



Issue Paper: *Monitoring a Rights based Approach: Key Issues and Suggested Approaches*

Defining the Issue

This paper explores issues and approaches relevant to the assessment of the application of a rights based approach to the planning and implementation of HIV/AIDS strategies.^{1,2} It builds on the premise that the Reference Group may wish to recommend to UNAIDS a set of practical steps towards integrating human rights in HIV/AIDS policies and programs and monitoring the compliance of HIV/AIDS policies and programs with international human rights principles and guidelines, in particular those that have been explicitly promoted by UNAIDS in its publications and other work.¹ Some suggested key issues are highlighted and, HIV testing strategies will be used as an example to the extent necessary to clarify concepts.

Key Issues: Applying a Rights-base Approach

When reviewing the UNAIDS global strategy and other relevant documents, several key issues are raised by the practical application of a rights based approach to HIV policies and programmes. Among these are:

- **Processes and/or Impact? Monitoring and/or Evaluation?**

While monitoring has traditionally taken a primary focus on processes and evaluation on impact, the dividing line between these two domains is often blurred. A balanced approach should be applied to monitoring and evaluating the impact of HIV policies and programs, and the ways in which relevant rights are considered in each case. In relation to HIV testing, questions could be raised as to how testing programmes are established, what quality standards are applied, who accesses testing and who does not, what is being done with the results, and what services are made available to those undergoing testing.

Monitoring could determine if the optimal trade-off exists in any particular setting between impact and process from a dual public health and human rights perspective (e.g. have there been restrictions on rights? Are these legitimate and if so, what impact have they had on equitable access to and use of prevention, care and support services?). More specifically, if VCT is considered as a process issue in the context of access to ARVs, it should have a measurable impact on knowledge of HIV status by people undergoing a test.

To delineate the scope of concern of the Reference Group in this area will require the Group to have greater clarity with regards to the specific objectives of “monitoring rights based approaches in the context of HIV/AIDS” (e.g. what are the essential, specific questions that have to be answered). Furthermore, as progress is being achieved in a particular country or globally towards developing rights based VCT policies, monitoring and evaluation should shed some light on specific factors that have facilitated or hindered their development and application. To this end, the combined use of monitoring and

evaluation methods would require coherence between the two processes and harmonization with other monitoring and evaluation methods promoted by UNAIDS.

- **Intervention-specific or comprehensive approach?**

The experience in monitoring human rights dimensions of HIV/AIDS work is vast, yet diverse and unsystematic. A structured approach to monitoring may require a step-by-step approach, for example using HIV testing as an entry point, or it may examine the broader context of prevention, care and support issues to which HIV testing is linked. The choice between these approaches, although a dividing line between them may not be clear, will determine the magnitude of efforts, likelihood of success and ultimate credibility of the project.

- **Level of assessment**

Concerns about human rights in the context of HIV/AIDS are relevant to global, national, sub-national and community levels, particularly where communities are defined by their assumed risk of HIV infection and subjected to discrimination. Current UNAIDS monitoring methods are focused on the national level. Particular issues may require examination of data and analyses at the sub-national and community levels as differentials across population groups may be more revealing than average status in any country.

- **National capacity building or international watchdog function?**

Monitoring the application of right based approaches to HIV/AIDS work may aim at one or more objectives, including to: document the effectiveness of programme or policy efforts; document human rights neglect or violations, obtain information on the impact of human rights promotion and protection on HIV/AIDS risk and vulnerability (thereby feeding into an evaluation process); create global awareness on local/national/global patterns of convergence or divergence of human rights and HIV strategies; and/or build capacity in government and NGO programmes to perform the above functions. To use testing as an example, the objective of monitoring taking place that recognizes the interface between human rights and HIV testing would have to be consistent with UNAIDS's overall goals and clearly stated as such. In this regard, the specific role UNAIDS intends to fulfill, and the specific guidance it seeks from the Reference Group, would need to be clarified.

- **Different levels of monitoring for different purposes?**

The monitoring of rights based approaches to HIV/AIDS takes different shapes, requires different tools and fulfills different purposes depending on what specific questions are being asked. For example, monitoring on the global level may aim to ascertain whether programmes that have achieved the greatest level of compliance with human rights principles are also those where vulnerability to HIV and risk of acquiring or of being denied care and support are lowest. On the national level, in contrast, the focus of analysis may be on verifying the coherence between policies and actual practice while ensuring that the populations identified as most vulnerable receive greater attention than the rest of the population and that discrimination more generally does not impede HIV/AIDS efforts.

- **Avoiding redundancy or contradiction (internal, and across cosponsors)**

Close interaction between UNAIDS, the Reference Group on HIV/AIDS and Human Rights, and the UNAIDS Monitoring and Evaluation Reference Group (MERG) should result in mutual strengthening and harmonization of approaches.³ There may be several concurrent approaches towards building this synergy, including coordination through the UNAIDS Secretariat, cross-attendance at group meetings, or through a formal feedback process by the Reference Group to MERG.

UNAIDS co-sponsors and the Secretariat are also actively involved in the work of other entities such as the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM). Indeed, national programmes (including those deployed by Governments, NGOs, the private sector and other entities) are likely to be strongly influenced by massive funding originating from the Fund. A search of documents published by the GFATM has revealed a lack of guidance to countries or partners on the integration of human rights into their HIV/AIDS efforts.⁴ Of particular interest would be to develop an understanding of how the GFATM intends to monitor the human rights dimensions of the work it finances. HIV testing could be used as an example if there was interest in pursuing this.

- **Building on existing information**

UNAIDS has developed a set of monitoring guidelines and tools which provide useful information that can be linked to human rights norms and standards. If efforts have to be made to limit the number of indicators or to refine their nature in order to make these methods and tools more “sensitive” to human rights, a systematic review of methods, indicators and their actual application would be necessary. It is likely that human rights monitoring requires access to multiple sources of information, in particular from government sources other than Ministries of Health and NGOs, which may not serve as information sources in more traditional service monitoring efforts. If the information from multiple sources is used with a focus on the national level, mechanisms may be needed to ensure that the reports governments make to UNAIDS leave room for dissenting opinions.

- **Collecting and analyzing existing and new data from other sources**

Human rights may come into play in the development of policies, their actual application or in relation to ongoing practices--even if these have developed in a policy vacuum. The extent to which information originating from NGOs should be considered in monitoring the human rights sensitivity of HIV/AIDS efforts would have to be ascertained and qualified. For example, linking certain HIV testing policies or practices to discrimination may require the collection and analysis of information coming from sources other than the usual providers of information to UNAIDS. The Reference Group may consider what additional sources UNAIDS may tap into to monitor and evaluate rights based approaches in countries, and what critical information would be required to reveal a problem on the local, national or global levels with regards to VCT policies and practices.

- **Validating information**

In certain instances, UNAIDS may have to validate the information it receives so as to avoid giving it legitimacy by serving as the vehicle for its dissemination without assurances as to its validity. The Reference Group may wish to propose options to the

UNAIDS Secretariat for the handling of such situations, for example for clarifying divergence between reported policies on VCT and actual practices in countries.

- **Using information for action**

The actual use of information arising from the monitoring of rights based approaches to HIV/AIDS is essential to both avoiding the waste of human and financial resources and improving data quality. In turn, the use of information to help shape policies and guide action may itself be subjected to some form of monitoring. The collection of information for the purpose of monitoring rights based approaches at the local or national level should be used for analysis and to shape action. Local capacity to perform this essential function would require some degree of monitoring in relation to the focus of different actors (e.g. service providers vs human rights monitoring organizations) and what is done with this information once collected (e.g. what corrective action was undertaken on the basis of monitoring information revealing gaps in VCT access or active discrimination? And/or how was this information made public and to what end?).

Possible approaches to the development of Monitoring methods for Rights Based approaches to HIV/AIDS

The four proposed action items listed below follow a chronology for further action (define purpose, define information, look at what is available, define what more is needed and how it can be obtained, and link with MERG to ensure coherence). The final paragraph suggests a two-entry conceptual table that would combine columns listing key components of an HIV Testing strategy and rows listing key elements of rights based approach. The table would then lend itself to a choice of essential indicators to be monitored.

- Define the actual purpose, level and intended use of monitoring and determine what information may be obtained through ongoing reporting and what information may necessitate an evaluation, for example through active collection of data from a selected panel of entities (countries, communities, vulnerable populations, groups speaking on their behalf) or from alternate sources (UN Agencies, NGOs).
- Use existing UNAIDS monitoring mechanisms, guidelines and data bases to assess the sensitivity of indicators to human rights and examine the value of data actually provided by reporting countries. On this basis, determine what available information can help answer the questions asked, and what information is lacking. Annex 1 provides an example of methods and data proposed by UNAIDS for national programmes to monitor the care and support core indicator on HIV testing and counseling which could be a suitable entry-point for work on human rights monitoring in the context of HIV/AIDS..
- Suggest methods to fill information gaps, including conducting a literature review (both published and gray literature), mail surveys, and interviews of key informants, or undertake focused studies when monitoring information is incomplete or unavailable.
- Explore with UNAIDS optimal ways to link the work of this Reference Group and the UNAIDS Monitoring and Evaluation Reference Group.

The above summary of key issues to consider in relation to a rights based approach to HIV/AIDS could prove a useful reference for the construction of a list of specific questions to be answered through a combined monitoring and evaluation process. To this end, the Reference Group may select specific questions raised by the intersection of two sets of factors: (1) key components of

an HIV testing strategy; and (2) defined criteria of a rights based approach. This work should be done in close collaboration with staff of the UNAIDS Secretariat and Cosponsors.

Supporting Document

- 1) A Guide to Monitoring and Evaluating HIV/AIDS Care and Support: Care and support core indicator 1 (CS1): HIV testing and counseling.

*This issue paper was prepared by Daniel Tarantola
to facilitate discussion at the Reference Group's August 2004 meeting.*

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¹ 2004 Report on the Global HIV/AIDS Epidemic, UNAIDS. Throughout this document, "UNAIDS" refers to the UNAIDS Secretariat and each of its nine current co-sponsors.

²UNAIDS activities in HIV/AIDS, human rights and law; Report - 26/10/2003 – UNAIDS.

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³ See for example the Report on the 7th meeting of the UNAIDS Monitoring and Evaluation Reference Group, Geneva, 2003. The role of MERG includes the review of the status of new indicators; of new indicators guidelines; and of current global reporting efforts and activities to support country monitoring and evaluation programmes.

⁴ The GFATM GUIDELINE FOR PROPOSALS (Annex I) titled GENERAL CHARACTERISTICS OF SUCCESSFUL PROPOSAL contains the only public reference to some aspects of rights based approach, as follows: "These characteristics will serve as a basis for the TRP to establish criteria for review of the proposals: I. Soundness of approach, with proposals demonstrating that they: (...) 4. Contribute to the elimination of stigmatisation of and discrimination against those infected and affected by HIV/AIDS, especially for women, children and vulnerable groups; 5. Are consistent with international law and agreements, respect intellectual property rights, such as TRIPS, including Declaration on the TRIPS agreement and Public Health at Doha, and encourage efforts to make quality drugs and products available at the lowest possible prices for those in need; 6. Improve service coverage and demonstrate a potential to achieve measurable impact.

Supporting Document 1

A GUIDE TO MONITORING AND EVALUATING HIV/AIDS CARE AND SUPPORT

National AIDS programmes (UNAIDS, 2004)

Care and support core indicator 1 (CS1): HIV testing and counselling

Definition

Percentage of the general population aged 15–49 years receiving HIV test results and post-test counselling in the past 12 months.

Numerator

Number of people aged 15–49 years who have received HIV test results and post-test counseling in the past 12 months.

Denominator

Total population aged 15–49 years.

Rationale and what it measures

HIV testing and counselling are important entry points for prevention and care needs. Measuring the number of people who access these services is therefore important to indicate the number of people who could potentially benefit from prevention and care. In addition, over time this indicator provides information on the number of new people tested over time. This indicator is designed to show how many people have been tested and received post-test counselling services. This indicator can be used as a proxy for the coverage of HIV counselling and testing services. At the local level, programme managers may be interested in collecting additional information, such as the number of people tested and counselled, the number receiving their results of those tested and the number found to be HIV positive of those tested.

Frequency

Annual

Measurement tools and how to measure it

The following methods are recommended.

- Health management information systems.
Ideally, information for this indicator can be collected by reviewing data collected at the local level and making them available through the health management information system at the national level.
- Health facility survey.
If the health management information system is not fully operational, health facility surveys with a testing and counselling component in all relevant units and departments may be necessary. At the local level, such information can be collected through record reviews. A random sample of health facilities should be used, and the denominator here would need to be defined as the number of people aged 15–49 years within a specified distance from the facility. This would represent the catchment area or the number of people who can potentially benefit from the services available at the selected health facilities.
- A household survey.
The indicator needs to be stratified by how these services are delivered and by age. Distinguishing how counselling and testing are provided is important to service delivery. In general, three service delivery methods should be considered: stand-alone or free-standing voluntary counselling and testing sites, counselling and testing units within health facilities to which people are referred (from tuberculosis, family planning and other health units, for example)

and fully integrated counseling and testing services in which a provider can refer the person to a laboratory for a test but the provider carries out the counselling. Age should also be stratified, to determine what age ranges are accessing and receiving these services. The age ranges could be: 15–24, 25–35 and 36–49 years.

The denominator, the total population aged 15–49 years, can be obtained from the latest census data.

Strengths and limitations

Because testing and counselling services are often not performed within discrete units (that is, outpatient or inpatient departments) or departments, reports can potentially be duplicated for the same individual being tested in multiple units or those being tested multiple times during the 12-month period. In other cases such as preventing the mother-to-child transmission of HIV and other HIV testing and counselling, services are performed in the same place. This too will lead to double reporting in the number of people tested. In addition, because of these various points of HIV testing and counselling

services, linking testing to counselling through facility records may be difficult in some situations unless a strong records system is in place to track testing and counselling. If a household survey is used, double counting can be minimized.

Collecting this information at the national level through a health management information system may not yet be possible in some settings. Alternative methods for collecting this information, health facility and household surveys, are resource-intense processes that make the annual collection of these data difficult in some areas. In addition, relying on vertical voluntary counselling and testing programmes does not present an accurate picture of all counselling and testing efforts in national facilities.

Finally, health facility surveys can be costly and complicated and should be done less frequently.