



Stigma and The People Living with HIV Stigma Index





“Many a time I have heard people saying don’t come next to me I am scared of you”

Theme of presentation...

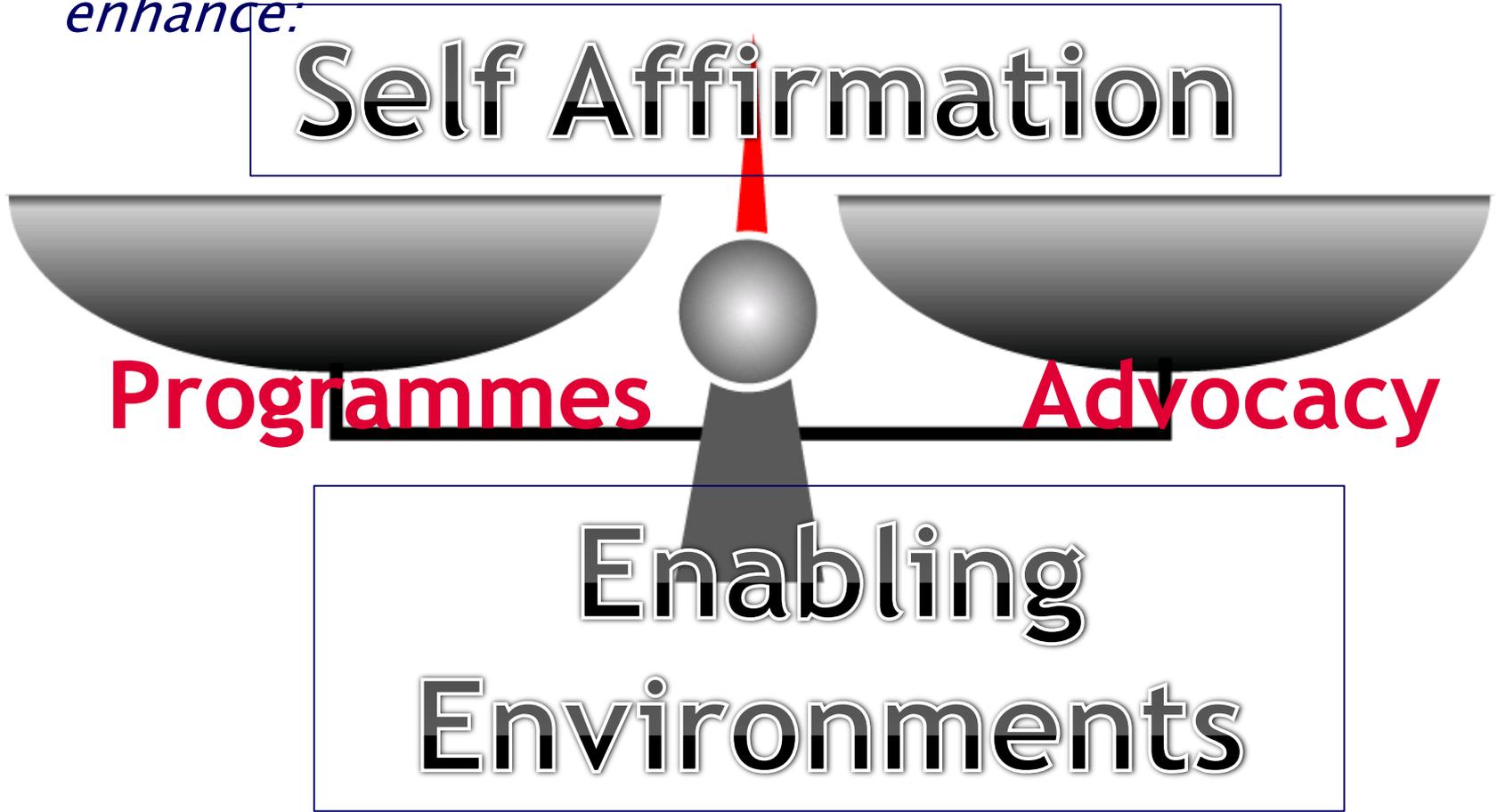
Suggesting ways how the PLHIV Stigma Index can enhance:

Self Affirmation

Programmes

Advocacy

**Enabling
Environments**





Why, What, Who

- HIV related stigma and discrimination are known to be barriers to accessing HIV prevention, treatment and care services, but much of what we know about this stigma and the resulting discrimination, is anecdotal or fragmented
- The Index is a tool to build evidence and measure the level of stigma experienced by PLHIV within their communities. It translates anecdotal evidence into systematically and measurable data to compare levels of stigma across borders, key populations and across time.
- As well as being a partnership product of the four organisations GNP, ICW, IPPF and UNAIDS it has been supported and is a partnership at a national and regional level by PLHIV networks themselves, Civil Society organisations and alliances, foundations , universities and others .



Some questions to start ...

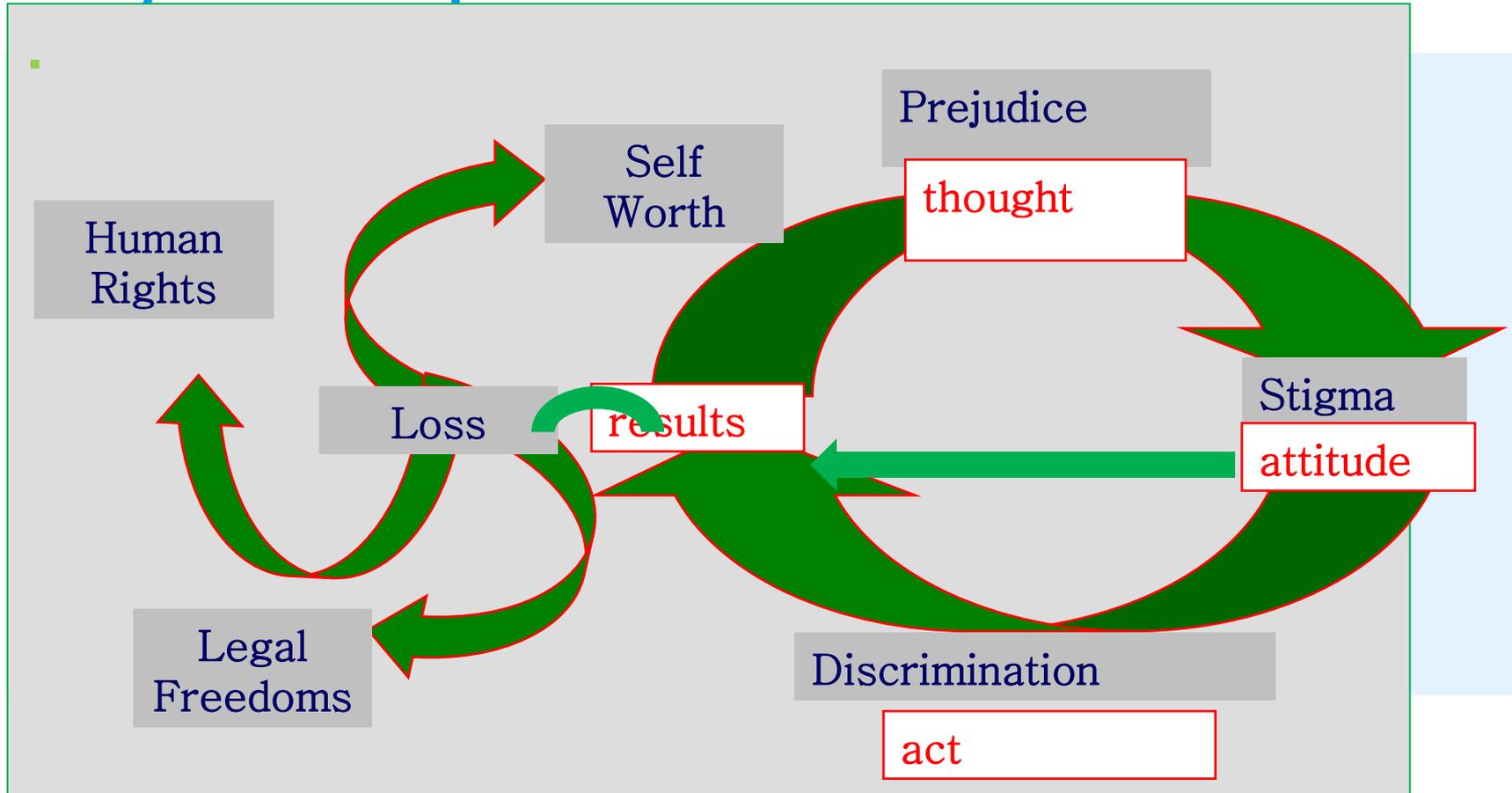
Stigma is widely recognised as a barrier to achieving universal access to prevention, treatment, care and support.

1. How does stigma have an impact on all the work we do?
2. How should we measure stigma?
3. How is the *People Living with HIV Stigma Index* different from other research initiatives to measure stigma?

And How can the evidence generate change in

- 1 The lives of people living with HIV?
- 2 Programme responses such as testing?
- 3 Policies such as criminalisation?

1 How does stigma impact on our work: A Cycle of Impact



A mind mapstarting with prejudice (both perceived as being there externally and internally self 'taught' – and real and actual) leading to the attitude of stigma ...the line from stigma to results is there to illustrate that the attitude may or may not result in a ACT of discrimination but still has impact

Understanding HIV related stigma...

- Pervasive power of stigma & discrimination
- Different forms (enacted, internal)
- Programmatic interventions create enabling environments not necessarily enabled people
- Subtly of stigma & discrimination has changed

Presenters Notes: So what then is Stigma and Discrimination?

We know that stigmatisation is a process and so in some ways it is a process of devaluation- rather than a thing. After 30 years of this epidemic we have also begun to recognise that self-stigmatisation- or the shame that people living with HIV/AIDS experience when they internalise the negative responses and reactions of others affects the uptake of services and use of information.

Discrimination - based on perceived or actual HIV status - is the act of treating someone differently; in the denial of services, in refusing employment.

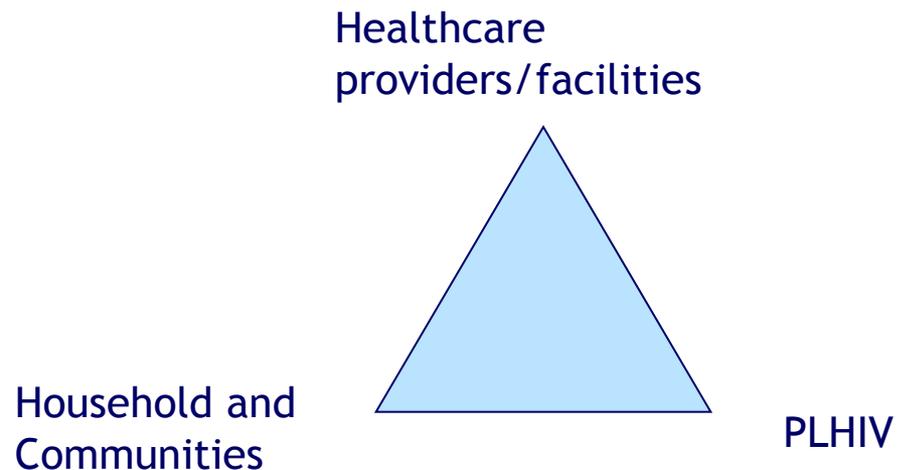
We as partners have recognised the absence of an adequate tool that specifically addresses the impact of stigma in the lives of those living with HIV/AIDS. While there are many initiatives that aim to address stigma at a programme level- the importance of increasing our global understanding at the PLHIV Level was a missing gap.

2. How should we measure stigma ?

Well, What have other indexes done

- Health Care Providers /Facilities Index
- Household and Community level attitudes

- Missing Gap:
Asking PLHIV



How is the *Index* different from other research initiatives to measure stigma?

“THE STIGMA INDEX WILL HELP US DOCUMENT OUR OWN EXPERIENCES AND STRENGTHEN OUR ADVOCACY WORK. THIS IS A WAY THAT WE CAN START TO CHANGE THE CONVERSATION – WE WILL HAVE EVIDENCE TO BACK US UP.”



**THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX**

What is the PLHIV Stigma Index ?

A way to understand experiences of stigma and discrimination, and how they change over time.

The process centres on PLHIV – making the Index a tool for, and by, PLHIV.

Key points:

- A Move away from ‘boxed’ responses
- Involves communities most vulnerable to infection (MSM, IDU, Sex workers, women and young girls) effecting change at the ‘personal’ level
- Tool for GIPA enactment - informs **ADVOVACY, ACTIVISM** and **CREATES PARTNERSHIPS FOR CHANGE**

What does the index look like?

Factors of stigma and discrimination the questionnaire addresses:

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

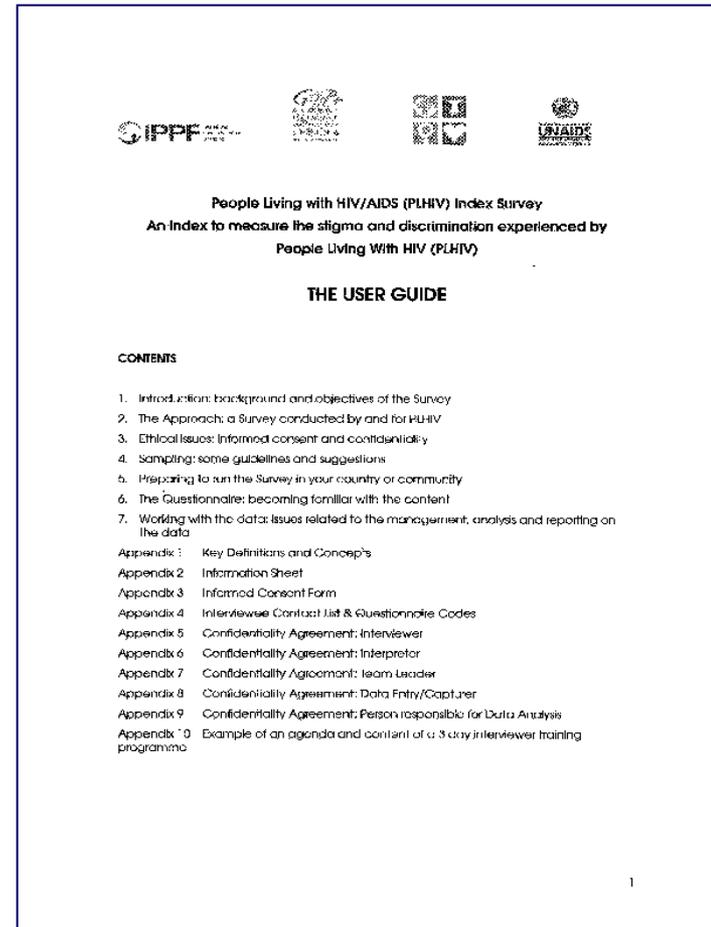
8 Treatment

9 Having children

10 Self-assessment of stigma & discrimination

The Userguide:

- The Userguide supports the implementation of the questionnaire.
- It gives guidance on ethical considerations, confidentiality and practical issues such as population sampling.
- This is key to the Index being a free-standing tool adaptable to local circumstance and needs but still robust.



"WHEN IT COMES TO CRYING, SHOUTING, SPEAKING OUT AGAINST STIGMA – I HAVE DONE IT. BUT I HAVE BEEN STRUGGLING WITH THE EVIDENCE TO QUANTIFY IT. AS A RESEARCHER AND AS AN ADVOCATE I NOW HAVE THE MISSING LINK."



THE PEOPLE
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Finally : the Impact of the INDEX

1. **Evidence to improve policies** and ensure that policies are grounded in the realities of living with HIV. The findings from the Index will be used to promote the human rights of people living with HIV and advocate for policy change on key issues including the criminalization of HIV transmission
2. **Improved programmes influenced by the perspectives of people living with HIV** to better meet the needs of people living with HIV and increased access to, and uptake of, services
3. **Models best practice for the greater involvement of people living with HIV (GIPA)** by putting people living with HIV at the centre of the process and ensuring that it remains by and for people living with HIV throughout all stages of implementation



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