Background: Understanding Stigma

HIV related stigma and discrimination are widely recognized as barriers to accessing HIV prevention, treatment and care services. Without concerted action the goal of universal access will be impossible to achieve.

Much of what we know about the stigma attached to HIV, and resulting discrimination, is anecdotal or fragmented. Existing surveys of community and healthcare provider attitudes mean much more is known about their influence. However, the only true test of whether stigma and discrimination is being reduced is to measure the opinions of people living with HIV themselves. Determining whether HIV related stigma is attributable to HIV status or because of associated factors (e.g. sex work; injecting drug use; sexual orientation; poverty) or a combination of these elements is a key determinant of revised programmatic interventions. To date, an in-depth and rigorous understanding of the personal experiences of PLHIV remains largely elusive.

The People Living with HIV Stigma Index - utilizing participatory and operational research methodologies - will fill this gap in our global understanding. The experiences of people living with HIV can then be triangulated with the two existing survey approaches to allow a comprehensive picture of stigma and discrimination to emerge. This can be used for informing policy and programme change and addressing the subtlety of HIV related stigma.

The Aims of the Index: Process and Product

1) Increasing advocacy and building the evidence base: The Index will increase the understanding of how stigma and discrimination is experienced by people living with HIV. The evidence gained will then shape future programmatic interventions and policy change.

Policy and programme managers have long recognised that action is needed to address stigma and discrimination. The information gained from the Index will provide evidence for the success (or otherwise) of current programmes and highlight neglected areas requiring future action such as improving workplace policies, informing debates about the criminalisation of HIV transmission, and promoting the realisation of human rights. Consequently, the Index will be a powerful advocacy tool which will support the collective goal of Governments, NGOs and activists alike to reduce the stigma and discrimination linked to HIV.

2) Operationalising the Greater Involvement of People Living with HIV: The Index is a tool to be used by, as well as for, PLHIV. The Index supports the GIPA (Greater Involvement of People living with HIV and AIDS) Principle through being driven by PLHIV and their networks. By acting on this principle the Index will simultaneously empower the individuals and communities most affected by the epidemic.

As the Index moves from concept to scale-up it will be adopted by a variety of different PLHIV groups. Its design and construction allow it to be used independently. Groups can then use it to understand experiences of stigma and discrimination in their locality. The use of the Index over time – in conjunction with these surveys – will be key to increasing our collective understanding and detecting changes and trends.

The benefits of the Index for those conducting it go further than collecting much-needed evidence. The process of empowering PLHIV, their networks and communities is crucial – a critical ingredient of ensuring that the GIPA principle is operationalised. The Index will therefore be both a catalyst for and foster change in the communities in which it is used.
Primary Partners: Collaborative Action

The Index is a result of a partnership between IPPF, UNAIDS, ICW (the International Community of Women living with HIV) and GNP+ (the Global Network of People living with HIV). Since 2004 these partners have led a broad consultation process and the final comprehensive tools build on existing work by numerous organizations and specialists in Index design. The Index questionnaire and user’s guide have been tested and piloted by networks of people living with HIV in India, Kenya, Lesotho, South Africa and Trinidad and Tobago. The tools (questionnaire and user guide) have now been revised and finalised, regional capacity building workshops have been conducted and strategic planning is underway for the worldwide rollout of the index.

The Index comprises a questionnaire with an accompanying users’ guide. The questionnaire explores ten key areas: 1. experiences of stigma and discrimination and their causes, 2. access to work and services, 3. internal stigma, 4. rights, laws and policies, 5. effecting change, 6. HIV testing, 7. disclosure and confidentiality, 8. treatment, 9. having children and 10. problems and challenges. The user’s guide supports the interviewers from the PLHIV networks. It ensures consistency, confidentiality and sensitivity in the use of the questionnaire.

Disclaimer

The People Living with HIV Stigma Index is intended for use as an empowering research tool for developing evidence based advocacy by and for people living with HIV. The Index has been developed through extensive field testing in pilot studies and when implemented in its entirety (as outlined in the user guide) has shown to be a valid and reliable tool. It is not intended for any other use. The coordinating partnership of the index accepts no responsibility for applications of the index beyond the intended purpose outlined and additional ethical and reliability tests should be undertaken if the index is adapted in part or in whole.

More information about the People Living with HIV Stigma Index

www.stigmaindex.org

Additional resources about HIV stigma and discrimination

6. The Greater Involvement of People Living with HIV (GIPA) (March 2007). This UNAIDS Policy Brief is available from the UNAIDS website: www.unaids.org.
7. Start the Press: How African communities in the UK can work with the media to confront HIV stigma (October 2007). Published by Panos London and the African HIV Policy Network (AHPN) and available from AHPN. Website: http://www.ahpn.org/.
8. A series of publications on various aspects of HIV-related stigma and discrimination, which was produced by the POLICY Project in January 2006 and available from their website: www.policyproject.com:
   b. Can We Measure HIV/AIDS-related Stigma and Discrimination? Current knowledge about quantifying stigma in developing countries; Laura Nyblade and Kerry MacQuarrie.