

HIV/AIDS Update

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With & for people living with HIV

The history of healthcare services has often seen a division between provider and client. A conventional view has been that the doctor or nurse 'knows best' and the client should accept this.

by Kevin Osborne

A key lesson of the last 25 years of the HIV epidemic is that this isn't the basis for a successful response. Many of the advances in the response to HIV have been driven by people living with HIV (PLHIV). PLHIV activism and leadership has forced governments, NGOs and communities to respond to HIV and has ensured that services are increasingly effective.

Ensuring that the voices of PLHIV are heard is both good policy and sound practice. Over the past few years a number of advocacy efforts have led to a greater recognition of the centrality of the Sexual and

Reproductive Health (SRH) of PLHIV. Work by IPPF with the International Community of Women living with HIV (ICW) and the Global Network of People living with HIV (GNP+) on publications such as 'Dreams and Desires' and 'Fulfilling Fatherhood' has focused attention on this. This work raised issues of the fertility desires of women living with HIV and the challenges for HIV positive fathers. Historically, many PLHIV had been warned by healthcare providers that they should never have sex or try to have children. Promoting the voices of those living with HIV has led to the reorientation of



services and approaches by the medical fraternity.

The GIPA principle (the greater involvement of people living with HIV and AIDS) is an international agreement that supports these ideas of participation and empowerment. First agreed in Paris in 1994, this principle is the foundation of a successful response. The UNAIDS policy brief featured in this newsletter (p3) illustrates some of the challenges in putting the GIPA principle into practice. In real terms this means addressing the hurdle that is stigma and discrimination. 'PLHIV Stigma Index', developed by IPPF, UNAIDS, GNP+ and ICW, is an innovative example of how the

principle can be turned into action (p2).

To live up to our mandate as a rights-based organization we must place participation and empowerment at the core of our HIV response. In practical terms, this means including people openly living with HIV (like we do our youth volunteers) in our governance at Member Association, regional office and Central Office level. Then the reality of HIV will become more vivid and our response more nuanced.

Love Kevin,
Kevin Osborne,
Senior HIV/AIDS Adviser

PLHIV's experiences of stigma and discrimination: the missing link

HIV-related stigma and discrimination pose critical barriers to HIV prevention, treatment, care and support programmes.

The role of healthcare providers and communities in perpetuating stigma is well known and understood. However, an in-depth understanding of people living with HIV's (PLHIV) experiences of stigma and discrimination remains largely elusive.

Any understanding is further obscured by reported changes in stigma. In contrast to the early stages of the HIV epidemic, many people in communities and health care clinics will now say they will share a cup, shake hands and even work alongside someone living with HIV. However, what people say under the controlled conditions of a survey can differ from their real underlying attitudes. To better understand real experiences, and not just reported attitudes, surveys also need to include the voices of people who experience stigma directly.

An Index

To fill this gap in understanding, IPPF - together with UNAIDS, the Global Network of People living with HIV (GNP+) and the International Community of Women living with HIV (ICW) - have developed an 'PLHIV Stigma Index'.

The Index has been developed through extensive consultation over the last three years, led by the four primary partners. This has involved consulting grassroots organizations, research experts, stigma and discrimination specialists and policy and programme managers. This has ensured that the Index will be effective, accessible and reliable.

The focus of the Index is a questionnaire structured around different factors of stigma and discrimination: personal experiences, having children, access to work and services,

internal stigma, causes, rights, laws, policies and HIV testing. When information is collected together it will allow trends to be detected in the experiences of stigma and discrimination. The questionnaire is supported by a user guide, which details the process of implementing the questionnaire with guidance on confidentiality, statistical significance, safeguards and ethical considerations.

By, and for, PLHIV

The process of gathering the information contained in the Index is as important as the goal of understanding stigma and discrimination. A central principle of the Index is that it will be done by, as well as for, PLHIV.

Fully in line with the Greater Involvement of People living with HIV and AIDS (GIPA) principle, the Index aims to empower PLHIV as well as address wider advocacy goals through data collection. In practice, this works by PLHIV being trained in using the questionnaire and then implementing it with PLHIV networks and individual PLHIV. The recent pilot of the Index (supported by IPPF and UNAIDS) involved a meeting of representatives from PLHIV networks in Kenya, India, Lesotho, South Africa and Trinidad and Tobago where they were introduced to the Index and trained in its use. This training played a key part in ensuring everyone understood the questionnaire and its development, and allowed useful feedback. These representatives field-tested the Index in their home countries. The resulting data has been used to adjust and finalize the questionnaire and also to build a preliminary picture of stigma in these countries.

The index allows the nuances and subtlety of stigma and discrimination to be detected over time. It has the potential to be an



Anandi Yuvaraj, a participant at the workshop in Johannesburg

important advocacy and policy tool for many different organizations working at community and policy levels.

Once finalized in July 2007, the Index will be free to be used by groups and organizations globally. It will be translated into different languages to facilitate this collaboration and global coverage. UNAIDS has also agreed to feature information on the Index in their annual report.

Several IPPF Member Associations (MAs) are starting to use the Index, using various funding sources, to start to understand the stigma and discrimination in their country. In addition, IPPF will be utilizing a number of opportunities, including conferences, to promote the Index. Regional offices and Member Associations that need support in the use of the Index are encouraged to contact Andy Guise in IPPF Central Office – aguise@ippf.org.

The People at IPPF

Anastasia Lomova

Russian Family Planning Association (RFPA), National Programme Coordinator

I have been at RFPA for more than 7 years. I am responsible for implementation of all projects under the Five A's. HIV-related issues have been incorporated into all activities undertaken by the Association. Recently, RFPA has been focusing on HIV and AIDS information campaigns for young, under-served, vulnerable people, and on integration of HIV prevention into our other sexual and reproductive health services. We are also paying a lot of attention to collaboration with other NGOs and establishing a multi-sectoral approach in the field of HIV in Russia.

I live and work in a huge country where HIV is still on the rise and the rights of people affected by HIV are not respected properly. The situation is severely affected by the poverty of the majority of the population, lack of gender-sensitive policies and sexual and reproductive health and rights education, and overall stigma and discrimination. This is the environment where HIV 'feels quite free and relaxed', which is unacceptable. Prompt actions should be taken in order to turn the situation around and stop HIV.

Being a member of the IPPF family is both an honour and responsibility. I feel lucky to be able to contribute to the global movement for sexual and reproductive health and rights.



Conference Update

FORO 2007

17-20 April 2007, Buenos Aires, Argentina

The Latin American Forum on HIV/AIDS and STIs (FORO 2007) was recently held in Buenos Aires, Argentina. This is one of the regional HIV conferences held every two years along with other conferences in Africa and Asia. The International Conference on AIDS in Asia and the Pacific (ICAAP) will be held in Sri Lanka during 19-23 August, and the International Conference on HIV/AIDS and STIs in Africa (ICASA) has been postponed until December 2008.

Many debates at the conference were framed around the drive towards universal access to HIV prevention, treatment and care services. There were several key themes within this debate:

1. the inequalities in access to HIV services across the region
2. threats to sustainability of services from international laws on patents and property rights concerning HIV treatments that limit the production and distribution of generic versions
3. the continued violations of human rights, particularly of groups most vulnerable to HIV infection (e.g. Men who have sex with men (MSM) and transgender)
4. low national government commitment to universal access efforts.

Underlining this whole debate is the low number of countries that have established targets for universal access. Of those with completed plans, only four countries included an indicator on condoms which highlights the lack of commitment to primary prevention in the region.

IPPF was well represented at the Conference by Member Associations (MA) from the region, the Western Hemisphere Regional Office and Central Office. The conference was a perfect opportunity for IPPF to promote our work and linkages agenda.



Buenos Aires - Argentina
Costa Salguero Convention Centre

"Latinamerica and the Caribbean:
united about diversity towards universal access"

The Western Hemisphere Regional Office and UNFPA organized a satellite session on the linkages between Sexual and Reproductive Health (SRH) and HIV. The session covered models for integrating services and the SRH needs of people living with HIV (PLHIV). Profamilia in the Dominican Republic presented their experiences of integrating HIV treatment and care into their existing services.

MEXFAM, the Mexican MA, was involved in a session organized by the International HIV/AIDS Alliance, promoting the NGO Code of Good Practice (also see News in brief). IPPF, along with CARE International, the Global Network of People Living with HIV, the International Council of AIDS Service Organizations, the International HIV/AIDS Alliance and the International Federation of Red Cross and Red Crescent Societies, are members of the Code steering committee. The presentation by MEXFAM highlighted the importance of the Code for NGOs that don't work exclusively in the field of HIV.

IPPF Central Office was also active in the Community Forum. This was an opportunity to highlight developments in the 'Index of stigma and discrimination experienced by PLHIV' (see p2). Interest in the Index was strong, and the groups and networks that attended are now following up in their countries to develop proposals for its use.

Another key theme at the conference was how the region has lost visibility in the global HIV arena, reflected in low international press coverage. Although in many respects the conference was a success, it suffered from poor organization and the lack of media profile undermines efforts to share its lessons, ideas and debates.

While the regional conferences continue, they provide important opportunities for IPPF regional offices to promote our collective work and linkages agenda. However, we also need to work with organizers to ensure efforts for these conferences reach much wider audiences.



Joint United Nations Programme on HIV/AIDS

UNAIDS

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Revitalising GIPA

"meaningful involvement,
not tokenistic participation"

In March, UNAIDS published a new policy brief, 'The Greater Involvement of People Living with HIV (GIPA)'. Since 1994 when it was first agreed, the GIPA principle has been a key part of the response to the epidemic. This policy brief aims to promote policy and programmatic action to ensure GIPA remains at the top of the agenda.

When the GIPA principle is put into action, it supports the right of people living with HIV to have active participation in decisions that affect their lives. This not only empowers individuals but also ensures that the response is relevant and effective.

The UNAIDS brief highlights the importance of people living with HIV (PLHIV) networks and organizations in GIPA. In addition, it recognizes the challenges faced by these groups: weak management, funding constraints and the difficulty of ensuring representation. Other than implementing GIPA, these organizations also face more immediate battles, such as ensuring universal access to treatment and prevention services.

The policy actions the brief contains are very relevant for IPPF: supporting legislation that mitigates discrimination; partnering with PLHIV organisations in training and capacity development; encouraging alliances and information sharing; and mainstreaming HIV in all areas of an organization. It is clear that IPPF has made huge strides in all of these areas.

Member Associations and regional offices are partnering with PLHIV networks and protecting rights through HIV workplace policies and the provision of services. As we strengthen our response to HIV it is essential that PLHIV, especially women and girls, are at the centre of our response.

The UNAIDS policy brief is available at
http://data.unaids.org/pub/Report/2007/jc1299-policybrief-gipa_en.pdf

News in brief

New project manager for the NGO Code of Good Practice

Having secured funds for the implementation phase of the Code of Good Practice, work has got off to a promising start. The new project manager, Susan Fox, has recently been appointed, and key projects have been initiated. Susan will be based at the International Federation of the Red Cross in Geneva, where the Code project is now hosted. The Code will also start developing its regional presence with staff based with AfriCASO in Senegal.

The targets for the Code over the coming years are to: Increase NGO endorsement and commitment to implementing the Code; improve the quality of programmes by enabling NGOs to apply Code principles in their work; and shape the funding and policy environment in favour of evidence based programmes informed by the needs of affected communities.

IPPF Sign-ons:

IPPF Central Office supports call for action on TB

Gill Greer, Director General of IPPF, recently signed a declaration demanding action on tuberculosis (TB) and HIV on behalf of the Federation.

The declaration will be submitted to the WHO, UNAIDS and other policymaking bodies, to advocate for urgent and coordinated action to address the dual TB and HIV epidemics. Those who have also signed the letter include advocates, researchers, and people living with TB and HIV from all regions of the world, gathering to mobilize an urgent response to the joint epidemics of TB and HIV.

Currently 40 million people are living with HIV, and at least 13 million are co-infected with TB and HIV. Yet, standard TB is curable. This letter supports action to deliver quality TB and HIV services and for a response to the epidemic of extremely drug resistant TB.

Treatment access and the G8

IPPF has also signed a letter to the G8 Heads of State highlighting the lack of leadership in supporting access to HIV treatment. Organized by the International Treatment Preparedness Coalition (ITPC) and the World AIDS Campaign it is being signed by groups from the HIV sector and beyond, including faith, labour, youth and women's groups.

IPPF WHR: PEPFAR and the PATHWAY Act

The IPPF Western Hemisphere Regional Office is supporting efforts to reintroduce the Protection Against Transmission of HIV for Women and Youth Act (the PATHWAY Act). If reintroduced it would be an important step in improving US HIV prevention policy. It would remove the requirement that the US spend a third of its international HIV prevention funding on abstinence-until-marriage programs (the 'abstinence earmark') and it would require the President to develop a strategy to address the specific prevention needs of women and girls.

Events

4–7 July 2007

YWCA International Women's Summit on Women's Leadership in HIV/AIDS
Nairobi, Kenya

22–25 July 2007

IAS Conference on HIV Pathogenesis, Treatment and Prevention (IAS 2007)
Sydney, Australia

23–27 July 2007

Competencies Workshop for IPPF HIV focus countries and Regional offices
Nairobi, Kenya

19–23 August 2007

International Conference on AIDS in Asia and the Pacific (ICAAP)
Colombo, Sri Lanka

29–31 October 2007

Asia Pacific Conference on Reproductive and Sexual Health (APCRSH)
Hyderabad, India

Internet resources

Understanding and challenging stigma – Change

<http://www.changeproject.org/technical/hivaids/stigma.html>

This toolkit has been developed through contributions from AIDS Activists from more than 50 different organizations. It contains workshop exercises that can be used to raise awareness of the issues and challenges around stigma and discrimination. They can be used with health care professionals as well as community groups.

UNAIDS case studies of stigma and discrimination programmes

http://data.unaids.org/publications/irc-pub06/jc999-hrviolations_en.pdf

This report from UNAIDS gives a clear and concise analysis of the causes and effects of stigma and discrimination. This is followed by 19 case studies of successful programmes that have been developed on stigma as a barrier to HIV prevention, treatment and care programmes.

PLHIV travel regulations

http://doc.ilga.org/ilga/publications/other_publications/hiv_aids_regulations

It is a sad indication of the stigma and discrimination experienced by PLHIV that many countries place restrictions on travel and residence. This website links to a report that details these restrictions in countries around the world.

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