LIVING 2008 Summit themes:

Positive Prevention

"The responsibility for reducing transmission of HIV is a shared one and there should be no undue burden on people who are aware of their status. Safer and responsible sexual behaviour is the responsibility of all partners – irrespective of status."

(LIVING 2008 delegate Alejandra Trossero, IPPF)

1 What is the issue?

Positive prevention (PP) is an approach to prevention that seeks to increase the psychosocial well-being of PLHIV and encourage solidarity amongst and for PLHIV. Part of PP is to engage PLHIV to propagate HIV prevention through activities such as social marketing and peer education. Traditionally, many public health experts have been defining the PP agenda within a non-holistic, non-human rights based framework that tends to be associated with blame and lays sole responsibility for primary prevention on PLHIV. There is also a sentiment that PP might be something that has been "imposed" on PLHIV. Because of this, communities of PLHIV themselves tend to have narrow perspectives of what PP is and do not necessarily see the benefits of being involved in PP. The challenge for communities of PLHIV - including women and those most affected– is to build consensus and define PP for themselves so they can develop effective, evidence-informed advocacy strategies to influence policy and services in this area.

There is a need to clearly state what PP means for PLHIV. Many PLHIV are not familiar with the term or do not have a good understanding of this approach to prevention. For PP measures to be successful, it will require buy-in from the PLHIV community, peer support, and opportunities for PLHIV involvement in the design and implementation of PP initiatives as well as a coordinated communication mechanism to ensure an informed and knowledgeable PLHIV community. What is crucial in this, is that PP needs to be based on a culture of shared responsibility, which means that the responsibility for avoiding HIV transmission is not only placed on the person living with HIV but on both partners and that there is an environment of open communication and equality in relationships ("we are all responsible for prevention"). The focus of PP should be on people's well-being as a whole and not on "HIV positive versus HIV negative"; and that PP needs to be an empowering concept, not one associated with blame or shame.

In addition, there is a consensus that PP should be defined and owned by PLHIV - and not imposed and defined as a concept from outside the PLHIV community. Stigma and discrimination, which is still pervasive, needs to be tackled for PP to be successful.

2 What are the key advocacy messages on Positive Prevention?

At LIVING 2008, there was no consensus among delegates on the concept of positive prevention. Some of the contentious issues raised were:

Terminology: Most LIVING 2008 participants were not content with the term "positive prevention". For most participants, the term had "negative connotations", implying an unjust and unrealistic burden of responsibility for transmitting HIV on the part of the person living with HIV. The term was "too broad, meaning nothing" or could be "stigmatizing". In some Asian countries, positive prevention – when translated into the local languages – could imply or be reminiscent of quarantining PLHIV.
Donor-driven agenda: Some LIVING 2008 participants voiced that positive prevention was a donor or government driven concept and not owned by the community of PLHIV.
Lack of clarity regarding the target group of positive prevention: is it targeting only PLHIV or also HIV-negative people?

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LIVING 2008 participants objected most to the idea that positive prevention could imply a sole responsibility for HIV transmission on the part of the person living with HIV – and not a shared responsibility of both partners. As a matter of fact, regarding one positive prevention issue there was a clear consensus among LIVING 2008 participants: prevention should always be a shared responsibility of all partners, irrespective of their status.

In conclusion, there is a need for more discussion to reach agreement on the concept of positive prevention. PLHIV need to claim ownership of positive prevention if it is meant to work in the future.

3 What are the envisaged next steps?

- UNAIDS and WHO should revise their definitions of positive prevention and ensure PLHIV participation in this process.
- Establish a Latin America / Caribbean working group – and possibly other regional ones - to further discuss and better define positive prevention.

4 What is needed from the following audiences (in the next 12 - 24 months) to address this issue and remove some of the 'barriers?

International Donors

Support International agencies, NGOs and PLHIV networks that work within the (broad) framework of PP to work directly with PLHIV to define and implement positive prevention

Policy makers

Involve PLHIV directly in the development of polices related to prevention with positives, as well as primary prevention

National Programme managers

Directly involve PLHIV in prevention programme implementation.

PLHIV Community

Further develop the concept of PP and work towards consensus on the definition of PP, its components and what it means for PLHIV

Researchers

Involve PLHIV in the development and implementation of PP research agendas, including new productive technology, treatment as prevention, PEP, PREP and innovative ways to implement "traditional" prevention programmes.

5 Suggested additional reading/information on this issue:

Positive Prevention: Prevention Strategies for People with HIV/AIDS, by the International HIV/AIDS Alliance:
http://www.aidsalliance.org/graphics/secretariat/publications/Positive_prevention.pdf

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