Results of the People Living with HIV Stigma Index
Belarus
Challenges in moving from evidence to action

The People living with HIV Stigma Index s is the initiative of 4 founding partners
More details are accessible at : www.stigma index.org

THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX

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ICW Global
International Community of Women Living With HIV/AIDS

IPPF International Planned Parenthood Federation

UNAIDS

Acknowledgements

UNAIDS

HIV in Europe
Working Together for Optimal
Testing and Earlier Care

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Stigma Index Objectives

- To collect information on PLHIV related stigma and discrimination from the perspective of people living with HIV;
- To provide a baseline of PLHIV related stigma – for comparison across time and across countries
- To provide an evidence basis for policies and programs change;
- To develop more efficient programs to improve the medical and social condition of people living with HIV.

What does the Index measure ?

The index measures PLHIV experiences and perceptions of stigma and discrimination :

- That has been internaliseded by PLHIV(what we do to ourselves)
- That PLHIV experience or receive from family and community
- In the areas of health care -including sexual and reproductive health - work, education, accommodation

It also measures PLHIV knowledge about rights, and barriers to asserting these rights

Methodology

- **Total sample 370 , stratified to reflect epidemiology**
- **13 cities (Minsk, 6 local regions/oblasts)**

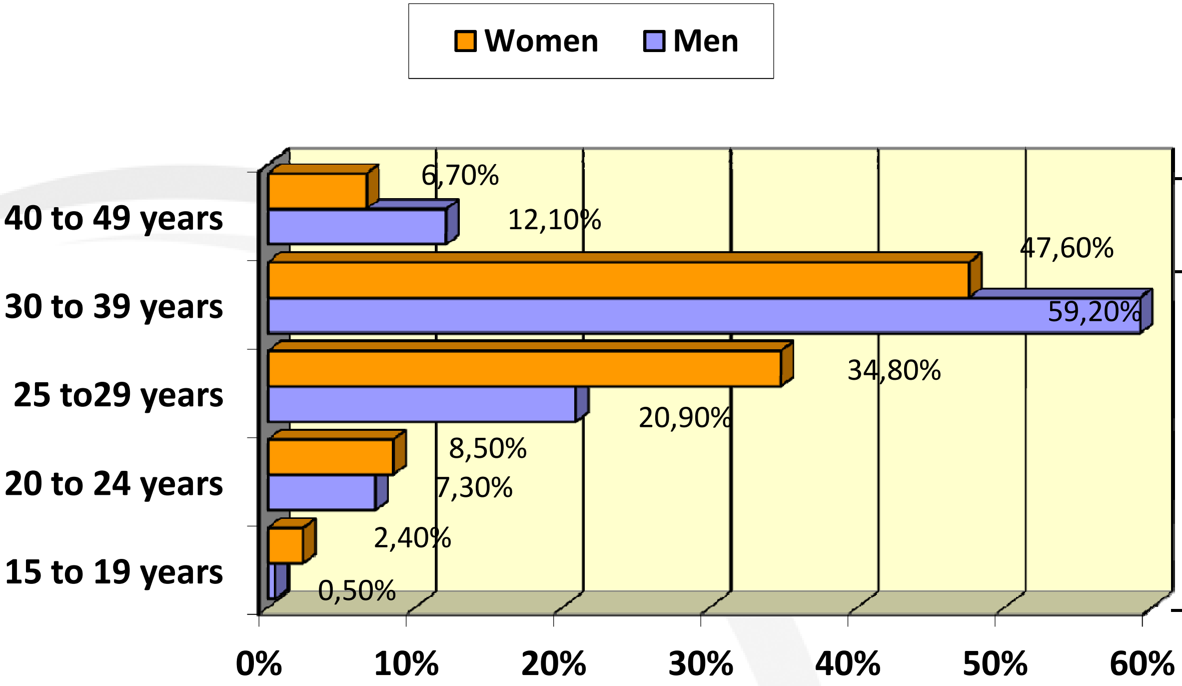
TOTAL SAMPLED POPULATION, PEOPLE		NUMBER OF REPORTED HIV-CASES
CITY	NUMBER OF RESPONDENTS	
BREST	16	138
PINSK	8	373
VICIEBSK	20	188
HRODNA	4	71
HOMIEĹ	38	666
ŽLOBIN	19	706
SVIETLAHORSK	144	2478
REČYCA	20	268
MAZYR	13	214
KALINKOVIČY	7	151
MAHILIOŬ	3	120
SALIHORSK	18	767
MINSK	60	1545
TOTAL	370	7685

Gender and Age distribution of respondents

55.7% male and 44.3% females

Age: majority 25-39 (81.7%)

The majority of PLHIV participating in most active reproductive and working age.



Age	
15–19	1.4%
20–24	7.8%
25–29	27.0%
30–39	54.1%
40–49	9.7%

Findings

PLHIV regularly encounter stigma and discrimination:
- gossiped about (66.8%),
- insulted (41.6%) as well as

physical harassment, threats and violence.

Internalised stigma is common (feelings of guilt, shame, loss of self-esteem) as well as related decisions and actions:

- not to have children (45.9%)
- not to get married (20.0%)
- not to go to school (17.8%)
- not to apply for a job (15.9%)
- not to visit local clinics/access healthcare(34.6%)

Findings

50% of respondents face problems about treatment issues: “the doctors provided little information,”
“I do not have clear understanding what it is,”
“I know little about side effects,” etc.

Disruptions reported of the supply of ARVs and diagnostic materials.

47% of respondents reported health care professionals advising them not to have children (35.9% of men and 61% of women), 11.4% of respondents reported being coerced into sterilisation

Challenges

This work was carried out in 2009 -10 but...

- The data (statistical quality and validity)
- The process (PLHIV researchers)
- The findings (highly critical)

We expected the agencies (the UN), the government departments, the medical institutions - all involved in the partnership to gather the data - to work with us to disseminate the data widely, to continue to work with us as we moved into an advocacy phase but…

So in 2011 we had to revise and have revalidated all of the data. This has happened. However there is still reluctance to change practice, consider changes, have real conversation around the issues, or fund us to provide services to improve the situation.

Actions for Advocacy

During 2011

Preparation

- Revalidation of data
- Building new partnerships (Belarus Red Cross)
- Lobbying for inclusion into new national strategy

Resource mobilisation

- developing partnerships with to fund advocacy from the results

Planning

As of the end of 2011 we had developed series of distinct activities to implement and found some funding to undertake them

Actions for Advocacy

2012 Activities:

- education and training events on raising awareness on human rights issues among PLHIV;
- counseling services to assist PLHIV to assert their rights, specific focus on PLHIV in prison settings;
- unite into stronger coalitions and alliances: Belarus-CAB, patients initiatives;
- inform programmatic decision-makers on quality of services to PLWH;
- ensure the development of effective measures aimed at overcoming stigma and discrimination against PLHIV via monitoring of quality of information on HIV/AIDS .

This work planned has been
made possible also within HiE

Conclusions

In a hostile and challenging environment (political, reluctance to change) and however robust the evidence PLHIV have to do it for themselves anyway

Special measures are needed to be taken by international community to support initiatives on overcoming stigma and social unjustice in difficult political settings in order to be able to move further.

Advocacy work for the benefit of PLHIV is not prioritized in the country.

Belarusian PLHIV stay alone in front of all the challenges brought by stigma, with no political and financial support.

Advocacy initiatives often meet persecusion and punishment.

Conclusions

Alliance

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Reproduced from the **Good Practice Guide on the Greater Involvement of People Living with HIV (GIPA)**, published in 2010 by the International HIV/AIDS Alliance and the Global Network of People Living with HIV (GNP+). The guide is available to download from **www.aidsalliance.org** and **www.gnpplus.net**

PLHIV and their allies ultimately have to do it for themselves

More information

More information is available via
www.stigmaindex.org
www.gnpplus.net
www.hiv.by

Thank you!