. Joanne Csete, a member of the Reference Group and professor at Columbia University, had been commissioned in her personal capacity by the Global Fund to provide extensive assistance in shaping this new special initiative; she added some observations about the Global Fund's initiative. This is a rare opportunity to advance this kind of human rights work at such a scale, with the buy-in of so many parties, including the whole Global Fund and in partnership with organizations such as UNAIDS, the Stop TB Partnership and Roll Back Malaria, and the support of a number of foundations. The primary goal is to scale up human rights programmes to a level not yet possible in most countries; building the evidence base for such programmes is an important collateral benefit. There are numerous challenges to rolling out and monitoring such a novel initiative at this scale. It should also be remembered that a number of the countries will soon be submitting proposals for continuation of Global Fund support and, given the timelines, there will not necessarily be the opportunity for in-depth research beforehand, which would be ideal. However, even if this catalytic initiative demonstrates success in some significant number of the 20 selected countries, it will be an enormous achievement for the field. She suggested the Reference Group should communicate to the UNAIDS leadership its strong support for this initiative, and for UNAIDS' engagement and collaboration with the Global Fund in this effort.

Reference Group members welcomed the exciting initiative by the Global Fund to scale up human rights programmes, and UNAIDS' collaboration in that effort. They offered a number of questions and observations:

- The diverse list of countries selected is welcome; is there buy-in internally at the Global Fund, including among Fund Portfolio Managers (FPMs) for the initiative to scale up human rights programmes in those countries? Lim noted there were extensive internal consultations in the course of selecting the 20 countries, including with FPMs; in addition, scaling up these programmes is reflected in the key performance indicators included in the Global Fund Strategic Plan.
- How will the Global Fund (and UNAIDS) seek to ensure that human rights programmes funded through this initiative are coordinated with the "key populations" funding initiative recently announced by PEPFAR?
- As always, there will be a need to ensure the inclusion of civil society organizations, including organizations representing key populations, in the development of proposals for human rights programmes; the Global Fund and UNAIDS will have important roles to play in ensuring this meaningful engagement, and not just of organizations that governments might choose because they are unlikely to pose challenging questions and

Congo (province-level), Côte d'Ivoire, Ghana, Honduras, Indonesia (selected cities), Jamaica, Kenya, Kyrgyzstan, Nepal, Mozambique, Philippines, Senegal, Sierra Leone, South Africa, Tunisia, Uganda, and Ukraine.

⁹ In upper middle-income countries transitioning off Global Fund support, it will be difficult to insist upon expansion of human rights programs out of existing allocations, when existing services are under strain from declining funding. The Global Fund is looking at how to best define the requirement of some sort of "matching" that may not always necessarily require strict quantitative ratios between human rights catalytic funding and matching those funds from other sources.

¹⁰ UNAIDS, *Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses*, 15 May 2012. Available at www.unaids.org/en/resources/documents/2012/Key_Human_Rights_Programmes. A group of TB experts convened by the Global Fund has confirmed that these programmes are also relevant for TB.

propose initiatives the government is opposed to or reluctant to take on. It will be important to ensure that, of the human rights programme funding that is disbursed to a Principal Recipient, a substantial portion goes to community organizations working in and with key populations.

- The Global Fund should also consider flexibility in the funding that would allow for the possibility of supporting emergency responses to human rights violations on the ground. In response, Lim noted that this support may not be part of the catalytic funding initiative as it has been defined, but noted that the Global Fund has other capacity to respond to emergencies.
- It will be important to have the monitoring and evaluation component accompanying the implementation of human rights programmes. Governments will want to see this, but it will also be helpful in building the evidence base regarding the need to remove legal and human rights barriers to services and the benefits of investing in human rights programmes.
- Proactive communications regarding this initiative will be key, not simply reporting results after the fact. Partly this will be important to ensure expectations are realistic about what such interventions can achieve, particularly in the short time frame of a couple of years. It will also be important to communicate how human rights programmes will often differ qualitatively from direct HIV services, and that the monitoring and evaluation (M&E) of their impact also will need to be approached differently. It will be important to have suitable monitoring and evaluation frameworks, and also realistic expectations about how directly the impact of certain kinds of human rights interventions can be demonstrated. Lim and Csete agreed that the Global Fund shared those concerns, and noted that the Global Fund has established an M&E expert working group that is looking at developing suitable methods for monitoring and evaluating human rights programmes, including modelling their impact.
- This is also an opportunity to document how countries and implementers have gone about scaling up human rights programmes, with lessons to be learned and applied elsewhere. In addition, one welcome outcome of such an initiative can be better documentation about the needs of key populations, the interventions implemented and their impact.
- Documenting the human rights barriers to HIV services, as well as the barriers to the implementation of human rights programmes, is also an important part of the process because it also then establishes further evidence of the need for certain other kinds of human rights interventions (e.g. litigation, law reform advocacy, etc.)
- Human rights issues need to be addressed in TB grants as well. Lim noted that USD 7 million in catalytic funding has been set aside for removing human rights barriers in TB grants; this funding is in addition to the catalytic funding on human rights in HIV grants.

DRUG POLICY, HIV AND HUMAN RIGHTS

As 2016 was a year with some significant developments internationally regarding drug policy, the Reference Group was pleased to welcome Mr. Aldo Lale-Demoz, UNODC Deputy Executive Director and Director of the UNODC Division for Operations, and Vinay Saldanha, Director of the UNAIDS Regional Support Team for Eastern Europe and Central Asia (based in Moscow).

Lale-Demoz thanked the Reference Group for the invitation, noting that Joint Programme co-sponsor UNODC is committed to human rights and that he chairs the senior management advisory group on human rights within UNODC (created in December 2011). He noted that in April 2016, the UN General Assembly had held its special session on "the world drug problem," and that while the Outcome Document was far from perfect, it does represent progress in comparison to some previous such documents. He noted that one of the roles of UNODC is to provide technical assistance to states in responding to drugs, and the outcome documents provides several bases on which UNODC can advance the right to health, and human rights more broadly, when providing such advice. He noted that it was unfortunate the UNGASS Outcome Document does not include any reference to abolition of the death penalty for drug offences, but noted that the UNODC Executive Director's submission for the UNGASS did reiterate this recommendation. From UNODC's perspective, the best drug control policy is a criminal justice

system that is just and humane; therefore, UNODC consistently emphasizes human rights considerations such as the principle of proportionality in the response to drugs, concerns about the treatment of women and young people in drug control, and the rights of prisoners and other detainees (the latter attracting some additional donor support recently in light of the recent process of developing and adopting the Mandela Rules, the new UN Standard Minimum Rules for the Treatment of Prisoners). UNODC feels it has been making good progress in some parts of the world in advancing an efficient, humane, proportional criminal justice system as a key drug control measure.

Saldanha spoke of the "cataclysmic situation" regarding HIV among people who inject drugs in Eastern Europe and Central Asia (EECA), but noted that there are signs of progress in some countries in the region. UNAIDS has naturally been engaging with health ministries and officials as a natural port of entry for shaping the HIV response, including encouraging the adoption of evidence-based interventions, but in much of the region, health ministries often have little or no power compared to other actors who are determining policy directions and priorities (including drug policy). Given this situation, there needs to be a shift in how we advocate, including at a higher political level, for such programmes. Saldanha noted the example of the meeting between the UNAIDS Executive Director and the Prime Minister of Kazakhstan, which helped secure a decision to double the national HIV budget; the right evidence put forward at the right time with the right decision-maker is key to securing action.

Saldanha noted the strong criticism that the Political Declaration adopted at the High-Level Meeting on HIV in June 2016 has no new explicit target on addressing HIV among people who inject drugs — even as the previous targets have been widely missed. However, if countries in the region take seriously their commitments to achieve the fast-track target on prevention, in a setting such as the EECA, this target simply cannot be achieved without strengthening HIV prevention efforts among people who inject drugs. This approach will offer another entry point for holding governments accountable and for pressing for the evidence-based interventions for this key population that are so often inadequate in the region.

He noted that while data (from 2014) regarding diagnosed HIV infections in Russia indicate 1% of the population is HIV-positive, this does not in fact translate into it being a "generalized epidemic" in the country; it is, for the time being, still a somewhat concentrated epidemic, and the priority must be to urgently bring harm reduction programmes to scale. He also noted that two-thirds of the European HIV epidemic is now in 12 countries of the EECA. Of these dozen countries, 10 have needle and syringe programmes (NSPs) and 9 have opioid substitution treatment (OST). However, only 4 of these 12 countries have harm reduction programmes that are supported by domestic government funding, and even in countries where these programmes exist, they are nowhere near the scale needed. For example, Ukraine has now committed to nationwide OST but is only reaching an estimated 8,000 people who inject drugs out of an estimated population of 250,000 — and this is the biggest harm reduction programme in EECA. Most harm reduction initiatives still remain extensive pilot programmes, not yet having a decisive public health impact at population level, although there is definite evidence of the benefit of such programmes for those who have access to them. UNAIDS has also done cost-effectiveness studies of harm reduction for 5 EECA countries; these studies also inform UNAIDS' advocacy in the region. Belarus has now adopted harm reduction as government policy, and the government is providing funding to implement NSPs and OST. Evidence of benefit from such settings closer to home may eventually prove useful in convincing the Russian government to implement evidence-based harm reduction measures.

Reference Group members raised a number of points for discussion with Lale-Demoz and Saldanha:

• The UNGASS outcome document may include some very modest points of progress with respect to language on a few human rights points, but given the process that produced it, it unsurprisingly reflects a "lower common denominator" approach. It is disappointing on many fronts, including reiterating many prescriptions that ample evidence has shown do not work as good drug policy. We are at a moment where a growing number of countries are looking seriously at the prospect of reforming their drug laws in ways that will be more helpful for public health and for human rights; the outcome document is not helpful to those countries and UNODC should not accept the lowest standards agreeable to all countries in providing assistance to countries wishing to pursue alternative approaches based on a greater commitment to evidence-based interventions, public health and human rights standards.

¹¹ J. Csete et al., "Public health and international drug policy," *The Lancet* 387 (2 April 2016): 1427–1480. Available at www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(16)00619-X.pdf.

- With respect to advancing the right to health, it is worth remembering that the discussions at the UN Commission on Narcotic Drugs and the UNGASS process have begun to include references to a "public health" approach, but this is not necessarily a human rights-based discussion or conception of health, as evidenced by the continued unwillingness of some states to use the term "harm reduction" (which is essential to realizing the right to health of people who use drugs); the ostensible embrace of a "public health approach" by states that maintain policies and programmes for supposed "treatment" of drug dependence that amount to torture or other cruel, inhuman or degrading treatment or punishment; the continued view of many such states professing a "public health approach" that incarceration and other harsh penalties (up to and including the death penalty in some instances) are appropriate even for non-violent drug offences, contrary to the human rights principle of proportionality; and other examples. There is very much a continued need for UN agencies, including those in the Joint Programme (and in particular the UNAIDS Secretariat and co-sponsors UNODC and UNDP) to challenge facile references to "public health" or to "human rights" in these discussions that gloss over a real understanding of what such approaches to drug policy would entail. This means there is also a continued role for the Reference Group to continue taking up these issues, including with the Joint Programme. Lale-Demoz agreed with all the stated concerns about the limitations of the UNGASS outcome document. He noted that UNODC has been using, and will continue to use, the term "harm reduction" as part of a public health approach.
- The recent Lancet Commission on public health and international drug policy outlines the many ways in which drug policy affects public health (and hence also human rights) and what a public health approach should entail.¹¹ The Reference Group considers that international guidelines on human rights and drug policy will be useful not only for trying to hold countries accountable for their statements (including most recently in the UNGASS outcome document) that drug control should be in conformity with human rights, but also for countries that are at a point of thinking about the adverse consequences of the "war on drugs" approach and ready to shift in some ways from that approach. International guidelines will be of benefit to the HIV response. UNODC should support the development of such guidelines, including by creating spaces for engaging member states (and other actors) in building support for such a tool. Lale-Demoz noted that over the last three years, UNODC has been developing guidelines for human rights compliance in its own work, and developing similar guidance on gender issues. He indicated UNDOC would be very willing to take forward discussions on human rights in the post-UNGASS environment. He also suggested the Reference Group and UNAIDS could assist in advocating for some existing international standards and guidelines that are helpful for protecting and promoting human rights even if not explicitly framed in such terms, such as the international standards on drug use prevention and UNODC's international guidelines, principles and standards on drug dependence treatment.
- Reference Group members were interested in strengthening connections between the human rights field and those entities working to reform drug policy in ways supportive of human rights and health. A Reference Group member who is also a member of the UN Committee on Economic, Social and Cultural Rights (CESCR) noted that that the Committee has not seen many strong reports from either NGOs or from UNAIDS addressing human rights issues related to drug policy; the first time he mentioned "harm reduction" at the Committee, many member weren't familiar with the meaning of the term. More such engagement with the human rights treaty bodies is needed. There is a growing number of Concluding Observations and recommendations from treaty bodies that address harm reduction or broader drug policy questions as human rights concerns (and recent examples include the CESCR's observations to Poland and the Philippines).
- The Reference Group welcomed UNAIDS' contribution to the UNGASS discussions, including its statement to the UN Commission on Narcotic Drugs (March 2016) and the *Do No Harm* brief (April 2016), and its recommendations on decriminalisation. UNAIDS needs to advance such arguments more regularly at the CND, and to present the outcomes from the High-Level Meeting on HIV to the CND and its related processes including the reality that achieving the fast-track targets on HIV will not be feasible in many states without implementing evidence-based harm reduction measures, protecting the human rights of people who use drugs and more generally creating a more enabling legal and social environment for protecting and promoting health. The need for such engagement is underscored by the recent omnibus resolution at the

¹² UNAIDS, *Do no harm - Health, human rights and people who use drugs*, 15 April 2016. Available at www.unaids.org/en/resources/documents/2016/do-no-harm.

UN General Assembly in which, despite the goal of "ending AIDS by 2030" having already been adopted in the Sustainable Development Goals, there was resistance to even referencing the Political Declaration from the High-Level Meeting on HIV because it includes the term "harm reduction" — an essential feature of achieving the SDG. Lale-Demoz agreed that he would like to see more engagement not only at the CND in Vienna, but also with human rights bodies in Geneva, and with missions in New York. In his view, more engagement by a greater number of UN agencies, and by more civil society organizations, would yield more progress on human rights.

The Reference Group asked about the status of the "model legislation" on drugs that UNODC has been developing for a couple of years. It was noted that a number of civil society organizations have repeatedly expressed concern that this should not simply be a technical exercise by UNODC in translating treaty provisions into domestic legislative provisions, but would be more useful and helpful if it provided some normative underpinnings — such as human right standards, which member states have repeatedly said their drug control measures must comply with, and which the recent UNGASS outcome document addresses in a bit more detail on a few specific matters related to the criminal justice system specifically — and thereby providing guidance to states accordingly. Lale-Demoz confirmed that OHCHR had requested an opportunity to review, to which UNODC has agreed. A substantial number of comments have been received during the draft, but UNODC is also concerned that recirculating the entire revised draft would lead to further undesirable delay. Lale-Demoz agreed that the Reference Group could receive a copy of the most recent draft and provide further comments if this was feasible within the timelines for completing the resource.

There is a global crisis in harm reduction: according to the most recent global review, no new countries have introduced NSPs, and only 3 new countries introduced OST. This picture will likely worsen in the coming years in some of the countries where such programmes are most urgently needed to address the epidemic, given the retreat by many donors from middle-income countries heavily affected by HIV linked to injecting drug use, where there is often little will on the part of national governments to pick up funding for even those limited programmes that have been brought into existence with international funding. What are the most strategic steps for the UN, including UNAIDS and co-sponsors, in this context? Within UNODC itself, the co-sponsor with lead responsibility for addressing HIV among people who use drugs, the work on HIV is underresourced. Given the "repositioning" in UNAIDS, there was a commitment to report on how drug policy and HIV issues would continue to be prioritized within the Joint Programme.

- How will UNAIDS and UNODC engage governments in the EECA to invest more domestically in the response to HIV, including among people who use drugs that are a key population to be reached if the fast-track targets are to be achieved? And will UNAIDS and UNODC support domestic advocates in trying to get government action on harm reduction and on creating a more enabling legal environment for the HIV response among people who use drugs (e.g., by supporting advocacy for decriminalizing possession for personal consumption)?
- Finally, the Reference Group inquired about efforts by UNAIDS to engage faith-based communities in the EECA in the HIV response. Saldanha indicated that UNAIDS has had some involvement, including in an interfaith working group, but also noted the increasingly conservative influence of the Orthodox Church in Russia, including its influence with the government.

DISCUSSION WITH UNAIDS EXECUTIVE DIRECTOR

The Members of the Reference Group were pleased to meet again with UNAIDS Executive Director Michel Sidibé and to raise a number of issues for discussion with him.

UNAIDS' role and human rights in the HIV response

The renewed UNAIDS Strategy 2016–2021 identifies human rights as central to the HIV response, and the Reference Group welcomes the apparent interest of UNAIDS staff, including department heads, in engaging on human rights issues that are so central to an effective HIV response, including achievement of the fast-track targets. But the Reference Group is concerned that momentum for such advocacy is faltering globally, and may also be at risk within UNAIDS at this time of stalled funding for the global HIV response, financial constraints for the Joint Programme, and a restructuring of the UNAIDS Secretariat (which includes a seeming loss or freezing

of in-house capacity for work on various human rights issues related to HIV). UNAIDS – both the Secretariat and the Joint Programme as a whole – has a key role to play in advancing human rights in the response. In fact, being a voice for human rights in responding to a public health challenge should be seen as key to defining the identity of UNAIDS, particularly at a time when, despite talk of "ending AIDS by 2030," some long-standing donors appear to be losing interest in supporting the work needed to achieve this goal – including addressing the human rights challenges that will prevent success if they are not addressed.

The Reference Group invited the Executive Director to share his views regarding the role of UNAIDS in advancing human rights, and the role he envisions for the Reference Group in supporting that work. What is the level of his commitment as Executive Director to ensuring the UNAIDS Secretariat has the capacity to continue working on human rights issues? And beyond preserving that capacity at headquarters, how can UNAIDS – and he as Executive Director – ensure that capacity and competence exists at the country level? In the restructuring of the UNAIDS Secretariat (human rights and gender work are being incorporated as one of several elements under the new rubric of "community support"), how can we ensure that these dimensions of the work continue to receive adequate attention? Given the recent discussions regarding division of labour between the Secretariat and co-sponsors, in the context of serious financial constraints facing the Joint Programme as a whole, how does Sidibé perceive the roles of the UNAIDS Secretariat and UNDP in working on human rights aspects of the HIV response (including in responding to human rights crises in country)?

Sidibé reiterated his appreciation for the ongoing guidance of the Reference Group, which is always very useful to him and to UNAIDS. This is a time of growing conservatism and nationalism, with the growing expression of a populism that is linked to hunger rather than hope. Conservative voices in some of the most HIV-affected countries, including in government, will point to the growing conservatism and nationalism in the West to "justify" their own policies and measures that undermine human rights. And while some traditional donor governments may continue to be concerned about human rights and willing to consider supporting work on these challenges, where traditional beneficiary countries are experiencing economic growth without equality, or may be able to secure funding from other donor governments less concerned about human rights, they feel less need to attend to those issues — and hence are more amenable to domestic voices opposed to human rights, which in turn makes it all the more necessary to have capacity for human rights advocacy at country level, including from actors such as UNAIDS.

This dynamic has had, and will likely continue to have, a negative impact on both the policy and funding level for the HIV response. UNAIDS must therefore help define the narrative about how we address a global health challenge such as HIV; the Reference Group can assist UNAIDS in thinking ahead in this regard. As Executive Director of UNAIDS, Sidibé firmly believes that if we do not take on controversial human rights issues, particularly with respect to key populations such as sex workers, people who use drugs and men who have sex with men, the response to HIV will suffer and UNAIDS will lose its relevance. The social exclusion he witnesses regularly is what motivates him to be an advocate for human rights in the response, and advocating for human rights is the strongest raison d'être for UNAIDS.

In budget discussions, we need to remain focused on the common vision of the Joint Programme. It is also essential that, as a Joint Programme, we communicate a common, clear message to donors about the efficient and appropriate division of labour between the constituent entities in the Joint Programme. Advancing human rights is a cross-cutting concern of relevance to the mandates and work of not only the UNAIDS Secretariat but also several co-sponsors (e.g., UNDP, UN Women, UNODC). Longstanding key donors have been reducing some of their funding in part because of perceived duplication of work.

Sidibé assured the Reference Group that the restructuring of the UNAIDS Secretariat, including the placement of human rights work alongside other thematic areas under the rubric of "community support," would not weaken this work. He shared his concern that there is a need for UNAIDS to strengthen its ability to work at the country level, including with regard to human rights issues. He values having a competent human rights team in headquarters, but wants to make sure such work is brought closer to the country level — and demonstrating this connection to strengthening the response at country level is more generally an important necessity for UNAIDS as a Joint Programme.

The Reference Group welcomed the Executive Director's observations and underscored that, at this moment in history when there is a backlash against what has always been an under-resourced effort to defend and advance

human rights in the HIV response, it is essential that UNAIDS be an authentic voice for human rights — and this voice needs to be reflected across the Secretariat and the co-sponsors, and from headquarters to country level. While some donor governments may be stepping away from HIV and may be more conservative and reluctant to support human rights work, this shift makes it all the more important that UNAIDS — and in particular the Secretariat that has a sole focus on HIV, as opposed to some co-sponsors who may have other programmatic areas to consider as well — to step up for such work. UNAIDS may also find that this change opens up other sources of funding, from foundations or possibly certain private sector sources to whom the value of this role can be clearly communicated. The Reference Group reiterated its concern that UNAIDS should not fall in to the trap of certain donors' views that support to UNAIDS, including for human rights, can be reduced because that work is being or will be done via other entities; it is essential to communicate the importance of UNAIDS' role, as part of the Joint Programme, in coordinating such work, and to also lead in ensuring engagement with communities and key populations.

The Reference Group welcomed the Executive Director's commitment to support greater capacity for work on human rights issues across UNAIDS, including at the country level; this has been a longstanding concern of the Reference Group raised in previous discussions. Members of the Reference Group are available and willing to assist with this task in their regions, including strengthening connections between UNAIDS and civil society organizations. In keeping with his remarks about ensuring human rights expertise within the agency at all levels, the Reference Group urged the Executive Director to provide strong, visible support for the upcoming roll-out of the new guidance on integrating human rights into the fast-track approach to ending HIV and AIDS; this support will send an important signal throughout the agency, including to country-level staff, that these issues must be taken seriously. The Reference Group also noted that it would be pleased to discuss further with him and his staff steps that could be taken to raise the level of human rights literacy and competence within the organization.

The Reference Group shared its view that, beyond providing technical guidance, from headquarters and at country level, there is also an important political role for UNAIDS in promoting human rights in policy discussions internationally. There are a number of areas in which this is particularly relevant:

- Drug policy, HIV and human rights: The Reference Group welcomed UNAIDS' Do No Harm report as a contribution to the UNGASS on drugs earlier this year, but it needs to have more of a presence in Vienna at the UN Commission on Narcotic Drugs to engage in those discussions more regularly, including in the follow-up to the UNGASS. The Reference Group also noted the importance of the UNAIDS Secretariat continuing to ensure human rights are present in the response of the Joint Programme, and of co-sponsor UNODC, in those forums; Sidibé concurred with the need for this engagement. The Reference Group also underscored the importance of UNAIDS engaging with governments in middle-income countries and those transitioning out of eligibility for support from the Global Fund (or otherwise being increasingly left out of consideration by other donors), and specifically with a view to convincing them to support civil society organizations responding to HIV and to address the human rights barriers to effective responses. The need for pressure on this front is only increasing as funding and services dwindle and the epidemic continues to worsen. The Reference Group also recommends that UNAIDS should support the development of international guidelines on drug policy and human rights (as it has previously collaborated with OHCHR to elaborate the International Guidelines on HIV/AIDS and Human Rights).
- *Sex work*: It is important that the UNAIDS Executive Director keep stressing to UN Women that there is an established Joint Programme position on sex work, including decriminalisation. Sidibé assured the Reference Group that he will continue to advocate in support of that position, including vis-à-vis UN Women as a Joint Programme co-sponsor.
- Access to medicines: The Reference Group expressed its concern that the restructuring of UNAIDS has meant the abolition of the sole position that existed to address questions of intellectual property policy and access to medicines. This is an unfortunate loss of capacity to address a critical human rights issue, even as the UN Secretary General's High-Level Panel on Access to Medicines to whose work UNAIDS Secretariat had contributed has highlighted the need for more attention and action on various fronts that are highly relevant to the HIV response, including the achievement of the 90-90-90 fast-track targets on treatment and viral suppression. The Reference Group had prepared a submission regarding the importance of this work to the Programme Coordinating Board and noted it had expressed some recommendations specifically for action by the UNAIDS Secretariat and Executive Director to ensure sustained attention to these issues, including

follow-up on the High-Level Panel report, which requires capacity within the Secretariat. There is a clear need for continuous conversation with the UNAIDS leadership on their plans and approaches to ensure that UNAIDS and the Joint Programme has the human and financial capacity and resources to address key questions of intellectual property and access to medicines in the context of efforts to scale up HIV prevention, treatment and care.

- Gender and HIV, including the impact of violence and criminalisation on particular populations such as young people, sex workers: Reference Group members noted that HIV "lives in the cracks," in society's fault lines, and this was certainly the case when considering the intersection of gender inequality (including gender-based violence) with the vulnerability of certain key HIV-affected populations such as adolescents (and particularly girls and young women) or sex workers. Joint Programme co-sponsors may have a role to play, within their particular mandates, in addressing certain aspects of the problem, but often a given co-sponsor cannot or will not address the issue in a more comprehensive fashion witness, for example, the ongoing tension with UN Women on the matter of sex work. UNAIDS Secretariat has an important role to play in advancing the more holistic response that is needed, whether in shaping international policy discussions on these issues or providing technical advice or other support at country level.
- Stigma and discrimination, and engaging faith-based communities: Reference Group members noted their concern that the heavy focus on achieving treatment targets, certainly an important human rights imperative, has perhaps encouraged a neglect of prevention efforts, and the emphasis on this medicalization of the response to HIV has reinforced a neglect of the human rights issues that must be addressed — including stigma and discrimination that remains a major barrier to scaling up both prevention and treatment. Sadly, some of the rising conservatism that is of shared concern to the Reference Group and Sidibé is emanating from some faith leaders and communities, and these voices are eroding human rights and undermining an effective HIV response, including reaching the fast-track targets. Yet faith leaders could also be a major resource in challenging stigma and discrimination within their own countries and communities, and could be voices, speaking from a place of faith, in support of measures to address other barriers that must be overcome if we are to prevent infections and save lives (e.g., the intellectual property barriers that have been identified). What might UNAIDS consider as a strategy for addressing the barriers being raised in the name of faith and engaging faith-based communities as positive actors in advancing human rights and HIV prevention and treatment? Sidibé noted that he and UNAIDS wished to be careful to avoid reopening the false, unhelpful dichotomy between prevention and treatment, particularly when treatment is still not reaching so many. He recognized the multiple barriers to achieving universal treatment, including stigma and discrimination. He declared that it is very important to address faith-based organizations in the response.

The Reference Group thanked Sidibé for the opportunity to meet. The co-chairs noted the group would be continuing the discussion of these issues with his Deputy Executive Director and would follow up in due course with both of them with a number of conclusions and recommendations.

ACCESS TO MEDICINES

Tenu Avafia of UNDP started the Reference Group's discussion of access to medicines with an overview and update of the work of the UN Secretary General's High-Level Panel (HLP) on Access to Medicines.

The work of the HLP fits under SDG3 (good health), and health is of course an accelerator for many of the other SDGs (e.g., SDG1 on poverty, SDG5 on gender inequality, SDG 10 on inequalities). HIV, TB and malaria of course remain major concerns, but so too are viral hepatitis and the wide array of non-communicable diseases that represent a major burden globally. Anti-microbial resistance is an additional emerging concern, including the subject of discussion within UN fora. UNDP and UNAIDS put forward a request to the UN Secretary General to convene the HLP in line with the earlier recommendation of the Global Commission on HIV and the Law (which the Reference Group has previously supported), as part of helping to advance the SDGs. In particular, how does the commitment in SDG 3 square up with international trade agreements and other measures leading to stricter rules on intellectual property or otherwise constraining countries' policy options for better access to needed health technologies? The mandate of the HLP, as set by the Secretary General, was to address the policy incoherence between the justifiable rights of inventors, public health priorities, human rights law and trade rules.

The High-Level Panel of eminent persons from various stakeholder perspectives was complemented by the work of an Expert Advisory Group (of approximately 25 people, including civil society, international organizations and private sector representatives), as well as two global dialogues (London and Johannesburg) and 182 submissions received from around the world (from various sectors, but civil society organizations especially took leadership on this front).

In its final report, the HLP addressed four main areas: (1) health technology innovation and access; (2) intellectual property laws and access to health technologies; (3) new incentives for health technology R&D; and (4) governance, accountability and transparency. The final report is pragmatic but constructive and forward-looking; there is no question the Panel could have been more radical in its recommendations, but Panel members decided fairly early on to adopt a more incremental approach, with a view to seeing where they could achieve consensus and achieve some traction with Member States and policy-makers.

The Panel made a number of key findings, including that there remain substantial barriers to treatment access, including those related to international and domestic policies and practices regarding intellectual property and the pricing of health technologies. For example, in the case of HCV, the direct-acting antiviral medication sofosbuvir is marketed in the US at USD 84,000 per course of treatment, and while the manufacturer has signed a 5-year voluntary licencing agreement that should permit greater access to generic formulations in 112 lower middle income countries, that licence does not extend to 50 middle income countries accounting for 49 million people with HIV (approximately 43% of all those estimated to be living with HCV). The Panel also found that affordability of medicines was not just an ongoing challenge for low- and middle-income countries, but increasingly a concern for high-income countries — witness the submission to the Panel from the Netherlands highlighting that their public health system would not be able to afford certain medications.

The Panel also found the current system poses considerable challenges not only for access to health technologies but also for innovation. The primary reliance on a market- and patent-based system has failed to generate new health technologies in important areas. Anti-microbial resistance is a crisis in waiting that the current system appears not well-equipped to address. Only 2 new antibiotics have been developed in the last 40 years; new incentives to stimulate innovation are urgently needed. The growing problem of multi-drug resistant TB (MDR-TB) is another area in which innovation is not being generated urgently: current treatment regimens can require nearly 20 months of treatment, involving 8 months of daily injections and some 14,000 tablets with serious toxic side effects (e.g., deafness, psychosis and severe nausea), at a cost of \$4,000 per patient per year in the US, and still only achieve a cure rate of less than 50%. For reasons of both innovation and access, the Panel concluded there was much room for improvement in the current system.

The Panel therefore put forward 30 recommendations. Highlights include the following:

- *Funding*: There is a need for substantially increased public sector investment, by both high-income and lower- and middle-income countries, in health R&D in order to fulfil obligations related to the right to health. The Panel recommended a binding treaty on health R&D, and that the UN Secretary General should initiate negotiations for such a convention that delinks R&D costs from end prices (taking this discussion beyond the WHO where it has been stalled for a decade).
- Access: WTO Members must make full use of policy space available under the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). This includes measures to curtail evergreening and reward genuine innovation; mechanisms to facilitate quick, fair and predictable compulsory licencing including revising the inadequate August 30, 2003 WTO Decision to replace it with a mechanism that enables the swift and expedient export of pharmaceutical products under compulsory licencing. The HLP did not recommend against countries ratifying "TRIPS-plus" agreements, because it formed the view that ultimately Member States were the ones to make their own assessment of such deals. But the Panel's concerns led it to recommend that countries conduct health impact assessments before deciding whether to enter into any such agreements.
- **Publicly funded research**: Governments should implement a code of principles that would apply to public funding of health R&D. Public funders of research should require that knowledge generated from such research be made freely and widely available in peer-reviewed literature. Universities and research institutions that receive public funding should prioritize public health objectives over financial returns in patent and

- licencing practices, for example, by offering non-exclusive licencing, participating in public sector pools and donating IP.
- Accountability: Governments must assess national situations regarding access to treatment and obligations to fulfil the right to health. They should establish national level inter-ministerial committees to ensure participation from all sectors.
- *Transparency*: This recommendation represents a front on which the HLP broke new ground. Governments should require all manufacturers and distributors to disclose the costs of R&D, production, marketing and distribution of their products, separated into each of these categories. Government should also mandate more transparency in clinical trials, the patent status of various products (including through databases with patent information on medicines and vaccines) and trade negotiations. WHO should establish and maintain an accessible database of prices of patented, generic and biosimilar medicines.

In addition, the Panel recommended that the UN Secretary General initiate negotiations among governments on the coordination, financing and development of health technologies; establish an independent review body tasked with assessing progress on health technology innovation and access; and convene a UNGASS on health technology innovation and access by 2018 (including involvement of civil society).

Reactions to the HLP's report have been mixed. Civil society has been largely supportive of the recommendations, although with some qualifications — including some key stakeholders disappointed that the panel did not go further. The Panel's work and report have been criticized harshly by some actors within the pharmaceutical industry and by some governments (e.g., the US government, which objects to what it characterizes as too narrow a focus on intellectual property policy issues; governments such as the EU, UK, Switzerland and Japan have generally adopted a similar stance, albeit less forcefully). Other governments have been supportive, from both high-income countries (e.g., Netherlands, Belgium, Portugal) and developing countries (e.g., Thailand issued a supportive statement on behalf of the G77 and China).

It is also worth noting that, at its session in June 2016, the Human Rights Council adopted its resolution on access to medicines (led by Brazil); this year's resolution "noted with appreciation" the decision to establish the HLP and called upon states to use TRIPS flexibilities to promote access to medicines. The HLP report was discussed at the TRIPS Council in November 2016; further discussion is anticipated (e.g., at the March 2017 session), as Brazil and India intend to continue raising the recommendations. The issue of intellectual property and access to medicines is currently before the UNAIDS Programme Coordinating Board; the report of the HLP is part of that discussion (and the Reference Group has made representations). Further discussion may be anticipated at the WHO Executive Board (January 2017) and World Health Assembly (May 2017), the next session of the UN Human Rights Council (March 2017) and the UN High Level Political Forum reviewing the SDGs (in July 2017).

The Reference Group thanked Avafia for this update, and discussed a number of points about the work of the HLP and the broader situation regarding access to medicines as an ongoing human rights concern. Reference Group member Dr. Michael Kirby, who served as a member of the HLP and the chair of its Expert Advisory Group, observed that time will tell whether the Panel was right to take the incremental approach it chose, or whether it should have been more radical in its aspirations. It was noted that while the Trans-Pacific Partnership (TPP) may be moribund for the time being, as a result of the withdrawal of the US, history tells us that the provisions sought and secured by the pharmaceutical industry and the US in those negotiations are certain to resurface in other forms and fora. It was also noted that human rights advocates have already signalled alarm with a number of the proposals being considered in the Regional Comprehensive Economic Partnership (RCEP) negotiations among 16 countries in the Asia-Pacific region.

In light of the HLP's recommendations, and the reality that the question of intellectual property barriers to treatment access remains a pressing human rights concern, Reference Group members discussed the need for continued engagement by UNAIDS on these issues. Yet there is now not even a single staff person who is the focal point on access to medicines within the UNAIDS Secretariat. While the Reference Group welcomed the statements by the UNAIDS Executive Director and Deputy Executive Director that they understood the importance of this issue, including to achieving the fast-track targets, it remained concerned that there is no clear plan on how to ensure that the capacity to work on this issue does in fact exist within UNAIDS.

It was also observed that there is a need to publicize this issue, and recommendations of the HLP, more widely; e.g., in Eastern Europe and Central Asia, where the hepatitis C (HCV) epidemic has highlighted the significance

of intellectual property policy in impeding access to treatment. The fact that some of the smaller, high-income European countries (e.g. Netherlands and Belgium) are supporting these concerns may also mean possible points of collaboration with other smaller EU countries with lower-incomes that are already struggling (e.g., Estonia, Bulgaria, Greece). Note as well that the EU action plan on HIV and hepatitis explicitly mentions the use of TRIPS flexibilities, and the discussion regarding hepatitis treatment has included critical questions regarding not just pricing but also the need for greater transparency, and different approaches to R&D. Perhaps UNAIDS and UNDP could play a role in convening interested European countries to discuss how to take the HLP recommendations forward.

Avafia noted that UNDP and UNAIDS have collaborated closely on these issues, and UNAIDS has been a vital actor in these discussions. There is a need not only for technical level work, but also for community mobilization work and for building treatment literacy (including on these issues) at the community level; UNAIDS has an important role to play here. Cabal noted that at the panel on HIV and human rights convened by UNAIDS at the Human Rights Council earlier this year, and at the panel on "leaving no one behind" at the High-Level Meeting on HIV, there were members of the High-Level Panel participating in the discussion.

The Reference Group agreed that it was essential have adequate capacity within UNAIDS to continue working on these issues. This concern must continue to be raised with senior management at UNAIDS, and the Reference Group's committee should identify specific recommendations and identify opportunities for UNAIDS to take this work forward.

SPECIAL FOCUS: ADDRESSING STIGMA AND DISCRIMINATION IN HEALTH-CARE SETTINGS

The Reference Group began its consideration of this issue with a series of reflections and presentations from Reference Group members and from Luisa Cabal and Alexandrina Iovita of the UNAIDS Human Rights and Law division.

Reference Group co-chair Joe Amon observed that stigma and discrimination are, of course, concerns that exist more widely than just in health-care settings, but they warrant specific attention in such settings given how directly they operate as barriers to achieving the 90-90-90 goals. Also, tackling stigma and discrimination in health-care settings with some concrete measures may be an easier, less controversial entry point than a broader agenda of eliminating stigma and discrimination (e.g., through legislative reform on particularly politically sensitive topics). Of course, for key populations in many settings, it is difficult to ultimately separate discussion of discrimination being a barrier to access to health services without also addressing the larger environment of criminalisation that plays into that discrimination, so it may offer opportunities to open up a broader human rights discussion as well. Addressing stigma and discrimination specifically in health care that impedes an effective HIV response is also a way to bring HIV and human rights into the broader discussions underway about universal health care and achievement of the SDGs.

Luisa Cabal reiterated that her team, particularly as it is now more limited in its capacity, would welcome input from the Reference Group on the best, priority entry points for this work. UNAIDS and WHO launched the "Agenda for zero discrimination in health-care settings" on 1 March 2017 (Zero Discrimination Day), and are convening a wide range of partners to increase collaboration among (and accountability for) countries, UN and development partners, civil society organizations, professional health-care associations, academics and others. She noted that it in advancing the "Agenda for zero discrimination in health-care settings," there is a need to undo the conflation of "stigma" and "discrimination": these terms are often used interchangeably, and there is lack of understanding of non-discrimination as a legal obligation. There is clear data showing the negative impacts of stigma and discrimination in the HIV response; i.e., poor uptake of HIV testing, denial of health care, increased loss to follow-up. It will be essential to highlight these adverse health outcomes in making the case for addressing stigma and discrimination in the health care setting. UNAIDS is focusing efforts on three key recommendations from the consultations for developing and launching the Agenda:

- 1. Political impact: increase political commitment by mobilizing all key constituencies
- 2. Accountability: promote M&E frameworks and mechanisms to build evidence, monitor progress and ensure accountability

3. Implementation: foster scale-up of implementation of effective actions to achieve discrimination-free health care

The Agenda sets out several priority areas for action. UNAIDS is helping to develop a virtual community of practice (EqualHealth4All) to share lessons, existing tools and best practices in reducing stigma and discrimination in health-care settings. It is also developing and helping to deliver training on how to implement the agenda, including collaboration with member states such as Thailand, Canada, Ghana and Kazakhstan. A UN interagency statement is also being finalized to help amplify political commitment and catalyze action to take the Agenda forward.

Iovita reviewed some of the key findings from the literature review as to what works to reduce stigma and discrimination in health care. Key lessons include the following:

- the need to focus efforts across multiple levels, not just targeting health-care workers; there needs to be an enabling environment within health-care settings, so this requires looking at institutional level interventions as well
- the need to involve all staff members in health-care settings
- the use of participatory methods and meaningful involvement of people living with HIV in initiatives
- providing training regarding stigma and universal precautions aimed at protecting safety of health-care workers
- one-off trainings are usually insufficient to effect measurable change
- the value of periodically monitoring stigma among health-care workers

There is a substantial number of tools, in varying formats, for measuring stigma and discrimination. Few of these are rooted in international human rights standards or a legal definition of non-discrimination. However, bringing health and justice together is effective as one means for addressing stigma and discrimination in health care. This includes legal empowerment initiatives; access to grievances and redress mechanisms; making health-care services an entry point for legal literacy/services; human rights legal literacy programmes for both providers and users of health care; and the meaningful engagement of communities.

Iovita noted that UNAIDS plans to include questions about stigma and discrimination in health-care settings in the GARPR, as one way to create a measure of accountability on the part of members states to follow through on commitments to eliminate stigma and discrimination.

Reference Group member Shen Tingting shared experiences from working on this issue for many years with the human rights NGO Asia Catalyst, including in China and more recently a number of other countries in the region. In 2016, the NGO took its work on stigma and discrimination in health-care settings to the regional level, publishing a report (in March 2016) documenting the situation in China, Myanmar, Cambodia and Vietnam. It is apparent that there is a definite need to build the capacity of groups working on the ground to document stigma and discrimination in health care. She shared some additional lessons:

- The work must be long-term.
- While building capacity to document stigma and discrimination, extend this work beyond just health-care settings; this expansion generates valuable data for broader advocacy as well.
- Discrimination in health-care settings is complex, with no one solution. In China, the issue is a lack of understanding of HIV, concerns by health-care workers regarding their safety which confirms, as has been noted, that it is important to not just target knowledge and attitude of individual health-care workers but also other stakeholders, especially those who can shape the health-care system and the conditions of work for service providers.
- There is a need for systematic coordination of efforts on different levels.
- In trying to bring community voice to bear on policy-makers, recognize that patients who get access to medicines or other services also then paradoxically have a disincentive to speak out about problems in the health-care system, because they risk losing that care.

It would be helpful for the Reference Group to clearly state in its recommendation to UNAIDS that it invest political and financial resources in taking this work forward, including engaging and building the capacity of country-level UNAIDS staff to advance the Agenda – as has already been discussed in relation to country-level

human rights capacity more generally. These initiatives also need to be considered for potential inclusion in the Global Fund's special catalytic initiative to scale up human rights programmes in select countries.

MEETING WITH LUIZ LOURES, UNAIDS DEPUTY EXECUTIVE DIRECTOR

The members of the Reference Group were pleased to meet again with UNAIDS Deputy Executive Director Luiz Loures and to raise a number of issues for discussion with him.

Operationalizing the commitment to human rights by and within UNAIDS: The Reference Group welcomed the commitment of UNAIDS staff to engagement on human rights, and the commitment of the UNAIDS Executive Director to ensure that human rights are integrated into the work of the organization at every level, from headquarters to the country level. The challenge is how to put this commitment into practice in concrete terms. The Reference Group reiterated its offer to work with UNAIDS at headquarters and in the field to increase human rights literacy and competence (including, for example, requiring human rights training before staff go to the field), to examine ways in which these skills and this work is appropriately evaluated and encouraged by staff, and to explore ways that staff are held accountable for taking up human rights issues in their work, as this is not consistently the case at country level). The Reference Group also reiterated its recommendation that senior UNAIDS leadership clearly support the roll-out and use of the forthcoming UNAIDS guidance document on "Fast-track and human rights" aimed at integrating human rights principles and standards into HIV prevention, testing and treatment services.

The Reference Group also wished to clarify what UNAIDS sees as the role of the Reference Group going forward. It noted its willingness to support efforts at securing funds for the human rights work of the UNAIDS Secretariat; UNAIDS could make better use of the Reference Group and of the civil society organizations to which they are connected in making the case to funders regarding the value of UNAIDS — if UNAIDS is indeed committed to being a proactive voice for human rights within the UN system.

Loures guaranteed that there would be resources to support the work of the Reference Group, whose advisory role is important. Work to address human rights is one of 3 key priorities for UNAIDS in responding to HIV (the others being civil society engagement and the development and use of strategic information and data). As the Joint Programme is in transition, with an advisory panel reviewing the model for the Joint Programme's functioning, it is important for the Reference Group to engage in that process. Beyond the review and possible reform of the Joint Programme model, the new UN Secretary General has initiated a broader comprehensive review and reform underway of the UN development system. This takes place against the backdrop of not only the new Sustainable Development Goals, but also a changing international political landscape and new fiscal constraints that likely mean increased challenges in maintaining human rights work, including by and within UNAIDS. He welcomed any opportunity for collaboration between the Secretariat and the Reference Group in looking for funds to support the human rights work of UNAIDS.

Operational considerations for the Secretariat: (1) the current capacity of the Human Rights and Law division within the UNAIDS Secretariat is being preserved and (2) the focus, particularly at the country level, is on implementing the fast-track strategy, and what this means for integrating human rights remains to be determined. Loures noted that he would welcome suggestions from the Reference Group regarding concrete actions that could be implemented quickly and easily to increase the human rights knowledge and competence of UNAIDS staff in the field. He also welcomed the Reference Group's offer to assist with training in this regard. He concurred that it was a very good idea to have a clear directive to all staff from the Executive Director regarding the use of the forthcoming guidance on fast-track and human rights. He was open to suggestions from the Reference Group regarding building up the human rights literacy of staff, including through training via various means (such as the previous global seminar on video a few years ago). He noted there are training officers within UNAIDS that could work with the Reference Group and the Secretariat's Human Rights and Law division to facilitate this activity, and that thought should be given to how to reach the whole organization.

¹³ UNAIDS, *Get on the Fast-Track* — *The life-cycle approach to HIV*, 21 November 2016. Available at www.unaids.org/en/resources/documents/2016/get-on-the-fast-track.

With respect to UNAIDS co-sponsors, Loures noted that the Global Review Panel examining the Joint Programme model would be studying questions related to "joint working" within the programme. He invited input from the Reference Group regarding the appropriate modes of working within the Joint Programme on human rights issues, noting the key role of UNDP on human rights. With regard to the existing model, Reference Group members noted that the Programme Coordinating Board demonstrated one of the fundamentally important features of UNAIDS as a joint programme: as a relatively unique governance mechanism that includes civil society, including affected communities, it offers an important means of defending human rights in the response to a global health challenge. This is one example of the value of UNAIDS that needs to be preserved, and also communicated to donors.

"Life-cycle approach": Loures highlighted for the Reference Group the commitment of UNAIDS to adopting a life-cycle approach to HIV — that is, to addressing HIV prevention and treatment in ways that are relevant to people at every stage of life, as laid out in the report released just a few weeks before. As this is an important conceptual framework for UNAIDS' work, he would welcome advice from the Reference Group as to what a human rights—based approach to HIV means across the life-cycle, and with whom UNAIDS should collaborate in addressing those issues.

Access to medicines: The Reference Group reiterated a concern it has raised on several occasions before with the Executive Director and Deputy Executive Director (including again with Sidibé at this meeting) about ensuring adequate attention to the issue of access to medicines, including intellectual property and other legal and policy questions, within UNAIDS. This is essential to achieving the 90-90-90 treatment targets, is included in the UNAIDS Strategy 2016–2021, and is an issue under active discussion not least because of the recent report of the UN Secretary General's High-Level Panel on the matter. It remains a pressing human rights issue in the HIV response and UNAIDS needs the capacity to engage meaningfully. Loures expressed the hope that UNAIDS would get strong support from the PCB for work on this issue, and agreed there was a need for more capacity on this issue across the organization.

Sex work: The Reference Group reiterated its view to Loures that UNAIDS must continue to engage UN Women, as a new co-sponsor, in adhering to the Joint Programme position on decriminalisation of sex workers, their clients and third parties. Recognizing that this is a controversial position for some donors (including some governments), Reference Group members shared their concern that the rights of sex workers not be sacrificed in the interest of preserving funding. Loures noted that UNAIDS and UNDP had shared substantial comments with UN Women on this point, and noted that the agency had not yet finalized a position on the matter.

Drug policy: The Reference Group urged UNAIDS to consider how it will sustain engagement in various forums and processes, beyond the recent UNGASS on drugs, to advance human rights and harm reduction as essential to the HIV response among people who use drugs, particularly as the in-house capacity for work on this issue is also reduced now. How will UNAIDS seek to advance the recommendations laid out in its Do No Harm report, including the goal of decriminalizing people who use drugs? For example, the Reference Group has been advised that OHCHR and the WHO are coordinating a high-level working group on the intersection between health and human rights: what is the UNAIDS presence there to ensure the human rights of people who use drugs are understood as key to their health, including in addressing HIV, and to advance key recommendations such as needed changes to drug policy to achieve health and human rights? Loures noted that UNAIDS was trying to find funds from donors for UNODC's work on HIV.

THE YEAR AHEAD: REFERENCE GROUP PLANNING AND WAYS OF WORKING IN 2017

In looking ahead to 2017, the Reference Group reviewed its discussions with various guests and with the UNAIDS senior management and identified a number of conclusions and areas for action.

The Reference Group welcomed the statements from both the UNAIDS Executive Director and Deputy Executive Director that they continued to perceive a valuable role for the Reference Group in providing strategic advice. The Executive Director has outlined his plan for a reinvigorated organization with more staff in the field, but he is facing an environment in many places marked with the rise of more conservative forces resistant to human rights. The Reference Group has a number of recommendations to put forward about ensuring that UNAIDS has a firmly embedded organizational commitment to advancing human rights and the capacity to integrate that work at all levels, including at the country level.

Review panel looking at UNAIDS model

The Review Panel struck to examine the UNAIDS model is to complete its review by April and submit a report for consideration at the June 2017 meeting of the PCB. The Reference Group co-chairs will investigate options for engaging with the review panel, and the Reference Group will at least prepare a submission to the panel. The submission will underscore how essential human rights remain to the HIV response, and the need to ensure the capacity for taking up these issues is preserved in any new model for the Joint Programme.

Engagement with OHCHR

The Reference Group appreciated the reflections from Deputy High Commissioner Gilmore and her interest in strengthening collaboration between OHCHR and UNAIDS. The Reference Group would welcome reengagement by the OHCHR in the work of the Reference Group; this re-engagement should be explored, as should the possibility of drawing upon the expertise of OHCHR in building up human rights capacity within UNAIDS as an agency.

Human rights capacity within UNAIDS

The Reference Group will communicate again to the UNAIDS leadership its strong view on the need to preserve and build human rights capacity within UNAIDS through its restructuring, including at the country level and in regional teams. The Reference Group is available to assist in this regard. The Reference Group also proposes that UNAIDS consider internal mechanisms and incentives for making human rights systematically part of the agency's functioning (e.g., making human rights competency part of staff development and performance appraisals). The Reference Group will prepare a package of proposals to UNAIDS in this regard. Some Reference Group members are also available and willing to serve as resource persons to UNAIDS in their regions to assist with this work.

Fast-track and human rights

It was agreed that Reference Group members would provide any further comments on the draft Guidance Note on fast-track and human rights by December 19, 2016. The guidance will be finalized and launched by UNAIDS in early 2017. The Reference Group has urged the UNAIDS Executive Director to communicate his full support for the guidance when it is launched, including directing staff to incorporate it into their work as relevant.

Engaging faith communities and leaders

Given the rise of conservative resistance to human rights, particularly for key populations, often emanating from some faith communities and leaders, it is important that UNAIDS engage on this front. There are multiple initiatives that could be taken. The Reference Group agreed to have a call with Sally Smith who coordinates this work at UNAIDS to learn about the current priorities on this front and return with concrete ideas for consideration by the Reference Group and UNAIDS.

Sex work, human rights and HIV

The Reference Group agreed it will prepare an open letter to UN Women, to be shared with the UNAIDS Executive Director, emphasizing the importance of decriminalisation of sex workers, their clients and third parties as part of an effective response to HIV. The Reference Group will underscore the existing common position of the Joint Programme in this regard.

Drug policy, human rights and HIV

The Reference Group is concerned that any model law on drugs produced by UNODC should indeed reflect a human rights approach and provide appropriate guidance to states accordingly. It will follow up with UNODC as may be feasible to underscore this concern, including possibly providing comments on the latest draft of said model law. As communicated to UNAIDS senior management, the Reference Group supports the initiative to develop international guidelines on human rights and drug policy and is of the view that UNAIDS should support it institutionally as well.

Life-cycle approach

The Reference Group discussed briefly the new UNAIDS report on "the life-cycle approach to HIV," in light of discussions with the UNAIDS Deputy Executive Director inviting input from the group. It was noted that at the moment human rights issues are addressed under the heading of "key populations," but in fact human rights issues are relevant across the life cycle, and not just for key populations. The Reference Group was of the view that UNAIDS' current focus on applying this lens of a "life-cycle approach" should not be allowed to distract from the group's priority concerns (and the priorities of the in-house Human Rights and Law division), but that it would be worthwhile to assist UNAIDS in understanding how human rights issues can, and should, be addressed throughout the life cycle.

Access to medicines

The Reference Group noted the PCB's weak Decision Point just adopted on this matter. The PCB simply "takes note" of the report of the UN Secretary General's High-Level Panel and requests UNAIDS to "facilitate further discussions" bearing in mind the HLP report and the earlier WTO/WHO/WIPO trilateral report on the matter. It also requests UNAIDS to identify data gaps, and better support countries in addressing IP and other barriers to access to medicines. The Reference Group remains concerned that, it has not yet received clarity from UNAIDS senior management on what will be done to sustain work on intellectual property and access to medicines. The Reference Group and its subcommittee will need to pursue the matter further with UNAIDS, including referring to its recommendations to UNAIDS that it presented in its statement to the PCB.

Young people and HIV

Reference Group members remain unclear about what work UNAIDS is doing to address HIV among adolescents, and where responsibility for this lies within the Secretariat. It was agreed that this would be an item for discussion at the next meeting of the Reference Group.

Gender and human rights

As noted earlier in the meeting, human rights and gender work are now combined within the Secretariat as the responsibility of Luisa Cabal's team. She invited Reference Group members to write to her with any input or suggestions as she and her team sort out their priorities within this new, combined portfolio.

CLOSING SESSION

In closing, the Reference Group co-chairs and members thanked the UNAIDS Secretariat staff and particularly the staff of the Law and Human Rights team for their continued work. On behalf of UNAIDS, Luisa Cabal thanked the Reference Group for its important moral and technical support in keeping human rights on the agenda within UNAIDS.