

HIV Nurses Network

Living with HIV in 2017:
Issues for Healthcare

11th April 2017

My story



Angelina Namiba
Associate, Salamander Trust
anamiba15@gmail.com

HIV Nurses Network

Living with HIV in 2017: Issues for
Healthcare

Stigma and Language

11th April 2017



Angelina Namiba
Associate, Salamander Trust
anamiba15@gmail.com

Stigma and Language

Salamander Trust

Small, young with a global reach

Aims:

- Protect, Promote & Enhance the health and rights of people, particularly but not exclusively, marginalised as a result of their, Gender, HIV status or Sexual & Reproductive Health

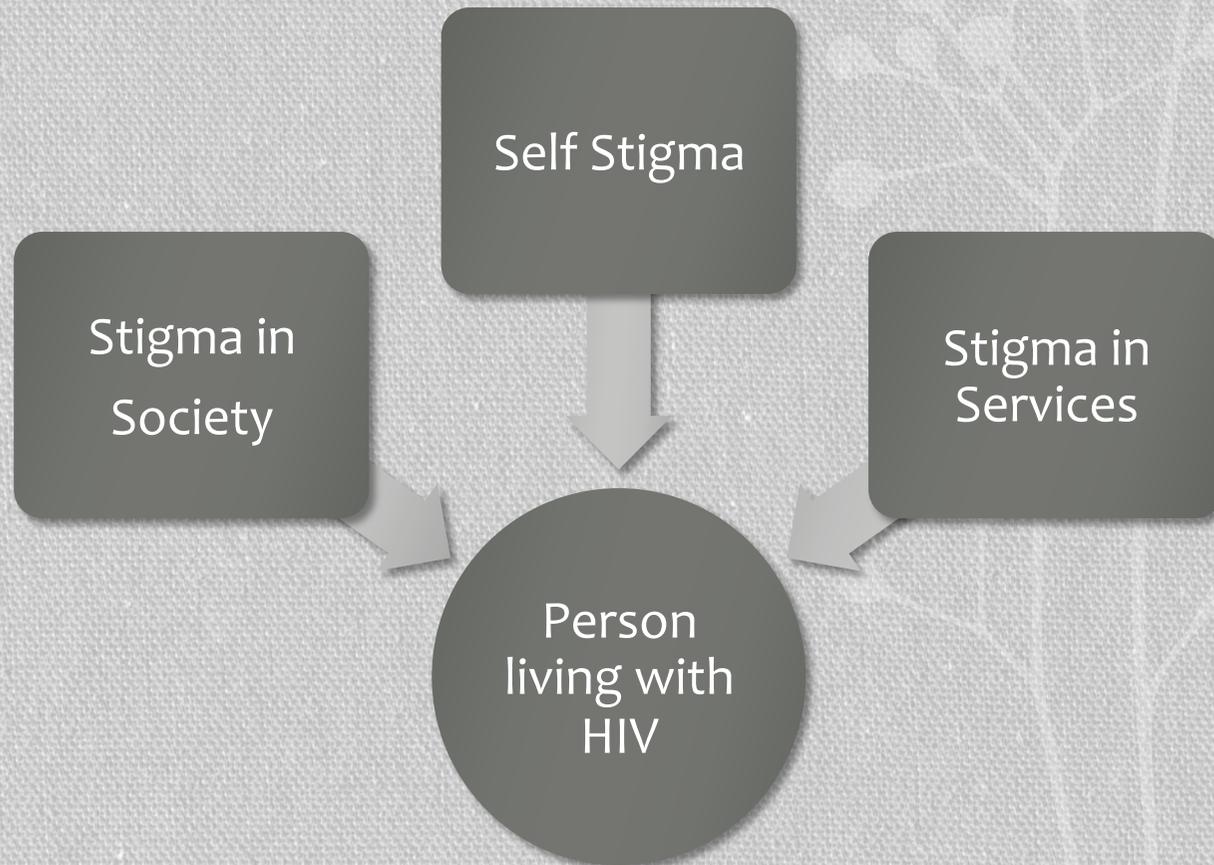
Through:

- Training, Global Advocacy & Research



Stigma and Language

People Living with HIV experience different types of Stigma



Stigma and Language

‘Health is a state of complete physical, mental and social Well-being and not merely the absence of disease or infirmity’.*

*WHO definition of health

Preamble to the Constitution of the World Health Organization as
Adopted by the International Health Conference, New York;
1946 June 19-22



Stigma and Language

PREFERRED TERMINOLOGY eg (UNAIDS)

Don't use	Background	Preferred term
AIDS carrier	This term is no longer used because it is incorrect, stigmatizing and offensive to many people living with HIV.	person living with HIV
	The terms AIDS response, HIV response, response to AIDS and response to HIV often are used interchangeably to mean the response to the epidemic.	HIV response Much of the response is now aimed at preventing the transmission of HIV and treating people living with HIV before they develop AIDS.
AIDS-infected; HIV-infected; transmitters	No one is infected with AIDS; AIDS is not an infectious agent. AIDS describes a syndrome of opportunistic infections and diseases that can develop as immunosuppression deepens along the continuum of HIV infection (from acute infection to death). People should never be referred to as an abbreviation, such as PLHIV, since this is dehumanizing. Instead, the name or identity of the group should be written out in full. Abbreviations for population groups can, however, be used in charts or graphs where brevity is required.	Refer to people as being HIV-positive or a person/ people living with HIV (if serostatus is known/ disclosed), or as having unknown HIV status (if serostatus is unknown).
AIDS orphans	This term not only stigmatizes children, but it also labels them as HIV-positive, which may be untrue. Identifying a human being by his or her social condition alone shows a lack of respect for the individual, in the same way as identifying a human being by his or her medical condition. Contrary to traditional usage (but consistent with the dictionary definition), UNAIDS sometimes uses orphan as a subset of orphans and other children made vulnerable by AIDS to describe children who have lost either one or both parents to HIV.	orphans and other children made vulnerable by AIDS



Stigma and Language

50.50
inclusive democracy

openDemocracy | oD-UK | oDR | oD 50.50 | Transform

About | CanEuropeMakeIt? | ArabAwakening | openGlobalRights | BeyondSlavery | d

HIV and AIDS: language and the blame game

ALICE WELBOURN 27 July 2015

The negative and dehumanizing language used by scientists discussing global HIV policy is sapping the soul of those on the receiving end. The call for an alternative language of nature and nurture must be heard.

About the author

Alice Welbourn is Founding Director of the Salamander Trust and is on the steering group of the Athena Network. Diagnosed with HIV in 1992, she is a former chair of the International Community of Women living with HIV and developed the Stepping Stones training programme on



<https://www.opendemocracy.net/alice-welbourn/hiv-and-aids-language-and-blame-game>



Stigma and Language

Dilmitis S et al. *Journal of the International AIDS Society* 2012, 15(Suppl. 2):17990
<http://www.jiasociety.org/index.php/jias/article/view/17990> | <http://dx.doi.org/10.7448/IAS.15.4.17990>



Letter to the Editor

Language, identity and HIV: why do we keep talking about the responsible and responsive use of language? Language matters

Sophie Dilmitis¹, Olive Edwards², Beri Hull^{3,4}, Shari Margoese⁴, Naisiadet Mason⁵, Angelina Namiba⁶, Moono Nyambe⁷, Susan Paxton⁸, Silvia Petretti⁹, Gracia Violeta Ross¹⁰, Alice Welbourn¹¹ and Anna Zakowicz⁷

¹Corresponding author: Beri Hull, International Community of Women Living with HIV Global, 1345 Emerald Street, NE, Washington, DC 20002, USA. Tel: (202) 397-8488. (bericwglobal@gmail.com)

Abstract

Language matters. It impacts on how we think about ourselves, as individuals within our families and within society. As advocates and activists, we constantly use language as a tool to effect change. People living with HIV have been critical in shaping this language over the last 30 years and still play a central role in ensuring that new discourse in the HIV field does not stigmatize, but rather that it catalyzes empowerment for our community members. In this annotation, we seek to shift the language used in relation to ourselves, our medical condition, our bodies, our identities and the events we face, towards something more life-enhancing, self-affirming and positive in outlook.

Keywords: people living with HIV; women living with HIV; vertical transmission; MTCT; identity; terminology; language.

Received 13 June 2012; Revised 14 June 2012; Accepted 15 June 2012; Published 11 July 2012

Copyright: © 2012 Dilmitis S et al; licensee International AIDS Society. This is an open access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by-nc/3.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Discussions

Language matters. It impacts on how we think about ourselves, as individuals within our families and within society. Our words are the tools we use to share our experiences and to create shared visions of the future. A simple shift in language can speak volumes not only about where we are but where we would like to be. When we make our language inclusive, we break down barriers and build new bridges for greater mutual respect and understanding.

As advocates and activists, we constantly use language as a tool to effect change. We think about how our words affect others, and we reflect on the words others use to learn what language is damaging and what language is constructive and enabling. We listen, and we act and we lobby others to do the same. Language can make all the difference towards achieving our goals.

People living with HIV have been crucial in shaping this language over the last 30 years and still play a central role in ensuring that new discourse in the HIV field does not stigmatize, but rather that it catalyzes empowerment for our community members. As a community of people living with HIV around the world, we represent diverse groups in constant change. Language is not static, and what is appropriate today, may not be in future years. As our under-

standing of HIV grows and the reality of living with HIV changes in response to improvements in treatment care and support, the language used to describe these realities must also change.

One big challenge, which we face with language as found in medical textbooks, is that it focuses on managing, avoiding or eradicating disease, rather than enhancing health. Therefore, whilst the WHO definition of health ("Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity," Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York; 1946 June 19–22) is essentially positive and life-enhancing in concept and tone, we are immediately and unfortunately faced with the language of medical textbooks, which is focused on "ending disease" (two negative words) rather than on "promoting health" (two positive words).

In this annotation therefore, we seek to advocate to shift the language used in relation to ourselves, our medical condition, our bodies, our identities and the events we face, towards something more life-enhancing, self-affirming and positive in outlook. Much of the wording we offer may still be perceived as negative in tone, so we still have a long way to go. Nonetheless, we offer these initial suggestions as some first steps to promote research,

<http://www.jiasociety.org/index.php/jias/article/view/17990>



Stigma and Language

Audience Participation

What do you think are the most stigmatizing words from our perspective as People Living with HIV?



Stigma and Language



Stigma and Language

Some stigmatizing words

HIV Infected person

Use:

People/Person living with HIV

Stigma and Language

Some stigmatizing words

Prevention of **Mother To Child Transmission** **(MTCT)**

Use:

**Comprehensive Prevention of Peri-Natal
Transmission**



Stigma and Language

Some stigmatizing words

Use of the word **Infection** and its derivatives

Use:

Acquire; Transmit



Stigma and Language

Some stigmatizing words

Sero-Discordant couple/relationship

Use:

Sero-Different

Stigma and Language

Some stigmatizing words

Lost to follow-up; Failed to adhere

Use:

Need to Find

Retain in care

Stigma and Language

Some stigmatizing words

Language around cure strategies:
Elimination; Shock & Kill

Use:

Ending...

Promoting (something positive).....

Stigma and Language

Some stigmatizing words

Disclosure of HIV

Use:

Telling; Sharing...

Stigma and Language

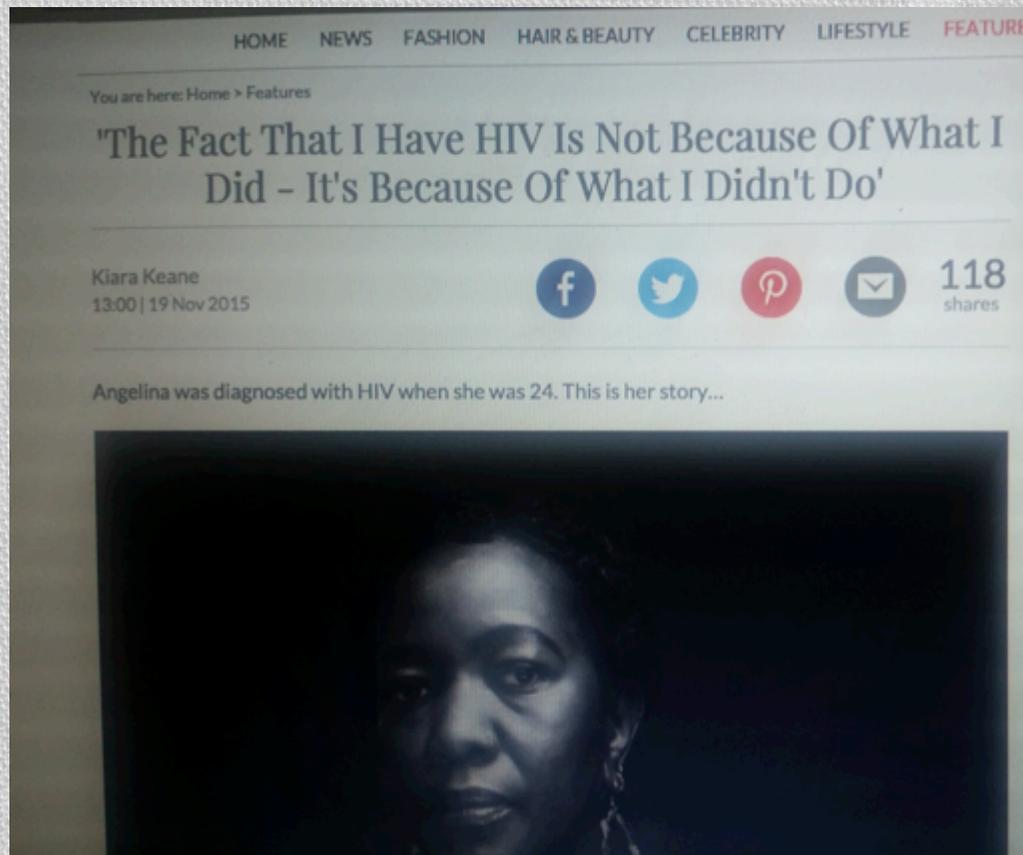
‘It is only when people who are directly affected take action, can there be change in society.’*

*Zackie Achmat. South African Treatment Activist.



Stigma and Language

What am I doing?



Marie Claire 19 November 2015



Stigma and Language

What are we, people living with HIV, doing about it?

www.stigmaindex.org

Provides a tool that measures and detects changing trends in relation to stigma and discrimination experienced by People Living with HIV. It aims to address stigma relating to HIV while also advocating on the key barriers and issues perpetuating stigma, which is a key obstacle to HIV treatment, prevention, care and support.

- Since 2008, more than 65 countries have completed the study
- More than 1400 People Living with HIV have been trained as interviewers
- The questionnaire has been translated into 54 languages
- 65,000 people have been interviewed



Stigma and Language

What are we doing ?

We are Positive

<http://positivelyuk.org/wearepositive/>

The aim of the campaign was to challenge HIV stigma and to show the face of HIV in 2014, in all its diversity.

Positively UK wanted to make something that was upbeat and showed an alternative face of HIV.

It features People Living with HIV saying what HIV is and what it isn't.



Stigma and Language

What are we doing ?

Live HIV neutral

@LiveHIVNeutral

A working network of HIV activists developed to integrate and coordinate activity across the UK and Ireland. Their aim is to eradicate stigma.



Stigma and Language

A bit more audience participation:

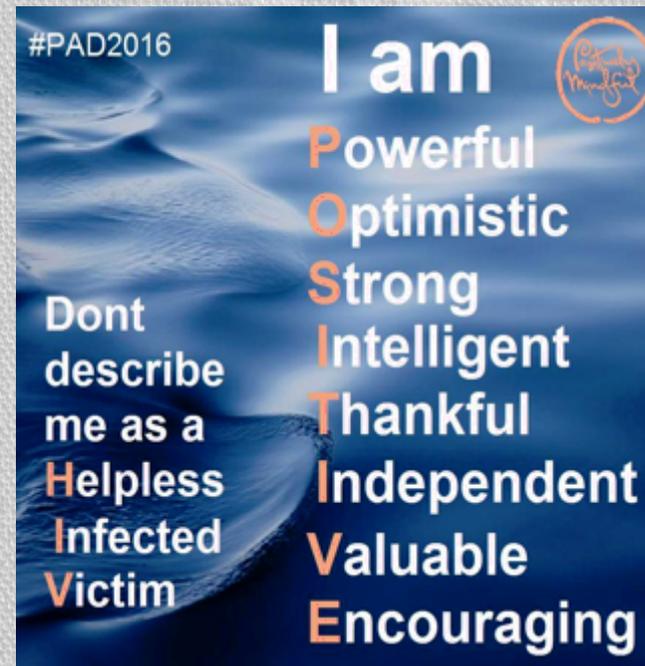
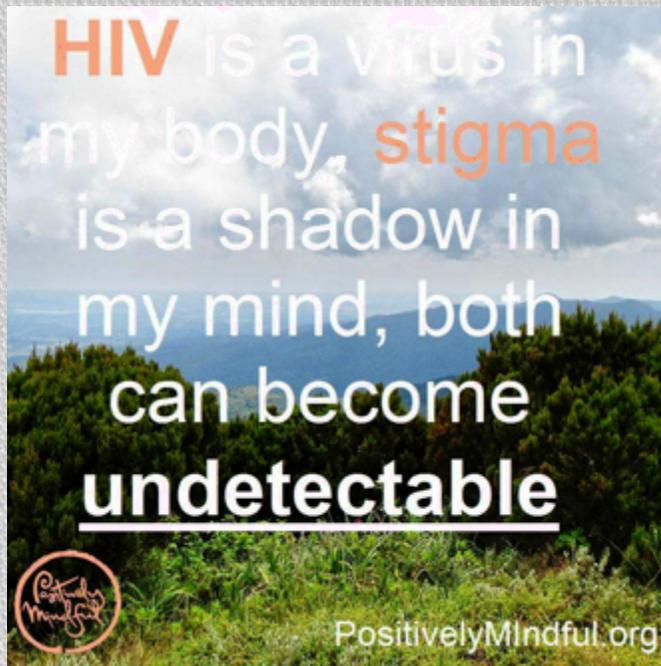
What can you do?/are YOU going to do?

All ideas welcome 😊



Stigma and Language

Some final thoughts



STIGMA & LANGUAGE

HIV NURSES NETWORK

QUESTIONS?



Angelina Namiba
Associate, Salamander Trust
anamiba15@gmail.com