PLHIV-related stigma

Stigma and discrimination are widely recognized as major hindrances to accessing HIV prevention, treatment and care services. Stigma is ‘an attribute that is deeply discrediting’ and results in the reduction of a person or group ‘from a whole and usual person to a tainted, discounted one’. This results in ‘the reduction of the life chances of the stigmatized person through discriminatory actions’. (Goffman, 1963)

HIV-related stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexuality and race. For example, the stigma associated with HIV is often based upon the association of HIV with already marginalized and stigmatized behaviours, such as sex work, drug use and same-sex and transgender sexual practices (UNAIDS, 2005). Internal stigma, also referred to as ‘felt’ stigma or “self-stigmatization”, is used to describe the way a person living with HIV feels about him/herself and specifically if he/she feels a sense of shame about being HIV-positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and depression and may result in a withdrawal from social and intimate contact.

About the People Living with HIV (PLHIV) Stigma Index

The PLHIV Stigma Index collects information on stigma, discrimination and the rights of people living with HIV that will help in advocacy efforts. The main aim of collecting this information and presenting it in the form of an index is to broaden understanding of the extent and forms of stigma and discrimination faced by people living with HIV in different countries. The intention of the participating organizations is to make the Index widely available so that it can be used as a local, national and global evidence-based advocacy tool.

The process of implementing the Index is intended to be an empowering one for people living with HIV, their networks and local communities – a critical ingredient for ensuring that the GIPA Principle is renewed. The PLHIV Stigma Index both fosters change within communities as it is being used, as well as being a tool to advocate for changes in laws, policies, programmes and practices according to the index data.

What are the objectives of the PLHIV Stigma Index?

The evidence gathered by the PLHIV Stigma Index allows quantifying the intangibleness of stigma, in other words, for the first time to gather evidence about what is already known anecdotally. This will enable:

- moving from a concept to real evidence;
- giving voice to thousands of PLHIV;
- the empowerment of all involved;
- documenting the experiences of people living with HIV within a particular community or country regarding HIV-related stigma and discrimination;
- creating a database that measures geographical, demographic as well as temporal trends;
- putting forward evidence-informed recommendations for policy and programming;
- designing and implementing stigma-reduction policies and programmes based on evidence;

Who implements the PLHIV Stigma Index?

- The national partnership should be driven by PLHIV networks, ensuring full participation of PLHIV throughout the process of implementation, including building partnerships, planning, implementation, budgeting and resource allocation, research and data analysis, monitoring, evaluation, disseminating the research results and other advocacy.
- Each national partnership should include a research partner (e.g. an academic institution).
Multi-sector government participation is recommended in the national partnership, and involved as appropriate in the planning, implementation and reporting on the Index. The National AIDS council and ministries responsible for health, human rights, education and other related areas could be included in information meetings, reviewing project proposals and research dissemination activities. Interested multilateral and bilateral donor agencies should also be included.

**PLHIV Stigma Index Methodology**

- The questionnaire should not be changed or adapted, though additional sections could be added as required by national partnership to focus on specific local context themes (e.g. gender violence), key populations (e.g. MSM), accessing services (e.g. experiences in different health care settings), and/or cultural needs (e.g. religion).
- Each national partnership should seek to develop qualitative work to compliment the work conducted through the index, in consultation with GNP+.
- Each national partnership should ensure that the work of the *People Living with HIV Stigma Index* is implemented and linked with other studies of stigma and discrimination relating to HIV in the country context.
- The national partnership should seek to maintain a gender balance in terms of PLHIV involved in the project at the level of leadership, capacity building, and data collection.
- In each country, ethical and data protection requirements must be met (see part 3 of the User Guide regarding ethical issues).

**Particularly important methodology issues:**

- In each country, the national partnerships should ensure that participation is open to all people living with HIV from a variety of different organisations and networks. Mechanisms should be put in place to protect the confidentiality of all individuals involved in the implementation of the Index, not only of interviewees.
- The national partnership should ensure that support (logistical, emotional, technical) is provided to the interviewers involved in the research.
- Transparency of the coordination of the national rollout and accountability to all stakeholders (national and international) is essential.

**Further Support**

Implementation is a lengthy process that could take from 6 to 12 months. Further guidance is available at www.stigmaindex.org or http://gnpplus.net/en/programmes/human-rights/plhiv-stigma-index.

For information on the HIV Leadership through Accountability programme visit www.hivleadership.org.