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International Planned Parenthood Foundation
(IPPF)

16-17 June 2011, Arena and Convention Centre, Liverpool



The People Living with HIV Stigma Index: A research and advocacy initiative by and for people living with HIV

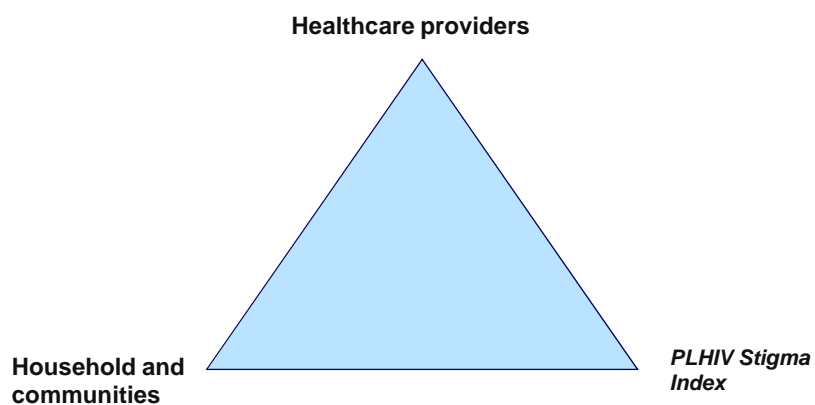
Kevin Osborne IPPF
13th Annual Conference of NHIVNA
17 June 2011, Liverpool

Is HIV- related Stigma still an issue in 2011?



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Why a Stigma Index?



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Understanding HIV-related Stigma

Stigma against those who are known or presumed to be living with HIV remains a fundamental barrier to HIV prevention, care, support and treatment.

- ... how to **measure** stigma to keep pace with the *changing face and realities of stigma* as it affects people living with HIV
- ... evidence of the **impact of current policies** exacerbate HIV related stigma and discrimination
- ... how experiences **change over time**, for example in response to policy change or specific interventions
- ... how **different experiences of stigma** are between people living with HIV e.g. women, young people, MSM, people who use drugs, sex workers



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The Stigma Index

1. Experience of Stigma & discrimination from others
2. Access to work and services
3. Internal stigma and fears
4. Rights, laws and policies
5. Effecting change
6. **Testing & diagnosis**
7. **Disclosure & confidentiality**
8. **Treatment**
9. **Having children**
10. Self-assessment of stigma & discrimination



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The people living with HIV Stigma Index:

4 'P's:

- 1) At every stage of implementation, it is an initiative that is by and for **People** Living with HIV
- 2) The **process** is just as important as the product of the research, and is about creating a peer-to-peer interview space that is empathetic, supportive, informed and includes useful and relevant referrals
- 3) The **product** of the research will be useful for informing better policies and practice relating to HIV and to address stigma
- 4) The rollout of the index will be done in **partnership**—internationally, regionally and nationally—and guiding standards and principles exist to support an ethical and effective rollout in every country



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Some of the countries that have implemented PLHIV Stigma Index ...

Argentina	Nepal
Bangladesh	Paraguay
China	Philippines
Colombia	Sudan
Dominican Republic	Swaziland
El Salvador	Thailand
Estonia	Ukraine
Ethiopia	United Kingdom
India	Zambia
Malawi	
Mexico	



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Using evidence to generate change

- **India:** feed in to the new National AIDS Plan
- **Bangladesh:** collaboration between 9 different networks of people living with HIV, other NGOs and CBOS for the first time.
- **China:** 'Positive Talks' results discussed publicly and with visiting celebrities e.g. Justice Edwin Cameron from South Africa.
- **Pakistan:** evidence used to get further funding for stigma reduction.
- **Ethiopia:** publication showing how HIV stigma affects women has been used to advocate on the rights of WLHIV.
- **United Kingdom:** in-depth quantitative and qualitative results have included in review by the House of Lords Committee on HIV and AIDS.



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Findings from the UK – Headlines

- **867** people interviewed around the UK (London, Belfast, Brighton Cardiff, Dundee, Edinburgh, Glasgow, Leeds, Manchester, York ...)
- **35** community researchers, all people living with HIV interviewing peers



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Stigma and discrimination remain a big challenge in the UK

46%

reported their rights may have been abused in the last 12 months

17%

reported having been denied health services in the last 12 months

31%

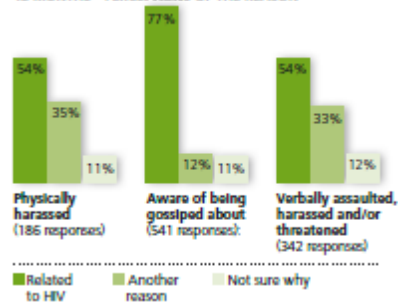
have not had a constructive conversation with their health care provider



"There is a need to educate about people's rights. For one to identify that they have been discriminated against they need to know their rights"

RESEARCHER, LONDON, MAY 2008

PARTICIPANTS REPORTING HARASSMENT IN THE LAST 12 MONTHS—PERCEPTIONS OF THE REASON



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People living with HIV are leading in the response to stigma

45% of participants reported challenging someone stigmatising them in the last 12 months

84% reported supporting other people living with HIV to overcome Stigma

"I don't need an HIV support group; I need understanding, people to understand I am not going to die from this."

PARTICIPANT, SOUTH YORKSHIRE, JUNE 2008



DO YOU KNOW OF ANY ORGANIZATIONS OR GROUPS THAT YOU CAN GO TO FOR HELP ...?



HAVE YOU SOUGHT HELP FROM ANY OF THE ABOVE ORGANIZATIONS OR GROUPS?



IN THE LAST 12 MONTHS HAVE YOU SUPPORTED OTHER PEOPLE LIVING WITH HIV?



Yes No Non-response

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Sexual Reproductive Health of PLHIV



UNFPA/IPPF/UNAIDS /Young Positives: Young people living with HIV from Russia, India, Mexico, Dominican Republic, Swaziland and South Africa, speaking about their experiences with having a family.



www.stigmaindex.org

www.ippf.org



