Defining the Issue

1. With an estimated 6,800 new infections every day, over 5,700 people dying from AIDS, 11.4 million children orphaned due to AIDS in sub-Saharan Africa, and a range of devastating impacts for individuals, families and entire communities, the goal of universal access to prevention, treatment, care and support is a human rights imperative in every respect. National consultations on universal access convened in late 2005 and early 2006 identified the major barriers to reaching the goal, and Governments made clear commitments in the 2006 Political Declaration on AIDS to overcoming those barriers. The commitments detailed in the Declaration of Commitment and the 2006 Political Declaration provide an unprecedented framework of accountability for achieving human rights goals in the context of the epidemic. We are far short of these goals, however, and with little more than two years remaining until 2010, countries and the international community need to dramatically scale up efforts to make good on their commitments. What is needed now is for UNAIDS and civil society to promote universal access as a human right, and devise ways to monitor steps toward it to ensure obstacles are overcome and promises are kept.

2. Human rights goals can be achieved through various programmatic and policy means: (a) implementation of sufficient programmes on HIV prevention, treatment, care and support that reach all those in need, (b) implementation of

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2 Specific commitments in the Political Declaration include: “overcoming legal, regulatory or other barriers that block access to commodities and services; promoting access to HIV education and information, full protection of confidentiality and informed consent; intensifying efforts to ensure that a wide range of prevention programmes, including information, education and communication, aimed at reducing risk-taking behaviours and encouraging responsible sexual behaviour, including abstinence and fidelity; expanded access to essential commodities, including male and female condoms and sterile injecting equipment; harm-reduction efforts related to drug use; expanded access to voluntary and confidential counselling and testing; safe blood supplies; and early and effective treatment of sexually transmitted infections; intensifying efforts to enact, strengthen or enforce, legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV and members of vulnerable groups; developing strategies to combat stigma and social exclusion connected with the epidemic; eliminating gender inequalities, gender-based abuse and violence; increasing the capacity of women and adolescent girls to protect themselves from the risk of HIV infection; ensuring that women can exercise their right to have control over, and decide freely and responsibly on, matters related to their sexuality; taking all necessary measures to create an enabling environment for the empowerment of women and strengthen their economic independence; reiterating the importance of the role of men and boys in achieving gender equality; eliminating all forms of discrimination, as well as all types of sexual exploitation of women, girls and boys, and all forms of violence against women and girls, including harmful traditional and customary practices, abuse, rape and other forms of sexual violence, battering and trafficking in women.”

law and policies that provide a supportive framework to enable those in need to take up available services, and (c) implementation of programmes that are specifically designed to overcome rights-related obstacles, such as discrimination and stigma against people living with HIV and populations at risk, gender inequality and violence against women. These programmes include, for example, “know your rights” campaigns, provision of legal aid, campaigns against harmful gender norms and violence against women, campaigns against stigma and discrimination, and programmes working with police and health care workers on behalf of marginalized populations, training of health care workers in informed consent and confidentiality.

3. Monitoring systems and accountability mechanisms must track progress and catalyse action in these three areas. However, to date, they have focused primarily on (a); to some degree on (b); and almost none on (c). While there have been improvements to monitoring tools, there is still little agreement on “human rights indicators”, and there is need for better information that shows what populations are affected and how, and gives insight into the quality of HIV programmes and services. Civil society has been playing an increasingly active role in monitoring, but challenges remain in terms of better supporting their involvement, and ensuring they are at the table when important decisions are made.

Monitoring universal access through UNGASS indicators

4. Under the Declaration of Commitment on HIV/AIDS (2001), Member States are required to submit country progress reports to the UNAIDS Secretariat every two years, and the next set of reports are due 31 January 2008. UNAIDS provides technical assistance to countries to strengthen their monitoring and evaluation capacity, including in the preparation of UNGASS reports. In the last reporting exercise (2005), 137 Member States (72%) submitted Country Progress Reports. Of these reports, 40 were from sub-Saharan Africa, 21 from Asia and the Pacific, 32 from Latin America and the Caribbean, 21 from Eastern Europe and Central Asia, 5 from North Africa and the Middle East and 18 from high-income countries. It is anticipated that the number of reporting States will increase this year, in both low- and middle-income countries as well as high-income countries.

5. While universal access is in a sense a new commitment, monitoring universal access is complimentary with monitoring the implementation of the UNGASS Declaration of Commitment. UNGASS indicators are divided into four categories:

- **National commitment and action** – These indicators focus on policy and the financial resources made available for national responses to HIV.

- **National programmes** – These indicators measure the coverage of essential services in the national response. These include programmes for the prevention of the spread of HIV infection, the provision of care and support for people who are infected, and the mitigation of the social and economic consequences of high levels of morbidity and mortality due to AIDS.

- **National knowledge and behaviour** – These indicators cover a range of specific knowledge and behavioural outcomes, including accurate knowledge about HIV transmission, age at first sex, sexual behaviours and school attendance among orphans.

- **National-level programme impact** – These indicators, such as the percentage of young people infected with HIV, focus on the extent to which national
programme activities have succeeded in reducing rates of HIV infection and its associated morbidity and mortality.4

6. The current round of UNGASS reporting is significant as it will provide the foundation of the “mid-term” assessment of progress towards universal access. UNGASS indicators, including the National Composite Policy Index (NCPI), continue to provide the basis for assessing progress, including in terms of human rights. They have been reviewed after each round of reporting to assess their performance, and where necessary, have been revised to take into account methodological concerns, reflect new programme developments, and better address human rights issues (e.g. quality and level of policy implementation). While an important tool to assess progress, there are concerns that accountability mechanisms must be strengthened much further – both in terms of content and process – if countries and the international community are truly going to be able to track progress. To take full advantage of the framework of accountability, there needs to be:

- Implementation of essential human rights, law and gender equality programmes within comprehensive, multisectoral national AIDS responses
- Identification of indicators that measure whether prevention, treatment, care and support programmes reflect human rights principles (e.g. informed consent, participation, inclusion, non-discrimination, accessibility, availability, affordability and quality)
- Support to civil society to measure stigma and discrimination and other human rights abuses in the context of HIV, and have these findings influence programming
- Support to national decision-makers and international development partners to act on rights-related information to overcome barriers to universal access.

The road towards universal access: target setting and National Strategic Plans

7. As of November 2007, 123 countries have held national consultations on obstacles to universal access to prevention, treatment, care and support. Some 101 countries have set targets for universal access, and approximately 60 of them have incorporated these into National Strategic Plans. National plans should bring together the efforts of Government, civil society, the private sector and international partners, and should include specific measures to overcome the obstacles to universal access identified in national consultations, including stigma, discrimination, gender inequality, and marginalization of populations at risk.

8. The UNAIDS Secretariat has taken preliminary steps to review National Strategic Plans5 put in place after universal access consultations to assess whether they

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5 At the time of writing, 42 National Strategic Plans were available to the UNAIDS Secretariat for review: Asia and the Pacific, 11 countries (Bangladesh, Cambodia, China, India, Laos, Malaysia, Myanmar, Nepal, Philippines, Sri Lanka, Thailand); Europe, 11 countries (Armenia, Belarus, Croatia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Moldova, Tajikistan, Ukraine); Latin America and the Caribbean, 3 countries (Belize, Jamaica and Peru); Middle East, 1 country (Iran); Sub-Saharan Africa,
are comprehensive and seek to address the obstacles to universal access. An initial framework for analysis of these plans was developed, with the UNAIDS human rights and law team adding parameters so as to identify whether specific programmes are envisioned that seek to overcome some of the human rights-related obstacles. These included: legal support for people living with HIV and members of vulnerable groups; legal audits and law reform; “know your rights” campaigns; training for key service providers in human rights and non-discrimination; and programmes to address harmful gender norms.

9. Preliminary findings show that many National Strategic Plans include programmes to reduce stigma and discrimination (35 of 42, or 83%), and carry out law reform or legal audits (83%). Considerably fewer, however, refer to programmes to address harmful gender norms (22 of 42, or 52%). It is difficult to generalise these preliminary findings as they are based on a relatively small subset of countries, which may be countries with greater capacity and commitment. There are also inherent limitations to such analysis. National Strategic Plans do not necessarily give insight into the quality or intensity of programmes, nor the Government’s capacity to implement. Furthermore, they do not generally include the level of programmatic detail necessary to assess if they are truly comprehensive and geared towards dealing with the many drivers of the epidemic in various communities within a country. Nevertheless, this small effort was a first attempt to assess whether National Strategic Plans include specific human right programmes towards the achievement of universal access.

Monitoring universal access by civil society
10. Civil society has made valuable contributions to UNGASS monitoring, both from within officials processes and from outside them. Shadow reports produced by civil society have been useful for identifying gaps and shortcomings in national responses, and serving as an advocacy tool at national level. They give voice to those most affected, and present their realities and priorities. Shadow reports also bring in data from civil society projects and HIV programmes that may not be reflected in or integrated into national monitoring and evaluation frameworks.

11. In a number of countries, however, civil society has expressed concern that the official reporting process has excluded them, or brought them into the process too late. At times processes have been more confrontational than constructive, have failed to be fully representative, and have not acknowledged the many contributions of civil society to advancing national AIDS responses. Nor is it clear that civil society actors are monitoring for the specific human rights programmes that many national responses do not include.

12. The 2005 UNGASS reporting process included significant effort to support civil society development of shadow reports. Groups involved in this work included the International Council of AIDS Services Organizations (ICASO), Care, Open Society Institute (OSI), Latin America and the Caribbean Council of AIDS Service Organizations (LACCASO), and PANOS. Support to civil society involvement in

16 countries (Angola, Benin, Burundi, Ethiopia, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, Seychelles, South Africa, Swaziland, Uganda, Zambia).

Civil society groups in approximately 40 countries produced shadow reports. ICASO (14): Cameroon, Canada, El Salvador, Honduras, Indonesia, Ireland, Jamaica, Morocco, Nepal, Nigeria, Peru, Romania, Serbia (and Montenegro), and South Africa; LACCASO (5): Argentina, Brazil, Chile, Paraguay, and Uruguay, and 5 from Andean countries; Care (6): Cambodia, Kenya, Malawi, Thailand,
2007 reporting is being expanded, based on experiences and lessons learned in the 2005 reporting. Many groups involved in 2005 reporting are prepared to be involved in the development of official government reports next year, and additional groups are working on shadow reports. Supporting such involvement in reporting remains a challenge, however. There is still low knowledge of the Declaration of Commitment in many places, lack of clarity about national monitoring and reporting processes, and limited time and capacity within civil society for monitoring efforts.

13. Beyond the UNGASS reporting process, there are other opportunities to support civil society-led monitoring and accountability efforts. For example, since early 2004 the UNAIDS Secretariat has been working with the International Planned Parenthood Federation (IPPF) to support work by networks of people living with HIV to develop an index on human rights, stigma and discrimination, by and for positive people. UNAIDS helped convene two meetings (March 2004, London; August 2005, Geneva) comprising people working on indices on HIV-related human rights, stigma and discrimination; representatives of groups of people living with HIV; and other technical experts, to share information on work underway or planned in this area. Participants at the August 2005 meeting articulated the following five key objectives:

- Increasing capacities to assess and measure change related to stigma and discrimination in the context of the epidemic
- Increasing understanding of the causes and effects of stigma and discrimination
- Increasing understanding of the means to reduce stigma and discrimination
- Increasing empowerment, involvement and capacities of people living with HIV in the response
- Increasing the pool of information useful for advocacy, policy and programme design and implementation

14. In October 2006, a small training meeting was convened in Johannesburg with representatives of networks of people living with HIV from five countries (India, Kenya, Lesotho, South Africa and Trinidad and Tobago) who carried out a small pilot to test the survey tool. The tool has been finalised based on feedback from the pilot, and IPPF has since recruited a programme officer to support national positive networks to use the Stigma Index survey tool. One bilateral donor has contributed funding to support the project, and others have expressed interest.

15. Supporting the use of the Stigma Index tool is a resource-intensive activity, but one that promises benefits far beyond the data that is produced. It has been stressed since the beginning of this work that the process by which this tool is developed and implemented is as important as the results obtained. All partners have agreed that it is essential that the process is driven by people living with HIV, and largely implemented with or by their networks, with technical input from international organizations, NGOs and others. For networks using the tool, it is an opportunity to build human rights capacity. For participants in the survey, the questionnaire provides an opportunity for increasing “human rights literacy”.

United Kingdom, and Viet Nam; OSI (6): Nicaragua, Senegal, Ukraine, the United States, Vietnam and Zambia; PANOS (6): Bangladesh, Haiti, Latvia, Malawi, Pakistan, and Sri Lanka.

Taking the project to scale, however, and linking findings to processes that will influence change, including towards universal access, will require significant additional resources. It will also require commitment on the part of the international community and national governments to ensure findings are used to inform advocacy and programming efforts, and promote accountability for human rights commitments in the response to AIDS.

Questions for discussion
a) What are the critical structures, programmes and outcomes that are significant in human rights terms and need to be monitored in the context of universal access?
b) What can UNAIDS do to better monitor human rights elements of universal access?
c) How can UNAIDS better promote universal access as a human right?
d) How can civil society be better supported to participate in national monitoring and evaluation processes, and in ways that promote human rights literacy?
e) What can the international human rights community do to support national networks of people living with HIV, make maximum use of the findings of the stigma and discrimination survey, and build findings into monitoring of universal access?

Supporting documents

Additional resources