



Issue Paper: *HIV/AIDS Indicators: Potential Role of the Reference Group*

Defining the Issue

A number of international bodies and organizations use indicators that specifically relate to HIV/AIDS and human rights issues. For the sake of discussion, these indicators can be organized into four major categories: 1) indicators based on the Declaration of Commitment on HIV/AIDS from the United Nations General Assembly Special Session on HIV/AIDS (DOC); 2) indicators that focus on stigma and discrimination within the context of HIV/AIDS; 3) indicators used by human rights organizations and human rights bodies to examine the degree to which governments are respecting, protecting and fulfilling rights in the context of HIV; and 4) HIV programming indicators that are sensitive to human rights issues. Examples of each of these are described briefly below. While these indicators coexist, they in fact have been constructed for diverse purposes and measure different things. Clarity is therefore needed as to their similarities and differences, and gaps identified to determine what is not measured but should be through current approaches.

Background

Core Indicators for Implementation of the Declaration of Commitment (DOC)¹ The core indicators outlined for implementation of the DOC include four indicators specifically identified as relevant to human rights. These indicators measure whether or not a country has:

- laws and regulations that protect against discrimination of people living with HIV/AIDS,
- laws and regulations that protect against discrimination of groups of people identified as being especially vulnerable to HIV/AIDS,
- a policy to ensure equal access for men and women to prevention and care, with emphasis on vulnerable groups, and
- a policy to ensure that HIV/AIDS research protocols involving human subjects are reviewed and approved by an ethics committee.

These indicators, while broad in scope, have limitations. For example, they measure whether or not policies are in place and do not attempt to explore the quality or degree of implementation.

There may also be questions as to whether these indicators are sufficient to capture human rights issues in the context of HIV/AIDS or even the human rights concerns intended, but they do potentially provide useful information. Other Core Indicators should be examined in light of the fact that they may have relevance to human rights but have not been constructed from a human rights perspective. According to the DOC, these indicators have been grouped to measure global commitment and action, national commitment and action (e.g., policy, strategic and financial inputs for prevention, care and support), national program and behavior (e.g., program outputs, coverage and behavioral outcomes) and national program impact (e.g., reduced rates of HIV infection). The 2003 DOC Progress Report describes the current status of implementation of

these indicators. For example, global HIV/AIDS advocacy efforts (indicator number 5 under “global commitment and action”) have been assessed through an analysis of media stories, particularly those that concentrate on stigma and discrimination.

Indicators on Stigma and Discrimination within the Context of HIV/AIDS A number of measurement instruments have been developed in the past few years ostensibly to assess both stigma and discrimination within the context of HIV/AIDS. A quick survey of these indicates that many predominantly focus on stigma. The UNAIDS General Population Survey, the Demographic and Health Survey AIDS Module, Family Health International’s Behavioral Surveillance Survey (both the adult and youth modules), and UNICEF’s Multiple Indicator Cluster Survey (MICS)² are examples of instruments that survey individuals in communities and include questions measuring stigma. In these instruments, “accepting attitudes towards those living with HIV” are measured through a range of questions. Another example is a set of instruments developed by an international NGO that aims to assess *both* stigma and discrimination in the workplace, family and community but largely concentrates on assessing individual attitudes towards persons with HIV or AIDS.³

In contrast, UNAIDS has produced a tool that specifically measures *discrimination* against persons based on their confirmed or suspected HIV serostatus or state of health in a range of key areas of everyday life. The *Protocol for the Identification of Discrimination against People Living with HIV*⁴ focuses on sources of institutional discrimination occurring in law; internal regulations and procedures of public and private bodies, organizations or groups; and practice. Indicators in the Protocol assess arbitrary discrimination in ten major areas of social life: health care, employment, justice/legal process, administration, social welfare, housing, education, reproductive and family life, insurance and other financial services, and access to other public accommodations or services (e.g. funeral services).

In follow-up to its collaborative project with Siyam’Kela in South Africa, Mexico’s National Institute of Public Health (INSP) initiated a project in August 2002 designed to reduce both stigma and discrimination related to HIV/AIDS throughout the country. The INSP conducted an extensive review of stigma and discrimination indicators in the literature and then developed indicators to measure stigma and discrimination within the following focal areas:⁵

- internal and external stigma in persons living with HIV/AIDS (e.g., persons who are afraid of asking their doctor, or being asked by them, questions about their sexuality or sexual life)
- provision of health services to persons living with HIV/AIDS and affected communities in Mexico (e.g., barriers to access and use of testing facilities, counseling, and treatment)
- laws and policy situation of discrimination for persons affected by HIV/AIDS (e.g., laws and regulations, involvement of PLHAs in advocacy efforts)
- images of PLHAs in the media (e.g., journalists who sign an ethical code of conduct related to HIV/AIDS).

Human Rights Indicators Used to Examine the HIV/AIDS Epidemics Human rights indicators derive from, reflect, and are designed to monitor realization or otherwise of a specific human rights norm, usually with a view to holding a duty-bearer to account.⁶ With respect to HIV/AIDS, states may be assessed on the extent to which their national and local HIV/AIDS policies, strategies and programs are rights-based, or the extent to which financial, technical and human resources are allocated in order to support rights-based approaches to HIV/AIDS. The Committee on the Rights of the Child, for example, recommends that special attention be given

to assess the extent to which HIV-related rights of children are dealt with in laws, policies and practices, with specific attention to discrimination against children on their basis of their HIV status or that of their family members.⁷ The focus of the Committee on Economic, Social and Cultural Rights (CESCR), on the other hand is on “discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement on the grounds of race, color, sex... [and] health status (including HIV/AIDS).”⁸

The Sensitivity of HIV Indicators to Human Rights Issues Many of the instruments in existence to assess HIV/AIDS programs and national responses include, at most, a limited focus on human rights issues – most notably stigma, as described above. Their focus centers primarily around HIV prevalence, reduction of risk, and the availability of services for HIV and other sexually transmitted infections. Further, many HIV/AIDS instruments do not yet measure which specific population sub-groups, with the exception of pregnant women, have access to services, care and treatment, and support, nor do they measure with respect to different population subgroups, the availability, accessibility, acceptability, and quality of the services being monitored – key rights-related aspects identified by the CSECR.⁹

In addition, the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA), which draws its strength from the right to participation, has been recognized as critical to effective HIV programming. UNAIDS has provided guidance for fully implementing GIPA into national policies and programs.¹⁰ However, the full spirit of this guidance has not yet been incorporated into most HIV policy and program indicators, such as those included in *National AIDS Programmes: A Guide to Monitoring and Evaluation*.¹¹

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¹ UNAIDS. (August 2002). *Implementation of the Declaration of Commitment on HIV/AIDS: Core Indicators*. UNAIDS: Geneva.

² <http://www.cpc.unc.edu/measure/guide/panel5.html#3>.

³ The Horizons Program. (June 2002). *Addressing HIV/AIDS Stigma and Discrimination in a Workplace Program: Emerging Findings*. Population Council: Washington, DC.
<http://www.popcouncil.org/pdfs/horizons/eskombslnsum.pdf>

⁴ UNAIDS. (2000). *Protocol for the Identification of Discrimination against People Living with HIV*. UNAIDS: Geneva. <http://www.unaids.org/publications/documents/human/law/JC295-Protocol-E.pdf>

⁵ National Institute of Public Health (INSP). (April 2003). *Reduction of Stigma and Discrimination Related to HIV/AIDS in Mexico*. INSP: Cuernavaca, Mexico.

⁶ World Health Organization. (15 May 2003). *WHO Workshop on Indicators for the Right to Health*. WHO: Geneva.

⁷ See for example, recommendations in General Comment No. 3 (2003) for *HIV/AIDS and the Rights of the Child* developed by the Committee on the Rights of the Child.

⁸ CESCR. (2000). *General Comment No. 14 on The Right to the Highest Attainable Standard of Health* (Article 12 of the Covenant on Economic, Social and Cultural Rights (ICESC)). E/C.12/2000/4. United Nations Economic and Social Council: Geneva.

⁹ Ibid.

¹⁰ UNAIDS. (1999). *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. UNAIDS: Geneva.

¹¹ UNAIDS. (2000). *National AIDS Programmes: A Guide to Monitoring and Evaluation*. UNAIDS: Geneva.