



Issue Paper for the Session: Rights-Based Responses to HIV: Human Rights Indicators

Defining the Issue

1. There is a great need for programmatic tools regarding rights-based approaches that are simple, straightforward, in lay language, and acceptable to those designing, implementing, monitoring and evaluating the response to HIV and AIDS. Overall, UNAIDS operates from the position that human rights should be protected because (a) they are human rights and (b) their protection results in more effective HIV programmes and more positive outcomes. This last point has been subject to debate since the beginning of the epidemic and creates an additional incentive to ensure that human rights concerns are captured by monitoring and evaluation tools. In this regard, it is intended that the development of monitoring and evaluation tools that are rights-sensitive will confirm the positive relationship between human rights protection and effective HIV programmes. The ultimate goal is to achieve effective HIV and AIDS programmes that are used by all those who need them to enhance their quality of life, wellbeing, health and dignity.
2. As progress is being achieved towards developing rights based policies and programmes relating to HIV and AIDS, monitoring and evaluation can shed some light on specific factors that have facilitated or hindered their development and application. Upon discussion with UNAIDS, and in line with its priorities, it was agreed that the ultimate purpose of this work is to monitor the effectiveness of HIV and AIDS programmes. However, for such programmes to be effective and to protect rights, countries need – among other conditions – to integrate human rights considerations throughout the process (from the situation analysis through to monitoring and evaluation).
3. It becomes clear that to reach the stated ultimate goal effectively we must first agree on a logical framework that begins by monitoring the degree to which existing indicators capture core human rights concepts, which in turn leads to an analysis of how incorporating rights can impact policy/programme effectiveness. Although not the ultimate goal, the current exercise may provide evidence as to whether integration of rights has led to increased effectiveness. Before a logical framework can be developed, however, there are conceptual and methodological issues that must be addressed.

Background

4. At the end of the 4th meeting, the Reference Group, in discussions with Paul DeLay, agreed that one of the key areas of focus for this work should be a review of the indicators available on the UNAIDS website in order to identify ways that these indicators can be used as they are, rearranged or grouped, and if necessary modified to capture human rights issues. It was further agreed that, after this initial effort, additional discussions would be needed to determine priority areas of focus for this work (e.g. addressing HIV testing, equity issues, and access to treatment). Following the meeting, the Reference Group Secretariat began the collection and preliminary review of available indicators. This preliminary review was carried out with the UNGASS indicators from 2003, the National AIDS Programme Guide to Monitoring and Evaluation, and UNAIDS country reports.

Results of Preliminary Review of Indicators

5. The preliminary review of 2003 indicators assessed the extent to which the human rights principles of participation, non-discrimination, accountability and 3AQ (availability, accessibility, acceptability and quality) were incorporated into these indicators. This review, (which is available but not presented here because the more recent work that it led to is presented) highlighted some important gaps:

- i. Most of the policy indicators asked if a policy existed. They did not provide information on the quality or implementation of these policies. While the existence of a policy is a sine qua non, mere existence will not indicate whether the policy is rights protective or not. It would be necessary to gather further information into the content and implementation of the policy to be able to make this analysis (e.g. if there have been restrictions on rights, are these legitimate, and if so, have they impacted positively or negatively on equitable access to and use of prevention, care and support services?).
- ii. There was a general lack of information on differences within countries: The indicators reviewed focused on the national level. Attention to human rights may raise particular issues that require examination of data and analyses at the sub-national and community levels as differentials across population groups may be more revealing than national averages.
- iii. Knowledge and behaviour indicators capture individual awareness, beliefs and self-reported behaviours which do not necessarily reveal human rights considerations: The data presented in the UNAIDS country sheets highlighted the difficulties with these indicators in that they present what people say they know or they do. This provides some information relevant to human rights, e.g. the right to information (and therefore health) but it would be useful if these findings could be linked and compared to policy, programs and reported actions.

Current Efforts

6. UNAIDS recently revisited and revised all of its indicators in preparation for the 2006 UNGASS report. It has also recently put out new tools and guidelines, such as the 2006 UNGASS Guidelines on Construction of Core Indicators (which includes the revised National Composite Policy Index – NCPI). The Reference Group Secretariat worked closely with the monitoring and evaluation team on their revision of the NCPI.
7. The 2006 indicators attempt to address some of the concerns noted above. For example, the NCPI now includes some indicators that aim to capture information relating to the quality and level of implementation of policies. The Guide on UNGASS core indicators includes recommendations for how data for each indicator should be disaggregated (at national and sub-national levels) e.g. by gender (male/female), age (<20/20+, <25/25+), location (urban/rural/national) and sector (public/private). If data are collected as recommended, it will be possible to assess, to a certain extent, the degree to which some human rights concerns have been incorporated into policy and programme work. It remains to be determined whether or not countries can collect and record these data as suggested. However, In light of the changes in the indicators currently in use and building on the preliminary review, a focused exercise is currently under way to ascertain the quality of these indicators from a human rights perspective.

The Logical Framework for Analysis

8. Based on the ongoing review of the 2006 indicators and interactions between the Reference Group Secretariat and UNAIDS, we have agreed that the work on indicators should be based on the following four-part framework for analysis:
 - i) Measure the extent to which rights are integrated into HIV and AIDS programmes. Any assessment would need to take into account the extent to which rights have explicitly or implicitly been considered in programme efforts. Publicity of the results of such an analysis could create global awareness on patterns of convergence or divergence of human rights and HIV strategies.
 - ii) Measure the extent to which the legal and policy environment is conducive to the protection of human rights. This step is concerned with assessing the extent to which the legal and policy environment facilitates or hinders effective programmes.

- iii) Measure the extent to which HIV and AIDS programmes have an impact on reported behaviour and HIV prevalence. This step looks at service delivery and the impact on services irrespective of whether or not a human rights approach has been adopted.
 - iv) Analyse linkages between policies, programmes, behaviour and HIV prevalence from a human rights perspective. This analysis builds on and brings together parts 1-3 above and would draw on a wide range of quantitative and qualitative data collected during that work. In this sense it would be subject to evaluative research and not part of the regular monitoring framework.
9. As noted above, current efforts are focused on looking at the updated indicators from a human rights perspective. This work, which is currently being carried out, is a necessary precursor to the logical framework outlined above: once it is complete it will provide a tool for addressing the first three parts of the framework.
 10. It is intended that the first step is to complete the analysis of the 2006 UNGASS Core Indicators, which focuses on their relevance in capturing human rights information. The second step will be to analyze the more detailed indicators found in other sources, such as the National AIDS Programme Guide to Monitoring and Evaluation), particularly where it is apparent gaps in information exist. A matrix for analysis organized around the logical framework described above has been developed to facilitate this process. The matrix brings together relevant human rights principles and specific indicators to enable the identification of indicators that are useful to a rights analysis as well as gaps in information considered key in a rights based approach to HIV and AIDS.
 11. We are still at the initial stages of working on this matrix and have tried to include enough detail to show how it might be useful.

Recommendations for moving forward with the assessment of whether integration of rights has led to increased effectiveness

12. Once the matrix is fully developed, completion of the first three parts of the logical framework, as outlined above, and their application to country level work should be relatively straightforward. Depending on the results of this analysis, these first three steps could lead to a proposal for the inclusion of additional human rights indicators in the UNAIDS list or a call for new data collection mechanisms that might result in data of more relevance to human rights concerns. The data collected could also be used as the basis for designing or extending studies to explore human rights issues in the context of HIV programming (e.g. with regard to health, education, housing, social assistance, employment).
13. The fourth step in the framework is the most complex, and will likely require evaluative research. It is intended to help assess whether the integration of rights has led to increased programme effectiveness. The focus of analysis here 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 and AIDS efforts.

Questions for Discussion:

- 1) Does this seem the appropriate way to proceed in terms of developing tools that will improve programmes from a human rights perspective?
- 2) To what degree are we concerned with how the data that is collected can be analysed from a human rights perspective or how the data collection itself can have an impact on human rights? Or both?
- 3) Should the analysis only focus on the human rights principles mentioned above or also try to identify to what degree the programmes being monitored further the realization of substantive rights (e.g. right to health, right to education)?

- 4) Is the logical framework presented clear? Does it allow for us to meet our goals?
- 5) What are our expected deliverables?
- 6) What are the next steps in moving this work forward to reach completion by end of 2005?
Beyond?
- 7) What will the roles of the Group and sub-group be?

This issue paper was prepared by the Reference Group Secretariat to facilitate discussion at the Reference Group's August 2005 meeting.