

HIV/AIDS Update

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Stigma

Stigma and discrimination against people associated with or living with HIV is often cited as one of the primary hurdles in addressing prevention and care issues, and as a stumbling block in ensuring access to essential services.

Despite all we have learned over the past twenty years about HIV-related stigma, it continues to thrive – fuelling the continued expansion of the epidemic. Stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexual orientation, behaviour and race. The devaluing power of stigma results in acts of overt discrimination and hampers access to vital services. As an organization founded on principles of human rights and ethics, IPPF is well positioned to ensure that we find creative and innovative mechanisms to combat its impact.

It is all too often assumed that stigma is directly related only to the HIV positive status of an individual, but key vulnerable populations such as sex workers, men who have sex with men, injecting drug users, and young women and girls, often face a 'double stigma'. *The People Living with HIV Stigma Index* aims to increase the global understanding

of stigma by ensuring that the experience of stigma (as 'felt' by people living with HIV) is succinctly addressed in both improved policy and programme responses (see page 2).

As champions of the *NGO Code of Good Practice* - which sets out evidence-based, good practice principles that underscore successful NGO responses to HIV – IPPF has been involved in the development of a number of self-assessment tools. Two relevant modules, focusing on stigma and discrimination and the meaningful involvement of people living with HIV, will help you consider your own programmes based on good practice, and will also help to identify areas that can be strengthened (see page 4).

Another way of combating stigma within an institutional setting is through an HIV workplace policy (see page 3). A workplace policy, by bringing HIV out into the open, reduces stigma and discrimination as it lays down

a standard of behaviour for all employees (whether infected or not). It gives guidance to supervisors and managers and helps employees living with HIV to understand the support and care available to them. IPPF has a sound and robust workplace policy and programme which has acted as a catalyst for many of our regional offices and Member Associations to develop their own policies. While the percentage of our Member Associations that have a workplace policy in

place has increased from 30.1% in 2005 to 40.7% in 2006, collectively we need to ensure that more is done.

Fundamentally the fight against HIV must be won at the individual level - where the realities of having to live, love, and work in the context of the epidemic need to be internalised. It begins with each one of us.

Love Kevin,
Kevin Osborne
Senior HIV Advisor



Understanding stigma

Listening to people living with HIV



Stigma limits access to health services by silencing discussions about taboo issues such as race, poverty, gender relations, sexuality and behaviours, all of which are integral to HIV prevention, treatment and care. Stigma reveals itself not only in issues that are presented as scandals or reported inaccurately, but also in what is left unsaid and voices that are not heard. It is both what is talked about and how, as well as what is silenced and why, that fuel the vicious cycle of stigma and marginalization.

Much of what we know about the stigma attached to HIV, and the resulting discrimination, is anecdotal or fragmented, and does not include the voices and perspectives of people living with HIV. The *People Living with HIV Stigma Index* will fill this gap in our global understanding, and build an evidence base to inform policy and practice. Guided by a trained facilitator, people living with HIV will complete a questionnaire about their perceptions of stigma in the following 10 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
- 10 problems and challenges

The questionnaire aims to delve into the complexity of stigma, and explore how the experience of living with HIV cuts across the other dimensions of a person's life (such as work, family, laws, accessing health services, activism and self-esteem).

The pilot phase was done in Lesotho, South Africa, Trinidad and Tobago, Kenya and India; the tools (questionnaire and user guide) have now been revised and finalised. With these building blocks now in place, we are ready for roll-out in 2008. The tools are currently only available in English, however translations into Spanish, French, Arabic, Russian and Chinese will follow shortly.

Building strong foundations

The strength of the index is that it is a research tool to be used by, as well as for, people living with HIV. All those chosen to be regional trainers will be people living with HIV. This is central to the rollout of the research at the regional and national level, as well as to the coordination of the project between the international partners (IPPF, UNAIDS, GNP+ and ICW). At all levels, there is a fundamental recognition that the process is as important as the outcomes.

“Being interviewed by another person living with HIV does make a difference – as you feel they really would understand more about how you feel about things related to being HIV positive”

Researcher, pilot workshop Johannesburg 2006

Drawing on the support provided by the different structures of the partners in each region, IPPF will coordinate the training of at least 10 representatives from networks and organizations of people living with HIV in every IPPF region. These global trainers will be responsible for supporting the application of the index in each country, which will happen once funding has been secured for the expansion of the index at a national level. Working together on the regional rollout of the index will also offer us the chance to strengthen relationships with networks of people living with HIV in every region. It will also provide an excellent opportunity to share ideas and lessons learned between each of the IPPF regional offices.

From Principle to Practice in the Dominican Republic

PROFAMILIA is coordinating the first national rollout of the People Living with HIV Stigma Index. The purpose of the project is to strengthen the actions intended to reduce the stigma and discrimination of people living with HIV in the Dominican Republic and to increase their participation in decision-making processes on prevention, care and treatment programmes. The project will also include a special focus on women, promoting their participation in decisions dealing with HIV prevention and care.

The stigma index will be rolled out in four regions of the country, aiming for a total of 800 responses (200 from each geographic region). The findings will be distributed to

decision-makers, donors and key actors in the response to HIV in the Dominican Republic and will enable comparisons of the situation among different groups of people living with HIV in different regions of the country.

The main results of the project will be:

- 1 An estimate of the levels of stigma and discrimination experienced by people living with HIV, and their participation in the national response
- 2 Support for actions directed at reducing stigma and discrimination towards people living with HIV, and improving their participation in decision-making mechanisms

Lucy Stackpool-Moore has recently joined IPPF to coordinate this project. Please contact her if you would like any additional information or to find out more about the workshops in your region (lstackpoolmoore@ippf.org).

Measuring up! Leading by example

“HIV stigma and discrimination occur within a wide range of settings – including in the workplace.”

(DfID, *Taking Action Against HIV Stigma and Discrimination*, November 2007, p.3)

Much emphasis has been placed on ensuring that organizations advocating for the rights of people living with HIV are actually protecting the rights of their own staff and volunteers as well. A recent conference in Amsterdam (organised by Stop AIDS Now) brought donors and NGO staff together to critically reflect on the processes of developing workplace policies and look at ways to allocate resources to ensure that policies can be put into practice.

There is an ongoing need for organizations working to promote human rights and health for people living with HIV to have their own houses in order. One of the presenters at the conference in Amsterdam, when speaking about the Code of Good Practice for NGOs responding to HIV, complimented IPPF for developing HIV workplace policies at all levels of the Federation, and for including people living with HIV in the process of developing the policies. For IPPF to continue to be one of the leaders in addressing HIV stigma and discrimination, we must continually strive to ensure that our HIV workplace policies and programmes remain proactive, relevant and responsive.

Some critical food for thought:

- Resource allocation: Even the best policies are meaningless without the resources to implement them. How can policies be owned locally and have enough resources for implementation, while also aspiring to meet international guidelines?

- Involving PLHIV: People openly living with HIV in an organization often take on a lot of leadership and responsibility for supporting colleagues and contributing to good management. This can often add increased workload which is not fully acknowledged in the formal job specification. How can these responsibilities and roles be appropriately recognized and appreciated?
- HIV exceptionality: Good policies relating to HIV in the workplace can offer an opportunity to improve workplace policies and management structures. How can the exceptionality of HIV offer opportunities to improve management and staff well-being more generally?
- Policy reach: We need to be mindful of who misses out even when excellent HIV workplace policies are in place. Does the policy provide cover for consultants, volunteers, or extended family members?

Strengthening the evidence base A modality of stigma reduction

Linking sexual and reproductive health and HIV is accepted as a way of providing comprehensive and integrated services. However, there is limited evidence on which combination of services will result in the reduction of HIV infection, HIV-related stigma and discrimination, as well as decrease in number of unintended pregnancies. IPPF, in collaboration with the London School of Tropical Hygiene and Medicine and the Population Council, has developed a research and service delivery initiative to assess the benefits associated with the provision of integrated services in Kenya, Swaziland and Malawi. This project has received support from the Bill and Melinda Gates Foundation and commenced implementation of activities for a five-year period from the beginning of January 2008.

What will the research look like?

Based on the experience of the Member Associations and government facilities in the three countries, three models of integration have been selected for the research study. They are:

- 1 Integrating HIV management through the provision of antiretroviral therapy into existing family planning and voluntary counselling and testing services.

- 2 Integrating voluntary counselling and testing into existing youth friendly family planning services.
- 3 Integrating HIV voluntary counselling and testing and clinical management of HIV into existing anti-natal and post-natal care programmes.

Within each of these models of integration, the research will assess the relative benefits of integrated services over separately provided services, and examine the effect integration has on the number and type of clients accessing services, the quality of the services offered, HIV risk behaviour, unintended pregnancy and HIV-related stigma. A full economic analysis is also planned to assess the feasibility and cost-effectiveness of providing integrated services.

What do we hope to achieve?

We have reached consensus on why it is important to advocate for greater linking of sexual and reproductive health and HIV but we do not, as yet, have the evidence to support this rationale. As IPPF continues to advocate for programmatic and policy decisions to be informed by evidence, the experience gained by this project will strengthen the research base.

The People at IPPF



Mathias Chatuluka

Programme Coordinator, Family Planning Association of Malawi (FPAM)

I have been working in the field of sexual and reproductive health and rights since the 1990s and acquiring a vast experience in programme planning, implementation and general project management. As a programme coordinator for FPAM, I am responsible for developing programmes and projects through proposal writing, publicity, communication and promotion of the organization's corporate image.

Over the years I have developed a special interest in HIV. It is an epidemic which has affected me personally with the loss of some relatives and friends to AIDS in the past 10 years. This has given me an inner passion to continue working towards reducing the suffering of those infected with and affected by HIV.

At FPAM, since 2004, there has been a shift towards focusing on vulnerable

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groups, especially young people aged 10-24, specifically young women, sex workers and market vendors. Apart from providing information in innovative ways such as safer sex promotion campaigns in discos and market theatres, the programme also provides voluntary counselling and testing, treatment

of sexually transmitted infections and opportunistic infections, and it links clients to programmes providing ART. Condom promotion and distribution is a major component of FPAM's HIV projects. I take special pride in this work as these innovations have helped a number of young people

to understand HIV and take the necessary actions to prevent its spread.

The desire to help people improve their lives and make the world a better place to live makes me wake up every day and want to go to work, even at times when I am not feeling very well!

News in brief

IPPF a new member of the Inter-agency Task Team on Prevention of HIV Transmission in Pregnant Women, Mothers and their Children (IATT)

In October 2007 IPPF became a member of the IATT. The IATT was set up in 1998 to contribute to the improvement and scaling up of programmes to prevent HIV infection in pregnant women, mothers and their children. This goal has since been expanded to address improving and expanding HIV care and treatment for children.

New publications Taking Action against HIV Stigma and Discrimination (DFID)

This new **Guidance Document and Supporting Resources** published by DFID acknowledges that stigma and discrimination against people living with HIV is a major cause of personal suffering and a major obstacle to mounting an effective response to the epidemic. The publication contains a wide range of information on the impact of stigma and discrimination and ways to address it. There is also a section on how stigma can be measured which includes information on the People Living With HIV Stigma Index. It is available at www.aidsportal.org/repos/stigma%20guidance%20doc.pdf.

NGO Code of Good Practice – Self Assessment Checklists

These new **self assessment checklists** on *Stigma and Discrimination and the Meaningful Involvement of People Living with HIV and Affected Communities* are designed to help NGOs measure where their programmes stand compared with the Code's global standards. These tools are available at <http://www.hivcode.org/>

Events

10 – 11 June 2008

UNGASS (HIV/AIDS)
New York, USA

29 July – 1 August 2008

Competencies Workshop for IPPF HIV focus countries and regional offices
Mexico City, Mexico

31 July – 1 August 2008

Living 2008: The Positive Leadership Summit
Mexico City, Mexico
<http://www.living2008.org/>

3 – 8 August 2008

International AIDS Conference
Mexico City, Mexico
www.aids2008.org

3 – 7 December 2008

15th International Conference on AIDS and STIs in Africa
Dakar, Senegal
<http://www.icasadakar2008.org/>

Internet resources

Criminalization Debate on AIDS Portal

<http://www.aidsportal.org/>

IPPF, in partnership with GNP+ and ICW, is facilitating an open series of discussions on the AIDS Portal over the next six months on the impact of criminalization of HIV transmission. Each of these discussions will seek to address the critical issues, and provide examples and case studies of criminalization of HIV transmission from different regions around the world. Issues raised will then inform a debate at the Mexico AIDS Conference and both will provide content for a booklet to be published by IPPF for World AIDS Day this year.

The first discussion will start on 1 March and run for two weeks. We need your contributions! It's free to sign up, just go to the web address above and follow the links on the right hand side. Please sign up and participate in the online discussions.

HIV Workplace Policy

If you would like to know more about HIV workplace policies you may find the following resources of use:

- **ILO Code of Good Practice** provides a set of guidelines for how to address HIV in the world of work and it can be used to develop an HIV workplace policy. It is available at http://data.unaids.org/HRM/hiv-workplace_ilo-code_en.pdf.
- **Code of Good Practice for NGOs responding to HIV/AIDS** www.ifrc.org/what/health/hivaids/code.
- **IPPF HIV Workplace Policy** is available on request from Jon Hopkins (jhopkins@ippf.org).

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