

13th Annual Conference of the
National HIV Nurses Association (NHIVNA)



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International HIV/AIDS Alliance

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*‘This sickness does infect
the very life-blood
of our enterprise’*
An overview of HIV stigma

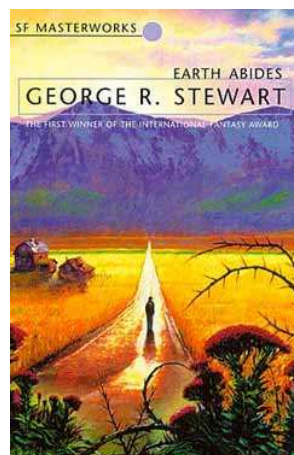
Ian Hodgson, PhD
NHIVNA 2011

This presentation

- What is stigma?
- What does stigma do?
- HIV and stigma
- Living with stigma
- Possible solutions



***Reinforcing the fear of disease was
a prejudice against strangers, and
all their strange ways.***



George Stewart, 1949

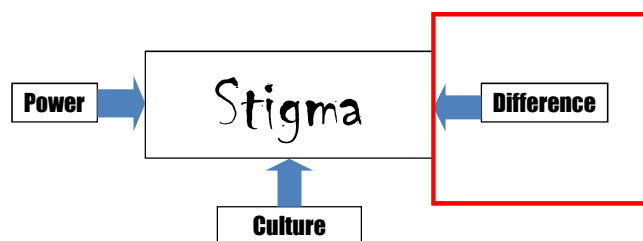
What is stigma?



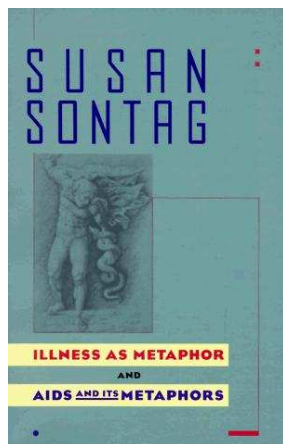
- Stigma marks an individual as being unacceptably different from 'normal' people with whom s/he interacts, and is...
- ...an attribute that discredits or disqualifies an individual from full social acceptance (Goffman 1963)
- Stigma is a social process; a feature of social relations reflecting the tension, conflict, silence, subterfuge and hypocrisy found in every human society and culture (Barnett and Whiteside 2002)
- More than just the way a person is *seen*. It is social and cultural...and we all do it 😊

Stigma: the cultural view

Stigma is a social product 'written' by powerful cultural forces, at the intersection between power, difference and culture...



[All] societies need to have one illness which becomes identified with evil, and attaches blame to its victims.



Susan Sontag, 1991



Points to note...

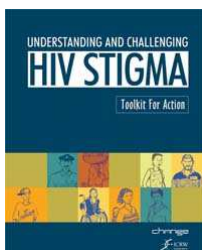


- Stigmatising illness is not unusual...
- ...leprosy, syphilis, mental illness, certain cancers and TB are/have been heavily stigmatised
- “TB patients and their families throughout the world continue to face stigma.” (IHAA, 2009)
- Beliefs about danger and pollution are often used as a form of **social control**...
- ...and attaching ‘dirt’ and infection risk to social groups is a common political strategy: e.g. Jews in the 1930s, Tutsis in 1990, immigrants to the UK in the 2000s
- Stigma by association is a potent force

The experience of being stigmatised



- | | |
|--|---|
| <ul style="list-style-type: none"> • EXTERNAL stigma <ul style="list-style-type: none"> – Avoidance – Rejection – Moral judgment – Stigma by association – Discrimination (the ACT associated with stigma) – Abuse of human rights & genocide | <ul style="list-style-type: none"> • INTERNAL stigma <ul style="list-style-type: none"> – Self-exclusion from services or opportunities – Low self esteem – Social withdrawal – Overcompensation: self-blame and guilt – Fear of disclosure |
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HIV-related stigma is exceptional in its scale, its context, and its causes...it hurts and imprints on the soul.



Mary Robinson, 2006

What are the causes of HIV stigma?



- **HIV IS A MYSTERY:** Invisible, incurable and infectious: blaming is a way of making mysterious and devastating diseases comprehensible
- **HIV IS FRIGHTENING:** 'How can it spread?'
- **LINKS WITH SPECIFIC BEHAVIOURS:** 'What did they do?'
- **IMPLICIT ASSOCIATION:** Many social responses are unconscious - even if we *think* we don't stigmatise, we do...
- **STIGMA FORMALISES EXISTING EXCLUSION RULES:** against unpopular groups - 'structural violence'

HIV and stigma

[Health & Development Networks eForum, 2005]



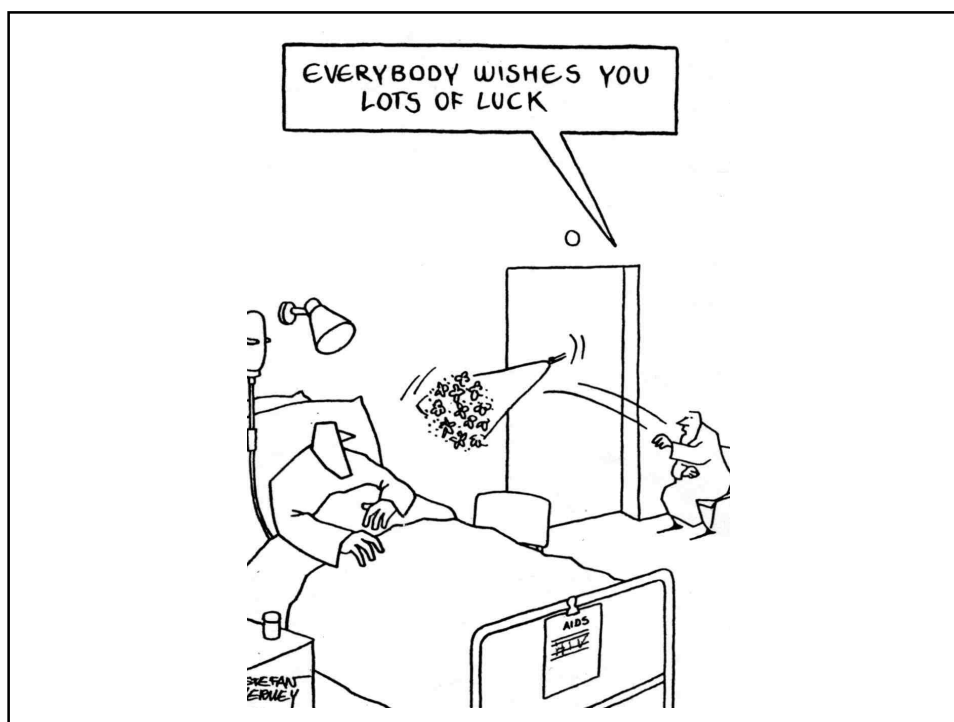
- Everyone seems to care and is sorry about what has happened, but no one comes within touching distance or is willing to touch or be touched. Your whole world disintegrates within one day.
- The way I saw myself fundamentally changed: I thought I was marked, different from everyone. I felt dirty, ashamed, guilty.
- I heard of a mother who sealed her daughter in a single room after she developed AIDS. She never even had a chance to walk to the toilet.

HIV and stigma

[ZAMBIA - International HIV/AIDS Alliance, 2011]



- It has to be my choice when to disclose; if I don't I will be considered normal just like any other person. [Male adolescent LHIV, Zambia]
- [My aunt disclosing my status] was very painful for me. I thought that it was my right to disclose. I actually cried.
She went around telling people that I am sick because my mother was a prostitute, and she brought this disease upon her brother.
I feel like my aunt does not love me. When I am taking my medicines she will look at me in a funny way. [Female adolescent LHIV, Zambia]



HIV stigma in health care



- [The nurses] were not treating me fairly. They wouldn't even come and clean the room. They didn't even clean the toilet.
So even just after the operation I was in pain. When I told the lady to hold me, to help me, to sit up, she refused. She gave me something, to hold on to. I was crying and saying, "Oh God, why me?" [PLHIV inpatient, UK - source: Sigma Research, 2004]
- I must admit now [my child] has just started school. I find myself not telling people where I work [HCW based on HIV Unit, UK - source: Hodgson, 2006]
- [PLHIV] are treated like they are dirty and contagious. The doctors and nurses put on masks and gloves to examine or treat them, unlike other patients [PLHIV In-patient, Thailand - source: HDN, 2006]



SOLUTIONS?



- **TRACK:** the experience of stigma for PLHIV, and...
- ...ensure organisational systems are in place to protect people against discrimination
- **PROMOTE:** the greater involvement of PLHIV (GIPA), and community mobilisation for better advocacy
- **PROVIDE:** information and education to challenge dominant discourses, and reduce notions of *difference*
- **ADVOCATE:** for effective human rights-based legislation and constitutions (Uganda problems, 2011)
- **APPRECIATE:** health care is not blind – how adept are we at being non-judgmental?
- **CONSIDER:** are things improving?



Stigma reduction...



- “[PLHIV] are more like friends than patients...they’re no different to me.” [HCW, UK, 2002]
- “[Stigma from the family] has now gone. People are aware that they can also be infected. They support and care for us.” [PLHIV, Uganda, 2010]
- Tanzania: *Baking the bread* [PLHIV Support Group, 2010]

Reducing 'difference'

For in the final analysis, our most basic common link is that we all inhabit this small planet. We all breathe the same air. We all cherish our children's future.



And we are all mortal.

John Kennedy, 1963

THANK
YOU

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