



**Meeting on development of index on human rights,
stigma and discrimination
by and for people living with HIV**

Report of the Meeting

Geneva, Switzerland
22-23 August 2005

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Meeting Objectives

The meeting was held as a follow-up to a joint UNAIDS Secretariat and International Planned Parenthood Federation (IPPF) meeting that took place in March 2004 in London. The meeting had the following objectives:

- To bring together representatives of networks of people living with HIV and technical experts on indices to share information on work presently underway or planned on HIV-related human rights, stigma and discrimination indices;
- To focus on the development of indices by and for people living with HIV, to assess the need for further work in this area, and to identify means by which to take possible new work forward in ways that compliment existing work.

Executive Summary

This meeting, convened by the UNAIDS Secretariat in collaboration with IPPF, brought together people working on HIV-related human rights, representatives of networks of people living with HIV and technical experts on indices to share information on work presently underway or planned with regard to indices on HIV-related stigma and discrimination.

A number of participants presented an overview of their past, current and planned work on indices regarding HIV-related human rights, stigma and discrimination. Though there was a significant increase in such work in the last two years, participants noted that it had become even clearer that there continued to be a tremendous dearth of information and research on HIV-related stigma and discrimination, as well as a lack of support for and implementation of effective programmes to address these issues. Furthermore, it became clear that, though much good work had been done with regard to the development of indices to capture data on HIV-related stigma and discrimination, the work to date still did not represent a sufficient tool to fully reflect the voices and experience of positive people. In light of these challenges, participants confirmed the need to outline a clear and complimentary focus and strategy for new work in this area, as well revised goals and objectives for an index on stigma and discrimination by and for people living with HIV.

It was stressed that the *process* by which this tool would be developed and implemented would be as important as the results obtained. As a process driven by people living with HIV and largely implemented with or by their networks with technical input from international organizations, NGOs and others, the use of a revised index for and by people living with HIV had the potential to build significant new capacity and confidence in the networks at a critical time in their development. The information that was to be gathered also could be a powerful advocacy tool in future work, and could be used to inform policy and programme development that promotes and protects human rights related to HIV.

Meeting participants agreed to move forward by building on existing work, and committed themselves to working together to create and implement, through collaboration, an index for and by people living with HIV. Towards these ends, participants reviewed the draft questions developed in the March, 2004 meeting in light of the significant work done by POLICY and the USAID Inter-Agency Working Group on Stigma and Discrimination (IWG S&D). The IWG S&D index comprised three components in terms of the sources of information relating to stigma and discrimination. These were: community, service deliverers, and people living with

HIV. Participants agreed that, in order to reinforce and compliment such ongoing work, it was necessary to work together to amalgamate and expand on the component addressing the experience of people living with HIV. Participants put together indicators from the POLICY work, the meeting of March 2004, the Asia-Pacific Network of People Living with HIV/AIDS (APN+) work and that of the International Community of Women Living with HIV/AIDS (ICW), and discussed, revised and refined these indicators. The result was the basis of an index for and by people living with HIV (PLHIV index) which could either be used on its own or be used in the context of the three-pronged POLICY tool (See Appendix 4). It was agreed that, when possible, it was best to use the PLHIV index as one part of the three-pronged approach, as the data derived from the other two sets of sources would validate and expand the data gathered from the PLHIV index. There was insufficient time to develop questions by which to implement the agreed-upon indicators, and it was decided that this would be part of future work. Draft indicators for the other two components of the index were circulated during the meeting, and comments were invited from participants.

Participants then outlined a strategy to move the work forward in the coming months, in particular identifying several strategic advocacy/coordination opportunities between September 2005 and August 2006 (See Appendix 5). These include the Lima conference of people living with HIV, the review of progress towards the goals outlined in the UNGASS Declaration of Commitment, and the XVI International AIDS Conference in Toronto, Canada. Participants identified critical steps in terms of: (a) discussion with and buy-in by networks of people living with HIV; (b) further refinement of indicators; (c) development of a questionnaire and operational guidance for use of the index; (d) pilot tests and possible field testing in key countries; (e) preparation of input into UNAIDS report to UNGASS and/or civil society shadow reports; and (f) use of results and roll out at the Toronto conference.

Participants agreed that continued work in this area and the greater implementation of such an index for and by people living with HIV might help galvanize commitment and action with regard to the reduction of stigma and discrimination, in terms of them being both violations of human rights and obstacles to achieving universal access to prevention and care. It was agreed that immediate work would be undertaken to engage additional partners, underlining the potential of the process to gather important data, build capacity and advocate for greater funding towards efforts to reduce stigma and discrimination experienced by people living with HIV.

Outcomes from this meeting included:

- A commitment by the groups represented at the meeting to work together closely and to collaborate on the further development and implementation of the PLHIV index;
- An agreement to use the PLHIV index to build on and complement existing work regarding collection of data on HIV-related stigma and discrimination, in particular to use the index, where possible, as part of the three pronged POLICY index;
- Greater clarity of how the PLHIV index might be used in the context of the broader monitoring and evaluation work taking place;

- An agreed set of next steps, with specified time frames and organizational commitments for follow up actions, including engaging respective constituencies;
- Agreed goal and objectives for the proposed PLHIV index; and
- An agreed draft set of indicators and sub-indicators to form the basis of the PLHIV index (See Appendix 4).

Opening and background

1. Following a brief round of introductions, UNAIDS Deputy Executive Director Debbie Landey formally opened the meeting. She noted that not only was there the right group of people assembled in the room to consider these issues, but it was also the right time to consider them, on the eve of the World Summit to review the Millennium Development Goals and address the recommendations of the Secretary-General in his report “In Larger Freedom: towards development, security and human rights for all”.
2. Purnima Mane, Director, Policy, Evidence and Partnerships, extended her welcome to participants and gave an overview of the background to and the objectives of the present meeting. The present meeting was a follow up to one co-hosted by the International Planned Parenthood Federation (IPPF) and UNAIDS Secretariat in March 2004 in London. Dr Mane noted that staffing changes had delayed the organization of the present follow up meeting, but confirmed UNAIDS commitment to the process.
3. Dr Mane underlined that, though UNAIDS has been keen to facilitate the meeting, it did not want to steer the process or outcome. Rather people living with HIV should and would take the lead, in partnership with and seeking advice from others. In light of significant work already done in this area, UNAIDS urged that there be a concerted effort to take stock, and ensure that efforts reinforce - rather than duplicate - each other.
4. The agenda and background of the meeting were reviewed. It was noted that three of the participants at the present meeting were in attendance at the March 2004 meeting – Kevin Osborne (IPPF); Anuar Luna (Red Mexicana de Personas que Viven con VIH-Sida); and Kate Thomson (formerly Global Fund, now UNAIDS). The background note for the meeting was distributed to participants (see Appendix 1), and it was agreed that one of the most important objectives and benefits of the creation of a PLHIV index would be enhanced capacity of groups of people living with HIV. However, it was similarly important to avoid duplication of efforts and to move forward together in advancing such work.
5. Challenges and issues of concern identified at the first meeting included issues of methodology, notably whether data would be verifiable, and the need to ensure that studies were representative. With only 10% of people living with HIV actually living with a diagnosis, “representativeness” was identified as a major challenge from the beginning. By necessity, the starting point for this work was the population of people living with an HIV diagnosis. Participants agreed to focus on what could be done to ensure that people living with HIV were empowered to lead the implementation of such as index.

Current work and developments since the March 2004 meeting

6. Participants agreed from the outset of the meeting that much important work has been done in the area of collecting data on stigma and discrimination relating to HIV and that it would be very important to build on this work and to work together collaboratively in the development of an index for and by people living with HIV. In this context, participants involved in current initiatives on indices relating to HIV stigma and discrimination gave brief presentations on their work. This overview provided an important baseline for subsequent discussions and established the context within which any future work would be placed. Full reports and presentations, where available, were provided as background documentation before the meeting and are referenced at the end of this document.

7. Participants described the following initiatives and projects.
 - Noel Quinto (APN+) reported on an APN+ questionnaire/ peer education study done by and for people living with HIV in Guangxi, Laos, Thailand, Viet Nam and Yunnan.
 - Lori Bollinger (Futures Group) reported on the work of the USAID Inter-Agency Working Group on Stigma and Discrimination (IWG S&D) to develop an index with core and expanded indicators and questions. It comprised three components, including one for people living with HIV. Some of the researchers who have implemented the tool in field trials have been people living with HIV. Two field tests (Mexico, South Africa) have been completed, and two were underway (Kenya, Tanzania). (Presentation available upon request.)
 - Ken Morrison (POLICY–Mexico) reported on work related to health service providers, media, policy and people living with HIV. His group was currently developing a manual on indicators.
 - Charles Katende (Synergy) reported on a field study carried out in Tanzania to refine the IWG S&D tool, and define essential, recommended indicators and questions. (Presentation available upon request.)
 - Kevin Osborne (IPPF) reported on the vision for a draft index to capture the voice of people living with HIV, and the results of the March, 2004 meeting In London (available on request).
 - Moono Nyambe, Global Network of People Living with HIV/AIDS (GNP+) raised the issues around criminalization of HIV transmission, including using the trend to criminalize transmission as an “indicator” of stigma, as well as seeing criminalization as a cause of increased stigma in some communities.
 - Felicita Hikuam, International Federation of Red Cross and Red Crescent Societies (IFRC) provided information on their campaign against stigma by and through local chapters and their partnership with GNP+.
 - Andrew Doupe presented an overview of a publication he authored for IFRC which summarizes projects and research to date on stigma and discrimination.
 - Fiona Pettitt (ICW) highlighted the *Voices and Choices* work on the sexual and reproductive rights of women living with HIV.
 - Nicolas Fasel, UN Office of the High Commissioner for Human Rights (OHCHR) reported on the broad range of work undertaken around human rights indicators.

For a more detailed account of the discussions on work and developments since 2004, see Appendix 2.

Identifying the goal and objectives of an index

8. The afternoon session began with a review of the highlights from the morning's discussion, providing the foundation for a discussion on the objectives of an index for and by people living with HIV, and the best way to take possible work forward and make use of the outputs. In the recap, it was underlined that future work should be set in the larger context of:
 - the need to see overcoming stigma and discrimination as one of the essential pillars of the response to the HIV epidemic, the other ones being prevention, care and treatment, and impact mitigation; without stigma and discrimination being overcome, there was little chance of reaching the goal of universal access to prevention, care and treatment by 2010;
 - possibility of generating interest in supporting future work on stigma and discrimination at the World Summit 2005;
 - potential to enhance reporting on progress towards the goals outlined in the UNGASS Declaration of Commitment on HIV/AIDS;
 - human rights indicators work being done by the UN Office of the High Commissioner for Human Rights;
 - possibility of using outputs in the context of reporting to the human rights treaty bodies responsible for overseeing the implementation of the major international human rights treaties.

9. In defining the objectives for a PLHIV index, participants noted the potential value added of such an index.
 - Increased funding for work to reduce stigma and discrimination.
 - Increased capacity to monitor whether programmes are making a difference in the lives of people living with HIV.
 - Enhanced advocacy efforts.
 - Tools that help measure the effectiveness of specific interventions to reduce stigma.
 - Tools that empower the people who develop and use them.

10. Participants also noted some of the broad conceptual and methodological issues that would have to be addressed.
 - Sources of information and the need for triangulation, e.g. people living with HIV, and/or other sources, including the community and specific health and social service providers, such as in the three-pronged POLICY index.
 - Collection of qualitative and quantitative information, considering the strengths and limitations of each.
 - Necessary sample size, particularly among people living with HIV, and the logistical and financial challenges associated with generating it.
 - Quality of questions and significance of information obtained.
 - Weighting.
 - Comparability.
 - Internal, as well as external, stigma.
 - Stigma and discrimination indicators versus more broadly framed human rights indicators.

- Gender, including capturing women’s experience.
 - Capturing the experience of specific groups, such as injecting drug users, sex workers and men having sex with men.
11. Participants also discussed funding and sustainability issues. Possible opportunities included ad hoc funding by different organizations and donors, and efforts to link to ongoing work of large outreach institutions or agencies. Participants agreed that, to the degree possible, use of such a PLHIV index should be tied to UNGASS monitoring and evaluation efforts, as well as linked to UN field offices, including UNAIDS Secretariat staff, OHCHR country officers, and UN theme groups on HIV.
12. General conclusions from the morning discussions underscored the fact that the development of an index for and by people living with HIV was an extremely complex exercise as demonstrated by the work already done in this area and the challenges identified. If additional work was to be successful, there was need for:
- clear objectives;
 - clear products;
 - clear frameworks; and
 - location in existing efforts
13. The participants considered key questions to guide the discussion.
- What are the objectives of groups of people living with HIV vis-à-vis the development of an index?
 - Is there a need for a different index by and for people living with HIV?
 - Can we build on existing index and indicators work?
 - Can such an index be put into larger monitoring and evaluation (M&E) frameworks?
 - How can we take this work forward?
14. Participants spent considerable time discussing the goals and objectives for a PLHIV index. A more detailed account of the development of the goal and objectives for the index can be found in Appendix 3. The following goal and objectives were agreed by the participants.

Overall goal

To contribute to ensuring actions to reduce stigma and discrimination are scaled-up, appropriately resourced and prioritized as part of a comprehensive AIDS response.

PLHIV Component – Objectives

Process driven by and for people living with HIV with a view to:

- 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 PLHIV in the response
- Increasing the pool of information useful for advocacy, policy and programme design and implementation

15. Participants agreed to assess existing indicators in light of these objectives. To facilitate this process, a small working group (Lori Bollinger, Charles Katende, Ken Morrison, Kevin Osborne, Fiona Pettit and Noel Quinto) agreed to compare existing sets of questions/indicators, giving particular attention to those already field tested by different groups represented at the meeting, looking for areas of overlap, as well as gaps. The working group assessed how to best bring together indicators to meet the goal and objectives for the proposed PLHIV index, with a view to fitting them into existing work to the extent possible.

Technical review of indicators and development of next steps

16. The working group reported that it had used the PLHIV component of the indicators that have been developed by POLICY (USA) and the IWG S&D as a starting point for their discussion. Questions and indicators were then added from the discussions held in London, as well as input from APN+ and ICW. The working group came up with seven indicators in total. Participants were satisfied with conclusions of the group, as presented to the plenary, noting that the resulting seven indicators included most of the questions found in the sources considered. Significant refinement of the wording, however, was still needed. The seven indicators were the following

- Indicator 1 Direct experiences of stigma and discrimination.
- Indicator 2 Fear of stigma and discrimination.
- Indicator 3 Disclosure and experiences of disclosure.
- Indicator 4 Internal Stigma: PLHIV excluding themselves from services.
- Indicator 5 Laws policies and practices.
- Indicator 6 Social capital.
- Indicator 7 Quality of care.

An eighth indicator was discussed, although not named. It was thought that could be constructed to include shame, blame, guilt and stigma associated with HIV.

17. Participants spent considerable time discussing and refining the grouping and wording of these indicators. For each indicator, participants agreed on a series of sub-indicators. Participants agreed that each sub-indicator would have to be implemented by the development of a number of questions to be asked by interviewers (preferably people living with HIV), trained to administer the questionnaires to PLHIV respondents. The refined list of indicators and sub-indicators can be found in Appendix 4. It should be noted that participants were in agreement on the content of this list, but acknowledged that the final wording for each sub-indicator should be refined by an editorial team.

18. Participants agreed that there would also need to be developed a standard set of demographic questions to precede the questions going to the substance of the indicators. This demographic information would allow for analysis by age, sex and a range of other factors. Participants also agreed that this section should include information regarding the length of time since HIV diagnosis and the circumstances under which diagnosis was made. For this reason, issues regarding mandatory testing were not included among the sub-indicators. It was agreed that information regarding disaggregation by sex and other factors would be collected in the demographic questions. However, participants stressed that survey questions elaborated under each indicator and sub-indicator should also address the different experiences of men and women living with HIV.
19. Participants noted the importance of conducting focus groups to pilot the questions and adapt them to local circumstances as needed, particularly in light of variations in the nature of the epidemic and cultural practices – the situation, for example, in Russia and Eastern Europe being very much different from what was seen in Africa. Questions relating to drug use in contexts where HIV transmission was predominantly heterosexual could be out of place, and vice-versa. Some participants suggested that there be “core questions”, with additional questions being used, depending on the nature of the local epidemic. Throughout the discussion, participants underlined that the questionnaire should be easy to use. It was furthermore pointed out that, in talking about this work, it is important not to lose sight of the fact that much of the power of this tool was *process*. In this regard, it was agreed that the methodology needed to be sound, but the project design process should not be taken over by quantitative research considerations.
20. Participants brought up a number of additional considerations based on their experiences. Sampling methodology would need to be addressed as part of the preparations to carry out this work in country. This was considered a particularly challenging aspect of the work, and special efforts would have to be made to reach people living with HIV who were not linked with support groups or similar bodies. Participants stressed that ethical considerations and obligations regarding the use of the index should be fully considered and covered in the operational guidelines, particularly to avoid possible harms associated with participating in the research process. For instance, many of the questions being asked would bring people back to difficult and painful times in their lives. Some discussion focused on the need to distinguish between stigma related to HIV status, and stigma towards positive people for other reasons, for example, on the basis of ethnicity or sexual orientation.

Locating the proposed index in current monitoring and evaluation framework

21. Paul De Lay, Director, Monitoring and Evaluation, UNAIDS Secretariat, presented a number of possible opportunities for collaboration within current monitoring and evaluation activities.
 - Refining the instrument through further field testing, and linking up with UNAIDS M&E officers in the field to assist with some aspects of this work.
 - Linking up with the Open Society Institute (OSI), which was working with a qualitative assessment tool to gather input from civil society as part of UNGASS reporting.

- Presenting work in progress at a meeting to be held in Recife, Brazil 15-17 September 2005, and thereby engaging other partners and discussing in the context of civil society capacity for enhanced UNGASS reporting and advocacy work.
- Exploring possible sources of funding, including UNAIDS support to Regional Support Teams (RST) to help in-country civil society organizations with UNGASS reporting. The 45 priority countries were the same as the Global Task Team (GTT) countries. This tool could be packaged along with the other two components of the index and sent to the UNAIDS Country Coordinators in these countries.
- Including information on the lack of good information on stigma and discrimination in the UNAIDS report being developed for UNGASS, and highlighting pilot work taking place.

22. De Lay noted that the UNAIDS Secretariat was working with Futures Group on a coverage survey which was more service-delivery oriented. Along with the National Composite Policy Index, it was going to all countries who signed the UNGASS Declaration of Commitment. It would be sent to the appropriate authority in the country via each country's permanent mission to the United Nations. Information was due back by December 2005. A new tool on stigma and discrimination could provide useful triangulation data. If data came in that looked useful, it might be possible to incorporate it into the report being prepared for UNGASS.

Financing, implementation and sustainability

23. A number of questions related to financing, implementation and sustainability were raised during the meeting.

- How could this work be used to feed into reporting related to the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)?
- How could the UNAIDS Secretariat and OHCHR integrate information produced through this process into their confidential briefings to the human rights treaty bodies?
- If this was to be a tool by and for people living with HIV, how would it be taken forward by these groups?
- How to make the best use of Recife, Peru, UNGASS, and Toronto opportunities?

24. Participants pointed out that no one group would be able to fund the collection of data in every country around the world. A more feasible "plan B" would be to support groups that were doing such work by providing a manageable set of indicators and disseminating it as widely as possible. It was suggested that such a list could be required in the standard reporting requirements of funders, promoting the collection of uniform data, and on a consistent basis. With active engagement of a range of partners, it was thought that it still might require five years to gather sufficient data for analysis of experience and trends. However, there were opportunities to move rapidly forward. For instance, if IPPF were to collect data together with its partners involved in the implementation of country level programmes, it might be possible to quickly bring this project into an institutional

framework, particularly as there were 28 national societies ready to go with this type of approach and only needed a set of questions.

25. Participants stated that it was important to be strategic and focus on how to provide input into the UNGASS reporting and key events listed above. It was felt that two participants from the meeting should attend the Recife meeting to present what was discussed and agreed during these two days, get additional partners on board and identify possible countries to focus on in the field testing stage. Attention should be given to the relationship between implementing partners and other organizations working in country. (e.g. MEASURE DHS and the International HIV/AIDS Alliance.) As much as possible, ways to coordinate with existing initiatives should be sought.
26. Participants closed the meeting by affirming their commitment to a cooperative, collaborative effort that would build on the work of the IWG S&D, POLICY, Synergy, ICW, the International Center for Research on Women, and further the development of international, regional and national PLHIV networks. The group outlined the key activities that need to occur, the timeframe in which they should occur and who should take lead responsibility. These included the following.
 - Meet in London with GNP+, ICW, UNAIDS and IPPF for discussion with these networks of people living with HIV.
 - Finalize PLHIV indicators and questions.
 - Make presentation to UNGASS 2006 Civil Society Planning Meeting in Recife, 15-17 September 2005.
 - Agree process to develop strategy to run indicators in pilot countries.
 - Develop questionnaire and operational guidance.
 - Finalize indicators for whole spectrum – people living with HIV, service providers, community.
 - Translate tool (and back translate).
 - Identify and train interviewers.
 - Carry out field test/piloting of indicators.
 - Develop self completion survey for Lima conference.
 - Report on stigma and discrimination to UNGASS and Toronto 2006.

For a more detailed list of activities, including timelines and allocation of responsibilities, see Appendix 5.

Appendix 1: Background Note



UNAIDS Secretariat
Meeting on the development of an index on human rights, stigma and
discrimination
by and for people living with HIV
Geneva, Switzerland
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Objectives of the meeting

The objective of the meeting is to consider possible further work on the development of an index on human rights, stigma and discrimination by and for people living with HIV. The meeting will bring together a small group 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 presently underway or planned in this area. Participants will discuss, at the technical level, what new work is needed and identify ways to take such work forward that are complimentary, mutually-reinforcing and sustainable.

Background to the meeting

This meeting is being organized as a follow-up to a meeting on this subject which was held on 1 March 2004 in London and co-hosted by the UNAIDS Secretariat and the International Planned Parenthood Federation. Participants discussed issues to be covered by such an index, as well as questions that might be included. Participants also identified a number of possible benefits associated with further work in this area, as well as challenges and issues of concern. Among the possible benefits:

- A clearer sense of whether laws and policies related to HIV are 'real' in people's lives, with specific attention to issues such as legal discrimination and mandatory testing, among others.
- Enhanced voice of people living with HIV.
- Country-level context and information.
- Enhanced human rights advocacy capacity for people living with HIV.
- Outputs that could be used by different organizations for different purposes (advocacy, policy development, etc).

Among the challenges and issues of concern:

- Methodological challenges, including the need to ensure that data is objective and verifiable, and that the data collected is representative in terms of gender, age and social and economic status.

Appendix 1: Background Note

- Ethical issues related to disclosure, confidentiality and informed consent for participation in the study.
- “User-friendliness” of data collection methods.
- Quality of training and sensitisation for interviewers.
- Ability to generate reliable data on access to treatment.
- Need to ensure that people living with HIV are empowered to be the leading force in the project.
- Usefulness of outputs – more than just numbers – oriented towards practical changes that will ultimately change the situation in country.
- Need to acknowledge strengths and weaknesses of methodology at the outset, and when presenting the data.
- Involvement of experts in advisory capacity is necessary to provide accountability and also enhance credibility.

It was agreed by participants that an additional meeting would be needed, particularly to discuss how questions could be weighted. UNAIDS made an undertaking to support such a second meeting, as appropriate.

In addition to the issues outlined above, a number of important issues were not sufficiently addressed at the first meeting due its short duration. These included questions of “ownership”, complimentarity with other work in this area, funding and sustainability of such an index, the focus of the index (general or focused to specific aspects of the experience of people living with HIV), connections to effective programmatic interventions, and connections to existing monitoring and evaluation efforts. Furthermore, since 2004, there has been significant work done by various parties with regard to the development and field-testing of indices on HIV-related stigma, discrimination and human rights.

In this context, this follow-up meeting provides an opportunity to take stock of the present state of efforts in this area and address the above issues regarding possible future work. Specifically, it brings together people who are in a position to share information on work in progress, as well as lessons learned. Complimentarity with past and current initiatives; ways of working that will result in actual improvements in the lives of people living with HIV; and implementation, funding and sustainability issues will be key considerations at the meeting.

Appendix 2: Discussion of current work and developments since 2004

1. Susan Timberlake, Senior Law and Human Rights Adviser, UNAIDS Secretariat, noted that there has been very significant work done since the last meeting, and that it would be important to look at it carefully. Not only should participants honour what has been done, but should also be strategic in collaborating and rolling out efforts. Since the beginning of the epidemic, stigma has been identified as one of the greatest barriers to an effective response, but very few resources have been dedicated to addressing it. In developing tools, participants should outline what should be done with the information such tools produce, focusing governments, funders and others for concrete action. There could be a variety of objectives, including advocacy, specific policy changes, reduction of stigma and discrimination, and empowerment of those involved. The most important aspect of empowerment from a PLHIV index would be for people living with HIV to be able to draw down their human rights into concrete demands for change.
2. Noel Quinto, Asia-Pacific Network of People Living with HIV/AIDS, described their peer-to-peer research focused on asking about human rights and the experiences of human rights abuses. He stressed that, in order to understand stigma, people must be trained on how to recognize stigma and discrimination, and to collect information about them. Research to date has shown that most discrimination takes the form of discriminatory measures by health care providers, including hospital staff. Using the findings of their efforts, there has been an opportunity to engage the National Human Rights Commission and others in the Philippines and focus their attention on HIV-related human rights issues. No additional funds exist to carry this work forward, however, and there is need for specific interventions to be designed and implemented that address the findings.
3. Nicolas Fasel, UN Office of the High Commissioner for Human Rights, noted that their work on human rights indicators has tended to focus on normative and definitional aspects, statistical tools and gathering topical human rights information relevant to data collection. One of the greatest observations by those involved related to the variety of perceptions people have about indicators. Many initiatives make reference to human rights frameworks. Others, such as poverty indicators, do not necessarily make specific reference to human rights, but still are useful from a human rights perspective. It was possible to categorize initiatives by four main groups: social, economic, administrative and other statistics; documentation of human rights violations, e.g. interviews with victims, most often in the civil and political rights domain; household surveys, including opinion surveys asking how people perceive policies and programmes; and indexes that assign a score to a country based on expert assessment.
4. Fasel noted the work of the human rights treaty bodies. He explained that treaty bodies are most often looking at what is compiled by national statistical offices, often in the context of international standards. In this regard, objectivity of data is enhanced through the use of agreed definitions and transparent methodology. This is particularly important in the context of possible political sensitivity and the need for credibility if governments and others are to take the findings seriously.

Appendix 2: Discussion of current work and developments since 2004

5. Fasel gave a brief overview of a meeting held in March 2005 which brought together members of treaty bodies, experts on indicators, and others in the human rights community. The meeting determined that a more detailed conceptual framework was needed to guide future work. Due attention needs to be paid to civil and political rights as well as economic, social and cultural rights in the conceptual framework. A meeting will be held at the end of August 2005 to follow up the March 2005 meeting.
6. Ken Morrison, POLICY, Mexico, highlighted how much has changed in the past three years. Their 2002 review of existing stigma and discrimination indicators and a literature review revealed that very little was being done. By Bangkok in 2004, there were signs of change, so that one can characterize the present as an “implementation phase”. Morrison explained that their work takes place in the context of the USAID Inter-Agency Working Group on Stigma and Discrimination, with expanding partnerships, including groups of people living with HIV and faith-based organizations. Their indicators manual was in an early stage of development, and would take considerable time for verification. Prominent among the lessons learned: this work was not easy! Translation, both linguistically and culturally, was difficult. When translating the individual indices into the matrix, there are the inherent risks of being reductionist to the point that there is little of substance left at the end. When designing the methodology, there has to be a clear framework, including clarity about what type of change one wants to come about. Indices should include positive and negative indicators, revealing the good implementation of good policy, as well as human rights violations. He pointed out the importance of analysing indicators together, noting that in Mexico there were situations where over 90% of people responded that HIV status should be kept confidential, yet 42% would say that employers have the right to know the status of their employees.
7. Felicita Hikuam, International Federation of Red Cross and Red Crescent Societies, gave an overview of their global campaign, “The Truth about AIDS... Pass it on.” In 2003, they became a collaborating centre with GNP+ and UNAIDS on stigma and discrimination. Getting all 120 member societies on the same page is demanding if there are to be meaningful partnerships. Red Cross Day was a strategic advocacy opportunity, getting people to speak out what is needed in terms of policy change. One of their key resources is a summary of projects and research to date on stigma and discrimination, written by Andrew Doupe.
8. Andrew Doupe explained that the report looks at what has been done up to the end of 2004. In his subsequent informal review of what has happened in the past 12 months, there has been an avalanche of work. The present goal is to move from awareness-raising to looking at programmatic and project work, creating a common baseline from which reduction of stigma can be measured. In addition to what this work tells us about the state of stigma and discrimination, there are also important implications for funding. It was pointed out that we need to make sure there is an attempt in stigma work to measure outcome.
9. Kevin Osborne, International Planned Parenthood Federation, noted that while there is more being done, what we have is still rather anecdotal, and we lack the voice of people living with HIV. The question that needs to be asked by all

Appendix 2: Discussion of current work and developments since 2004

involved: “Is there a difference being made in the lives of individual people living with HIV by all the efforts in the response to the epidemic?” The task of an index would be to crystallize work at the international level and ensure that people living with HIV have a space for bringing their voices to a host of issues. Osborne stated that this is where the London meeting left off. It was clear that, over time, there was the potential to enhance accountability. First steps would need to focus on countries that have had some successes and also have institutions behind the initiatives taking place. More and more organizations would have to be brought on board, particularly those with capacity to take things forward at a national level.

10. Charles Katende, Synergy Project (Tanzania), Washington, DC, USA, gave an overview of their work in Tanzania to field test a set of indicators. (Presentation available on request.) Some of the shortcomings and lessons learned from earlier work related to the generality of some of the questions which led to misleading results. For example, questions asking someone if they would provide care do not get to the quality of care – i.e. care could be provided in a stigmatizing way. There was a sense that they would need to go deeper. The Tanzania study focused on identifying why people are stigmatizing, looking at four primary domains: fear; values (shame, blame, judgement); “enacted stigma” – actions taking place on the basis of stigma; and disclosure (looking for patterns which may point towards the presence of stigma.) The complexity of the issue means that there is a need for a range of indicators, and the accompanying need to ask a range of informants. The study was linked with an ongoing intervention.
11. Sampling for such studies proves to be complicated, and it may be that one only reaches “obvious” people living with HIV. Many may be hidden, and there needs to be a concerted effort to access these groups. Training for interviewers is critical if the data collected is to be sound, and the study is to run well. In the field test, validity measures are important. There is confidence that this set of questions represents the necessary indicators for tracking change over time and evaluating the success of an intervention.
12. There was some consideration of the extent to which the “general population” part of the study was a useful component, complementing the perspectives of people living with HIV. Katende explained that they had set out to show where the stigma is, and where anti-stigma interventions have made a difference. Because the community is generally the source of stigma, and because in many cases the interventions are aimed there, too, it was felt that the community component was important in their indicators work. He noted that questions need to be flexible to accommodate different contexts and circumstances, e.g. low prevalence, high prevalence, predominantly heterosexual transmission, predominantly IDU transmission. Once local issues have been identified, then one can go out to assess.
13. Lori Bollinger, Futures Group (presentation available on request), explained that the inclusion of non-PLHIV data provides some validation, an avenue for triangulating the data. It was pointed out in discussion that in majority/minority situations, often there is a majority population that perceives the minority as a threat or a burden. In communities with low prevalence, many have noted that

Appendix 2: Discussion of current work and developments since 2004

stigma can be very high. For example, people may feel that resources are limited and that money being spent on care and support for people living with HIV does not necessarily produce a “community” benefit. She explained that, in an ideal world, a big population survey would form the basis of an index project, comprising data on the community level, service provision and people living with HIV. Collecting such data, however, is extremely costly. The Futures Group has sought to research secondary data and bring it into the framework of an index. The three different domains – community, service provider and people living with HIV – are equally weighted, with varying numbers of individual indicators in each of the three domains. Data to bring into the framework, however, is extremely limited, even in places that otherwise give significant attention to stigma and discrimination in qualitative and normative terms. There are remaining questions of how to represent the studies incorporated, i.e. with the number of studies stated or the number of people surveyed, and a confidence interval constructed on that basis.

14. Ralf Jürgens pointed out that all the indices under review did not sufficiently capture the experience of people living with HIV who were drug users, sex workers or men having sex with men. For these groups, much of the stigma and discrimination was attached to those statuses not to HIV.
15. Fiona Pettitt, International Community of Women Living with HIV/AIDS, spoke of the network’s activities to address the experience of stigma and discrimination in the lives of its members. In particular, she highlighted *Voices and Choices*, a research project that was conducted in Zimbabwe and Thailand to address sexual and reproductive rights. In both countries the project engaged positive women as researchers. There have been other ICW projects of possible relevance to the human rights and indicators work under consideration. ICW-Latina recently carried out research on the rights of positive women throughout Latin America, including a review of the legal framework in each country of the region. An IPAS ICW project is underway to produce a tool that can be used by and for women living with HIV to monitor the achievement of the Millennium Development Goals. The questions are directed towards positive women, as well as governments and service providers. ICW has also placed interns in the offices of parliamentarians in Namibia, Tanzania and Kenya to produce country profiles identifying national policies and assessing their responsiveness to international commitments, including conventions and treaties ratified. In the discussion, the importance of including questions with a gender focus in any future index or indicators work was underlined.
16. Moono Nyambe, GNP+/Positively Women, UK, noted the disparities between migrant communities and members of long-standing “majority” communities, and encouraged attention to how stigma and discrimination compounds. Often stigma and discrimination is generalised, and some questions will not get to these more nuanced points. Rates of prosecutions for transmission of HIV are growing in places, and perceptions of some people as criminal, and/or possibly HIV positive, are reinforced accordingly.

Appendix 3: Discussions leading to setting of objectives

1. Some participants noted the importance of the development of indices on stigma and discrimination in terms of the negative effects that stigma and discrimination have on the response to the epidemic and to programme effectiveness. For example, information gathered from the index should be of use to programme planners when designing interventions to overcome barriers to treatment and care. Such indices would also enable evaluation of efforts to reduce HIV-related stigma and discrimination, as well as foster responsibility and accountability in this regard within each national context. The failure to adequately address the determinants of the epidemic, including stigma and discrimination, which are blocking effective programmes, is sufficiently clear: in 20-plus years over 60 million people have become infected. But more data is needed on how exactly stigma and discrimination blocks efforts regarding testing, condoms, treatment etc. and what is effective in overcoming stigma and discrimination.
2. Some participants cautioned that an index should not aspire to only say something about the effectiveness of programmes. Where there are multiple programmes running, in addition to a range of other factors and circumstances, it will be difficult to attribute positive or negative developments to the existence of a particular intervention. An excellent anti-stigma programme may not touch other structural barriers which stand in the way of broader objectives. Stigma and discrimination reduction, while a significant objective in itself, will not directly address challenges such as cost of treatment, or geographic proximity of necessary care.
3. It was stressed that projects need to be of a scope and scale that allows groups of people living with HIV to lead, and build capacity through their activities. The goal should be to increase voice, understanding and, ultimately, empowerment. PLHIV networks in most places remain relatively weak. If an index could, for example, focus on the seven things that matter most in day-to-day life as a person living with HIV, then there might be a foundation for a global expression of the experience of people living with HIV and a means of monitoring trends and variation over time. It was underlined again that limited resources, as well as competing care and support priorities in many if not most places, mean that there is little room for an ambitious, multi country project with large samples of people living with HIV. An index would need to be closely linked with the overall objectives of stigma and discrimination reduction, as would the interviewing and measurement activities.
4. The potential to link this work with other mechanisms and initiatives was also considered, including monitoring and evaluation efforts and reporting for UNGASS. These linkages would also result in greater visibility for networks of people living with HIV, nationally and globally. It would also give specificity to some of the UNGASS indicators that are regarded as a bit “fuzzy” in the area of human rights.
5. The group considered what terminology and labelling to use for the index, notably whether it should focus on stigma and discrimination or whether it should address human rights broadly. In adding human rights, it was felt that it might not be helpful and could add a layer of complexity because one has to get into the views

Appendix 3: Discussions leading to setting of objectives

and understandings of “human rights” of study respondents, and the understandings of governments and others that are presented with findings. It would be possible to do human rights analysis for some purposes with the data that is produced, but it would be harder to do this from the beginning. Some elements will involve clear human rights violations, while others may only give partial insight related to the realisation of a particular right.

6. Other key points raised while finalizing the wording of the goal and objectives:

- The voices of people living with HIV need to be more audible in the response to the epidemic; people living with HIV are often best situated to articulate what environments enable them to do things they might not otherwise be able to do.
- Different groups have been working on stigma and discrimination indicators independently of each other, and as a result, no one has an instrument that has been used on a wide scale. This is an important opportunity to look at the questions that have been asked, and see where there is agreement on what could form a core set of questions that, if widely used, would produce data that is more easily comparable.
- If there was a tool that was supported and disseminated by UNAIDS, people would be more likely to take notice of it, and funders would hopefully be more likely to put money behind it. It will not only be an advocacy tool but a “process tool” that enhances the capacity of those who are engaged in using it.
- Agreement on key questions is important at the outset, creating a baseline from which one can measure change within countries
- It would be great if networks of people living with HIV took this idea up and ran with it, producing tremendous amounts of data – it could stimulate the other areas of work and funding for the related initiatives.

Appendix 4: Draft PLHIV Indicators

<input type="checkbox"/> % who report having been afraid of being excluded from religious/social activities as a result of HIV positive status	_____%	
<input type="checkbox"/> % who report having been afraid of being excluded from familial activities as a result of HIV positive status	_____%	
<input type="checkbox"/> % who report having been afraid of family members being discriminated against because of HIV status	_____%	
<input type="checkbox"/> % who report having been afraid of being refused services (employment, housing, education) as a result of HIV positive status	_____%	
<input type="checkbox"/> % who report having been afraid of rejection because of social or sexual contact as a result of HIV positive status???	_____%	
<input type="checkbox"/> % of PLHIV women who report having been afraid of being forced or coerced related to infant feeding practices	_____%	
<input type="checkbox"/> % who report having been afraid of being discriminated against by other PLHIVs	_____%	
<input type="checkbox"/> % who report having been afraid of being discriminated against for physical appearance (lipodystrophy, weight loss, etc)	_____%	
<p>HIV STATUS OR OTHER???</p>		
<p>Indicator #3: Percent of PLHIV who have disclosure issues related to their serostatus ???</p>	_____%	
<input type="checkbox"/> % who report disclosing beyond a few trusted individuals (family members, employers, health professional other than primary physician, etc.)	_____%	
<input type="checkbox"/> % who report disclosing to primary sexual partner within 6 months of knowing serostatus	_____%	
<input type="checkbox"/> % who report disclosing to injecting partner(s) within 6 months of knowing serostatus ¹	_____%	
<input type="checkbox"/> % who report positive reactions to disclosure	_____%	
<input type="checkbox"/> % who report HIV status was revealed without their consent	_____%	
<input type="checkbox"/> % of PLHIV who report being afraid that their records will not be kept confidential	_____%	
<input type="checkbox"/>	_____%	

Appendix 4: Draft PLHIV Indicators

<p>Indicator #4: Percent of PLHIV who in the past year have experienced internal stigma (Average of various answers)</p>	<p>_____ %</p>	
<p><input type="checkbox"/> % who report choosing not to access (or excluded themselves from) because of HIV status:</p>	<p>_____ %</p>	
<p> 1. Not to access local health care</p>	<p>_____ %</p>	
<p> 2. Seeking health services in general</p>	<p>_____ %</p>	
<p> 3. Education or employment opportunities</p>	<p>_____ %</p>	
<p> 4. Relationships with friends or relatives</p>	<p>_____ %</p>	
<p> 5. Social gatherings</p>	<p>_____ %</p>	
<p> 6. Having a sexual relationship, getting married or having a child</p>	<p>_____ %</p>	
<p> 7. Travel</p>		
<p><input type="checkbox"/> % who report negative feelings because of your HIV status in the past year (guilt, shame, blame, suicide, punishment, etc.)</p>	<p>_____ %</p>	
<p>HIV STATUS OR OTHER???</p>	<p>_____ %</p>	
<p>Indicator #5: % of PLHIV who report experience of protection through law, policy and practice in relation to HIV-related stigma and discrimination</p>	<p>_____ %</p>	
<p><input type="checkbox"/> % who report knowledge of laws and policies which respect or promote their rights</p>	<p>_____ %</p>	
<p><input type="checkbox"/> % who are involved directly or indirectly in policy-related development</p>	<p>_____ %</p>	
<p><input type="checkbox"/> % who report accessing system for legal OR ADMINISTRATIVE remedies</p>	<p>_____ %</p>	
<p><input type="checkbox"/> % who report accessing system for legal remedies which have had some resolution (dealt with)</p>	<p>_____ %</p>	
<p>HIV STATUS OR OTHER???</p>	<p>_____ %</p>	
<p>Indicator #6: % of PLHIV who report experiences with empowerment and support in relation to HIV-related stigma and discrimination</p>	<p>_____ %</p>	
<p><input type="checkbox"/> % who report having influence in community decision-making (questions to address type of influence)</p>	<p>_____ %</p>	

Appendix 4: Draft PLHIV Indicators

<input type="checkbox"/> % who report having confronted or challenged someone stigmatizing them		
<input type="checkbox"/> % who report having supported other PLHIVs		
<input type="checkbox"/> % who report the ability to have constructive dialogue with health care professional (sexuality, drug use, treatment options, treatment side-effects, etc.)	_____ %	
	_____ %	
	_____ %	
Indicator #7: % of PLHIVs who report issues related to access and quality of care	_____ %	
	_____ %	
<input type="checkbox"/> % who report being refused health services as a result of HIV positive status (including dental care)	_____ %	
<input type="checkbox"/> % who report having received lower quality or differential health services as a result of HIV positive status (including complete information, beyond universal precautions, hostile treatment)	_____ %	
<input type="checkbox"/> % who report having been afraid of receiving lower quality of health care as a result of HIV positive status	_____ %	
<input type="checkbox"/> % who report being denied health or life insurance because of HIV status	_____ %	
<input type="checkbox"/> % of PLHIV women who report having been forced or coerced in relation to pregnancy	_____ %	
HIV STATUS OR OTHER???		

Demographics

1. times since diagnosis
2. situation around diagnosis
3. age
4. sex
5. education
6. treatment access
7. socio-economic status
8. marital status
9. partner status
10. urban – rural settings

Other issues: comments

1. People not choosing to disclose
2. Consider consequences?
3. what is the legal or political framework

Appendix 5

Plan of Action for development of an index for and by people living with HIV

- **Distribution of the report from this meeting (UNAIDS)**
Deadline: 2 September
- **Agree to overall coordination of effort between GNP+, ICW, UNAIDS and IPPF**
Deadline: London, 6 September
- **Editorial finalization of PLHIV indicators and consolidation of questions (IPPF/UNAIDS/GNP+/ICW)**
Deadline: 9 September
- **Presentation to UNGASS 2006 Civil Society Planning Meeting, Recife (IPPF/UNAIDS to coordinate)**
Deadline: 15 September
- **Agree process to develop strategy to run indicators in pilot countries to reflect regional and epidemic differences and communicate to meeting participants (IPPF/ICW/GNP+/UNAIDS)**
Deadline: 15 September
- **Exploration of getting onto Toronto 2006 Agenda (UNAIDS)**
Deadline: 14-16 October
- **Developing questionnaire and operational guidance (IPPF to facilitate process – consultant)**
Deadline: End of October
- **Finalizing indicators for whole spectrum – PLHIV, service providers, community (L. Bollinger)**
Deadline: End of November
- **Translate tool (and back translate) (UNAIDS)**
Deadline: End of November
- **Identification and training of interviewers (TBC)**
Deadline: End of November
- **Pilot test tool with three interviewers in different countries targeting 10-12 individuals (TBC)**
Deadline: By end of December
- **Field Testing/Piloting of Indicators (UNAIDS M&E, ICW, GNP+, IPPF)**
Timeline: January-March 2006
- **Develop self completion survey for Lima and agree use of results (UNAIDS/GNP+/ICW to coordinate)**
Deadline: End of January 2006

Appendix 5

- **‘Global Self Completion Survey’ and session at PLHIV Conference, Lima**
(GNP+, ICW to coordinate)
Deadline: 13 March 2006
- **Report on Stigma and Discrimination – including lack of data and newly developed tool – to UNGASS and Toronto 2006** (UNAIDS to coordinate)
Deadline: End of April

Appendix 6: List of Participants

Meeting on the development of an index on human rights, stigma and discrimination by and for people living with HIV

Geneva, Switzerland
22-23 August 2005
Room 1, World Council of Churches (WCC)

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Appendix 6: List of Participants

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Nicole Massoud

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Sally Smith

Programme Development Adviser

Jason Sigurdson

Programme Officer

Joyce Matovu

Secretary

Appendix 7: List of background documents

International Federation of the Red Cross, *Developing Indicators for Measuring Stigma and Discrimination and the Impact of programmes to reduce it: Summary of Projects and Research to Date.* (pp.43)

<http://www.ifrc.org/docs/pubs/health/hivaids/antistigma/Stigma%20indicators%20and%20measurements-new.pdf#xml=http://www.ifrc.org/cgi/webinator/tehis.exe/webinator/search/xml.txt?query=Stigma+and+Discrimination&pr=english&order=r&cq=&id=42c0dcca2>

Asia Pacific Network of People Living with HIV/AIDS (2004), *AIDS Discrimination in Asia.* (pp.57)

<http://www.gnpplus.net/regions/files/AIDS-asia.pdf>

S. Paxton *et al.* (2005), "AIDS-related discrimination in Asia". *AIDS Care* 17(4):413-424.

<http://www.ingentaconnect.com/content/routledg/caic/2005/00000017/00000004/art00001>

Synergy Project and USAID (2005), *Measuring HIV Stigma: Results of A Field Test in Tanzania.* (pp.222)

http://www.synergyaids.org/documents/StigmaIndicatorsReportFinal_JuneEdited.pdf

International Center for Research on Women (2005), *Common at Its Core: HIV-related Stigma Across Contexts.* (pp.45)

http://www.icrw.org/docs/2005_report_stigma_synthesis.pdf

ICW (2002), *Positive Women: Voices and Choices -- Zimbabwe Report.* (pp.96)

<http://www.icw.org/icw/files/VoicesChoices.pdf>

ICW, *HIV Positive Women and Human Rights.* (pp.8)

www.icw.org/tiki-download_file.php?fileId=59

UNAIDS (2005), *HIV-Related Stigma, Discrimination and Human Rights Violations: Case studies of successful programmes.* (pp.74)

http://www.unaids.org/html/pub/una-docs/jc999-hrviolations_en_pdf.pdf

UNAIDS (2000), *Protocol for the identification of discrimination against people living with HIV.* (pp.44)

http://www.unaids.org/html/pub/publications/irc-pub01/jc295-protocol_en_pdf.pdf

Documents distributed by participants at the meeting:

USAID (2005), *Stigma and Discrimination Indicators Working group: An update from the field.*

S. Kalichman *et al.* (2005), "Development of a Brief Scale to Measure AIDS-Related Stigma in South Africa", *AIDS and Behaviour* 9(2)

POLICY and APN+ (2005), *Baseline Survey Results on GIPA and Stigma and Discrimination in the Greater Mekong Region.* (Draft, 3 August 2005.)

POLICY, ICRW, Horizons and Measure Evaluation (2004), *HIV/AIDS-related Stigma and Discrimination Indicators Development Workshop Report.*

ICW (2005), *Positive Women monitoring change: A monitoring tool on access to care, treatment and support, sexual and reproductive health and rights and violence against women, created by and for women living with HIV and AIDS.*