



ISSUE PAPER FOR THE SESSION:

**Development of a tool to measure stigma and discrimination experienced by people living with HIV**

**Defining the Issue**

1. Since early 2004, the UNAIDS Secretariat has been working with the International Planned Parenthood Federation to support work by networks of people living with HIV to develop an index on human rights, stigma and discrimination, by and for HIV 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. Following the August 2005 meeting, the UNAIDS Secretariat and IPPF worked with GNP+ and ICW to refine the draft survey tool that was developed based on questionnaires used in similar contexts.
2. 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 would carry out a small pilot to test the survey tool. Feedback has been gathered from the five pilots, and IPPF and UNAIDS will be supporting GNP+ and ICW to finalise the survey tool based on this feedback and work with national networks to use it.

**Objectives of the Stigma Index**

3. 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. Participants at the August 2005 meeting<sup>1</sup> 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
4. It is hoped that the development of the index tool is a possible means of building significant new capacity and confidence in networks of positive people at a critical time in their development. The information to be gathered should serve as a powerful advocacy and accountability tool, in the context of commitments made in

<sup>1</sup> See UNAIDS (2005), "Meeting on development of index on human rights, stigma and discrimination by and for people living with HIV; Report of the Meeting, 22-23 August 2005". Available on-line at [http://data.unaids.org/UNA-docs/meeting\\_hr\\_plhivindex\\_23aug05\\_en.pdf](http://data.unaids.org/UNA-docs/meeting_hr_plhivindex_23aug05_en.pdf)

the Declaration of Commitment (2001) and the Political Declaration (2006), and could also be used to inform policy and programme development that promotes and protects human rights related to HIV. Taking this project to scale, however, will require significant financial support from bilateral or multilateral sources. Beyond the implementation of the project, it will also require commitment on the part of the international community to ensure findings are used to inform advocacy and programming efforts.

### Questions for discussion

- a) How can UNAIDS better support people living with HIV to know their rights and demand them through the use of this Index and other tools? To what degree should this be the priority of UNAIDS?
- b) What can the international human rights community do to support national networks of people living with HIV to make maximum use of the findings of the stigma and discrimination survey?
- c) What can be done to support international and regional human rights mechanisms to use findings on HIV-related stigma and discrimination in their review of States' implementation of human rights treaties and other international/regional obligations?

### Supporting document

- Draft questionnaire used in the five country pilot