ISSUE PAPER FOR DISCUSSION PURPOSES ONLY:

Monitoring progress towards universal access to HIV prevention, treatment, care and support

Background

1. At its eighth meeting in December 2007, the Reference Group discussed both:
   - the need to clarify and articulate what processes, programmes and outcomes are required from a human rights perspective as part of governments' commitment to universal access; and
   - the need to continue work to ensure that indicators of universal access are both qualitative as well as quantitative; that a human rights analysis of UNAIDS' main indicators is undertaken; and that stand alone human rights indicators are established.

2. The Reference Group decided to establish a sub-committee on universal access and gave it the mandate to:
   - develop a short statement to guide states and civil society on universal access
   - assist UNAIDS Secretariat/UNDP in developing a list of “essential human rights activities” for universal access
   - continue providing input in the development of indicators.

Developments since the last meeting of the Reference Group

2008 UNGASS Reports

3. In June 2008, global progress towards the implementation of the Declaration of Commitment on HIV/AIDS (2001) was assessed at a high-level meeting on HIV in New York. Governments were requested to submit Country Progress Reports by 31 January 2008 to inform discussions at this meeting. In general, the country reports that were submitted show that countries have utilized the universal access process as a way to accelerate their national responses. Many countries report having made good progress in responding to the HIV epidemic, especially in providing anti-retroviral treatment, prevention of mother-to-child transmission and access to HIV testing and counseling. However, they report significant less progress on other HIV prevention efforts. Progress towards ensuring the care of orphans and vulnerable children also remains poor in many countries. Particularly worrying from a human rights perspective is that key vulnerable and marginalized populations are barely being reached in many countries.

4. In the National Composite Policy Index (NCPI), governments report increased attention in policies, laws and plans to address human rights issues in national responses:

---


2 The NCPI was part of this reporting process. It contains a human rights section which includes 15 questions (all of which require yes/no answers) concerning the existence of policies, programmes and laws that support human rights in national AIDS responses. See UNAIDS (2007), Guidelines on Construction of Core Indicators: Monitoring the Declaration of Commitment on HIV/AIDS. Available on-line at http://data.unaids.org/pub/Manual/2007/20070411_ungass_core_indicators_manual_en.pdf
The overwhelming majority of countries who provided information in the human rights section of the NCPI (94%) report that their HIV policy or strategy explicitly mentions the promotion and protection of human rights, and almost all countries (95%) report a stable or improving rating for their legal and policy frameworks addressing the promotion and protection of human rights in their HIV efforts.

As compared with 2003 and 2005 data, significant improvements are reported in the availability of HIV related legal services across the globe. 58 countries (48%) report the availability of these services. 94 countries (77%) report the existence of programmes designed to educate and raise the awareness of people living with HIV about their human rights.

Since 2005, the proportion of countries who report providing training to their judiciaries on HIV and human rights issues in Sub-Saharan Africa has increased from 70% to 74%. However, over the same period, the proportion of countries reporting such training decreased in Eastern Europe and Central Asia (from 38% to 13%), Latin America (from 57% to 43%), and South/South East Asia (from 75% to 38%).

A 2007 survey of UNAIDS Country Coordinators (UCCs), which like the NCPI reports has not been independently verified, indicates that campaigns against stigma and discrimination were included in 89% of national strategies or action plans of 66 countries surveyed. Similarly, training for health care workers on confidentiality, informed consent, non-discrimination and gender issues was included in 89% of the plans.

The same survey found that only 25% of the countries surveyed had included legal aid services or programmes to enforce/protect women’s property rights in the context of HIV in their strategies, and only 36% of the plans included programmes to transform harmful gender norms to reduce gender-based vulnerability to infection. Programmes to address violence against women and programmes to address women’s economic empowerment (e.g. access to credit, land, training) were included in 48% and 46% of the plans respectively.

5. There are many limitations to the data provided by countries. In particular, “yes/no” questions and the answers to them do not provide any information about the number of such policies or programmes, their size and coverage, their quality, or whether they have in fact been costed, budgeted, implemented or evaluated.

6. A majority of countries (67%) report that laws and regulations are in place to protect people living with HIV from discrimination, and 73% of countries report the existence of laws and regulations that specify protections from discrimination for most-at-risk populations, but only 26% report protections for men who have sex with men; 21% report protections for sex workers; and 16% report protections for people who inject drugs. In addition, many countries (57%) report the existence of laws and policies that present obstacles to their ability to provide effective prevention, treatment, care and support for most at risk populations. Increased attention is therefore needed to revise laws and policies that present obstacles to an effective AIDS response, and to ensure that these laws and policies are implemented.
7. Only 22 percent of countries report using performance indicators or benchmarks to measure compliance with human rights standards in the context of their HIV efforts.

Civil Society Monitoring

8. In addition to the data provided in country reports, work undertaken by civil society organizations underscored some of the human rights concerns. A research study commissioned by the International Council of AIDS Service Organizations (ICASO) highlighted the following concerns:
   - Even where countries report having achieved significant progress, for examples in increasing provision of antiretroviral treatment, “levels are still far from those required to save many millions of lives”.
   - In some countries, community sector involvement in country reporting remains minimal or tokenistic. In many countries, civil society is only invited to “legitimize” the process.
   - Issues relating to human rights and legal protection continue to “fall through the cracks” of national responses to AIDS. Indicators largely fail to ensure that the monitoring of the Declaration of Commitment plays a significant role in improving the environment for rights-based approaches.
   - In some cases, the lack or poor quality of information relating to most-at-risk populations is influenced by underlying stigma and discrimination and reflects a country’s lack of recognition of, or commitment to, supporting such populations.

9. The review also pointed out that quantitative data as provided by countries in their reports “can only ever tell part of the story. While a number can state how many people are accessing a service, it can not explain why others are not – for example, due to stigma. Until such qualitative issues are addressed, there will only ever be limited progress in meeting commitments to addressing HIV and AIDS”. Finally, the review highlighted that capacity for monitoring and evaluation remains low within the community sector and significantly limits its potential to engage in high level national processes such as reviewing progress towards the Declaration of Commitment.

10. The review recommended that governments “strengthen national indicators on human rights, especially of people living with HIV and other key populations – to enable [Declaration of Commitment] implementation monitoring to play a more significant role in promoting a rights-based response to AIDS”.

11. A special report on men who have sex with men, HIV and universal access, released at the International AIDS Conference in Mexico City, provides a detailed analysis of how one of the groups most at risk of HIV infection in many countries nevertheless continues to have little or no access to HIV services of any kind. For example, HIV programmes targeted to men who have sex with men comprise less than 1% of total HIV spending in Latin America – despite the fact that they

---


are severely affected by the HIV epidemic in many countries in the region. The report highlights how in many countries, institutionalized homophobia and criminalization of homosexual activity facilitate the spread of HIV by severely hindering efforts to provide treatment and prevention for men who have sex with men.

The Reference Group statement on Universal Access

12. In June 2008, the Reference Group wrote a letter to Peter Piot, and made a public statement. In the letter, the Reference Group expressed concern that human rights risked being once again marginalized at the High Level Meeting, instead of being discussed seriously with a view of moving from rhetoric to vastly scaling up programmatic action on human rights and HIV. In the public statement, the Reference Group highlighted that the goal of universal access to HIV prevention, treatment, care and support is a human rights imperative in every respect, and that countries and the international community need to dramatically scale up efforts to make good on their commitments. In particular, the Reference Group said that action is needed in the following areas:

- setting ambitious targets and including all populations at risk
- ensuring meaningful civil society participation
- scaling up programmatic responses promoting human rights and gender.

13. The Reference Group concluded by saying that “monitoring and evaluation of universal access targets and country plans should include a detailed assessment of how well country processes, programmes, and policies adhere to human rights”. It made a commitment to developing more detailed guidance on universal access and human rights, “providing detailed guidance about what human rights require in terms of setting goals for universal access, processes, and programmes”.

The way forward

14. In addition to the ongoing need to focus on scaling up access to HIV treatment, care and support, the 2008 data suggest a need, from a human rights perspective, to increase focus on HIV prevention and, in particular, for populations most at risk of HIV. This issue is addressed in more detail in Issue Paper 3.

15. The 2008 UNGASS data also points to the importance of much greater attention to human rights in national and global responses to HIV, through political commitment, funding, and implementation of programmes that both integrate human rights principles and that are specifically designed to overcome rights-based obstacles to universal access. Issue Paper 2 addresses such programmes in greater detail and represents a first step towards clarifying what are the programmes that support human rights in national AIDS responses, and what processes are fundamental for rights-based approaches to implementation and monitoring.

16. As work proceeds, it will be crucial to:

- ensure that these efforts – to increase access to HIV prevention, particularly for most-at-risk populations, and to increase programmatic action on human rights – are appropriately monitored; and
devote attention to the period following the 2010 Universal Access target, when Declaration of Commitment reporting obligations end. Many countries will likely remain far from achieving universal access to HIV prevention, treatment, care and support, and the UNGASS monitoring framework will remain a relevant accountability framework in the context of advancing towards the realisation of the Millennium Development Goals. However, a renewed political mandate may be necessary to ensure broad consensus on the continued use of the UNGASS monitoring framework.

Questions for discussion
a. What key recommendations should the Reference Group make to the incoming UNAIDS Executive Director related to monitoring universal access and how to ensure that commitments made (both to universal access and to monitoring and reporting on progress made) will continue to be relevant after 2010?

b. In which ways can monitoring of fundamental human rights aspects of national responses be improved, and how can such monitoring best be integrated in existing and future monitoring efforts?

c. How can the Reference Group statement best be expanded to include more detailed guidance about what human rights require in terms of setting goals for universal access, and related processes and programmes?

Supporting documents
- Letter to Peter Piot of 6 June 2008 on “Human Rights and Universal Access at High Level Meeting”
- Reference Group Statement on “Human Rights & Universal Access to HIV Prevention, Treatment, Care & Support”

This issue paper was prepared by the Secretariat to the UNAIDS Reference Group on HIV and Human Rights, with support by the UNAIDS Human Rights and Law team.

Please do not reproduce, redistribute or cite.
Annex 1: TOOLS USED FOR MONITORING PROGRESS TOWARDS UNIVERSAL ACCESS

To date, the following tools appear to be used to measure progress – qualitative or quantitative – towards universal access to HIV prevention, treatment, care and support.

1. UNGASS and National Composite Policy Index (NCPI) reporting: This is the main reporting tool for progress towards universal access.

2. CRIS (Country Response Information System): Universal Access targets have now been included in the CRIS data collection and management tool. This provides countries the option of including and monitoring the evolution of national universal access targets to be entered into the database, which will allow for easier monitoring of country progress towards universal access targets.

3. UNAIDS Country Coordinator survey (annual and mid-year): These surveys enable the collection of qualitative information regarding universal access processes at the country level. The annual survey contains some questions relating to universal access progress and processes which are collected for inclusion in the UNAIDS annual report. In addition, mid-year surveys have been carried out focusing on more specific aspects of progress towards universal access, such as progress towards addressing obstacles to scale up. The mid-year survey is typically sent out at regular intervals between the annual UCC survey although in 2008, will be integrated into the annual UCC survey.

4. WHO instruments to monitor universal access (progress towards targets set by WHO for health sector): Since the World Health Assembly in 2006, WHO is mandated to monitor and report annually on global progress in the health sector response to HIV/AIDS towards universal access by 2010. To implement this, WHO has developed a core framework of recommended national level indicators on the health sector response to HIV/AIDS to facilitate global monitoring and reporting. The framework (published in November 2007) includes indicators to measure the availability and coverage of interventions, as well as their outcomes and impact in terms of survival and improvements in quality of life. The selection of indicators has been guided by the principle of maximum alignment with existing international processes. National programmes are requested to report data on an annual basis and data from national programmes are aggregated and analyzed to produce an annual global progress report.

- **Key resources:**
5. **UNICEF Prevention of Mother to child transmission scorecard:** In 2005, the UNAIDS Monitoring and Evaluation Reference Group (MERG) defined a set of indicators for monitoring national programmes for the prevention of HIV infection in infants and young children. The standard questionnaire was administered through all UNICEF country offices. The questionnaires utilised closed questions to collect quantitative and semi qualitative national level data aggregated from all sites and all in-country implementing partners for the period January to December 2005. In 2007, the Expanded Inter-Agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children analysed the results of the data collected through the use of the scorecard and produced a working paper which attempts to measure where the world is in meeting its commitments to the thousands of children exposed and infected annually.


6. **International Treatment Preparedness Coalition:** ITPC is a leading civil society coalition of treatment activists. ITPC sees the push for access to AIDS treatment as a wedge to mobilize communities and other stakeholders around broader issues while always maintaining a focus on achieving the goal of universal access by 2010. ITPC carries out independent research and systematic analysis of the barriers to scale up ‘from the perspective of advocates not wedded to the fortunes of any particular agency or organization’. It has produced six issues of the report ‘Missing the Target’ since 2005. These reports identify barriers to scale up to universal access to treatment in selected countries and also identify strengths and weaknesses in the responses of international organizations. Reports can be found at: [http://www.aidstreatmentaccess.org/](http://www.aidstreatmentaccess.org/)

7. **Tools developed by World AIDS Campaign (WAC) and the Global Network of People Living with HIV (GNP+) to measure stigma and discrimination and human rights violations:** WAC and GNP+ are developing tools to measure stigma and discrimination and human rights violations, including documenting and analyzing experiences in criminalization of HIV transmission and human rights violations against people living with HIV. While these do not directly measure progress towards universal access, such tools can be used to collect data that is relevant to measuring country success in addressing obstacles to universal access.