Why and how efforts to end pediatric HIV rely on ending discrimination and protecting the sexual and reproductive rights of women living with HIV

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GATHERING THE VOICES OF PEOPLE LIVING WITH HIV
People living with HIV are the PRIMARY stakeholders in efforts to prevent vertical transmission (PVT).
Our study presents their unique insight into ongoing barriers to PVT.

METHODS
Combined qualitative and quantitative approaches, between November 2010 and December 2011:
» moderated online consultation (66 participants from 16 countries);
» three facilitated focus group discussions (27 men and women living with HIV in Jamaica);
» an e-survey for people living with and affected by HIV (591 respondents from 58 countries);
» an expert panel to discuss the content and accessibility of the framework (22 participants).

Barriers to Preventing Vertical Transmission Identified by People Living with HIV

- Experiences of Stigma
  » 70% of survey participants identified healthcare worker attitude as a barrier to accessing care
  » 58% of survey participants felt couples living with HIV did not have enough support to conceive safely, with stigma identified as the major cause

- Health Provider Pressure
  » 19% of survey participants had been coerced to make a decision about their sexual and reproductive health by a health care provider once and 12% had been pressured more than once
  » The most common pressures were related to preventing or terminating a pregnancy.

- Gender Based Violence
  Consultation and survey participants explained that violence prevents women from:
  » disclosing their status to partners
  » accessing voluntary testing and counseling and family planning;
  » exerting control over their fertility, negotiating safe sex, or confronting marital infidelity

- Male Involvement
  » 51% of the e-survey respondents felt that men were not encouraged to consult family planning services and only 28% could name such services in their respective countries. Respondents thought that this was because family planning was still regarded as a ‘woman’s domain’.
  » 63% of survey respondents found that lack of programs targeting HIV discordant couples was a barrier to male involvement.

- Peer Support: A Voice from Southern Sudan
  ‘To be counseled by someone who is living with HIV, it is very good because he or she knows the pain. And, she will know how to handle you, and which type of words she should use, and which type of words she should not use with you. She will not neglect you because if she feels like neglecting you, she will be neglecting herself as well…”

December 2011

RECOMMENDATIONS:
» Educate health care providers on how to provide non-judgmental support to PLHIV accessing PVT services;
» Incorporate programs to recognize and address gender based violence within PVT services;
» Provide accurate information to PLHIV and their partners;
» Peer support must be included as part of post-test counseling and PVT programming;
» Meaningfully Involve People Living with HIV to ensure policies and programmes are responsive to their needs and experiences.

A Voice from Uganda
“The day I was tested, I was with my husband ... I was positive and he was negative. When we were told, to be given back the results, it was as if the health care worker did not have enough time for us. She was like, do you know what discordancy is? And she said ‘you are negative, you are positive. May I have another couple?’ They didn’t give us enough time, which resulted in my husband leaving me at the health facility, abandoning me there…”

‘I HAVE THE RIGHT TO HAVE SEX & THE RIGHT TO HAVE A CHILD’

Knowledge of Sexual and Reproductive Health and Rights (SRHR)
59% of the e-survey respondents felt that women in their countries s were not aware of their SRH-related rights.

Facilitators of Preventing Vertical Transmission Identified by People Living with HIV

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