

Talking about stigma – Alice Welbourn

REFERENCES Suggestions

Definitions

Emile Durkheim – the first academic to define stigma
Erving Goffman - Developed a classification of stigma
Phelan and Link – *Conceptualising stigma* (2001)
Useful summary [webpage](#) from UC Davis.

Possible solutions

Good article about stigma in several different health contexts – and what can be done to address it. Nyblade, L., Stockton, M.A., Giger, K. et al. Stigma in health facilities: why it matters and how we can change it. *BMC Med* 17, 25 (2019). <https://doi.org/10.1186/s12916-019-1256-2>

Developing brain during childhood and youth

Explains brain development and the role of the ‘reptile’ [brain](#). We can support and train both ourselves and train children as they grow, to use other parts of the brain rather than resorting to our ‘reptile’ brains. This can help us to process our reactions and avoid fight/flight mode in response to people (including ourselves) or events (including our own).

Trauma-aware care

(Nb often this is called trauma-informed care. But as Elder Valerie Johnson from Vancouver pointer out, sometimes it can be too hard for people accessing care to tell healthcare providers what has happened to them. So it is better for healthcare providers to understand that trauma is likely to have been present in some shape or form, rather than for them to be asking for the details.) See for example two webinars from our 4M Webinar series: one on mental [health](#) issues facing women living with HIV in pregnancy; and one on the value of trauma-informed [care](#).

Unconscious bias training

This *does not* mean a one-off 30-minute session on line or face to face. This needs to be ongoing and repeated regularly, as a part of much broader explicit process. See, for example this [article](#) about it.

Involving people living with HIV in training

There are many great examples of this but few are written up. See, for example, a podcast in Spanish with Marijo Vázquez about her work with medical students in Barcelona, [Spain](#) (the English transcript is [here](#)).

Involving people living with HIV as patrons, board members etc.

We didn’t mention this, but Angelina Namiba, for example, who is a woman living with HIV who created the 4M Mentor Mothers [programme](#), and who does a lot of training of student midwives and other HIV healthcare professionals, is a patron of the British HIV Nurses Association.

Social norms change

Think about the amount of time it has taken to introduce laws about smoking in public spaces or seat belts in vehicles. Ongoing work to enforce and educate on these two topics is still needed. This is what social norms change is about and how long it can take to make change happen. Social norms change is how people describe what happens in communities, for instance to reduce intimate partner violence (IPV), or to reduce HIV. However social norms can – and do – also exist in institutions, such as healthcentres, the police, the judiciary, parliaments, schools, the workplace, faith institutions and more. Here is an [article](#) about the challenges and opportunities facing us in the context of IPV – which is known both to increase women’s vulnerability to HIV and to start or increase – especially in healthcare settings – on diagnosis. We conclude: *“CUSP makes the following recommendations for donors and implementers to scale social norms initiatives effectively and ethically: invest in longer-term programming, ensure fidelity to values of the original programmes, fund women’s rights organisations, prioritise accountability to their communities and demands, critically examine the government and marketplace’s role in scale, and rethink evaluation approaches to produce evidence that guides scale-up processes and fully represents the voices of activists and communities from the Global South.”* There are a number of parallels here with our emphasis on the critical need for community involvement in effective responses to stigma and discrimination.

Understanding where violence comes from and how it can be addressed

Violence as a volcano model – we use this in our *Stepping Stones for Peace and Prosperity* and our *Stepping Stones with Children* programmes.

Appreciative inquiry

Whilst all formal research traditionally begins with a problem-statement and a needs analysis, focusing on problems, needs and negative events can offer retrigger past traumatic events for those being ‘researched’. Instead, in recent years there has been a strong growing recognition of the power of forward-focused, solution-oriented thinking and conducting visioning exercises and priorities / desires assessments instead. ‘Ending stigma’ and ‘ending discrimination’ are double negatives. By contrast, ‘Ensuring positive attitudes, policies and practices’ are double positives.

In all these examples below, meaningful involvement of those most affected is critical to their success. It is also much easier to envision and measure what positive experiences can look and do feel like than to try to measure stigma. (See eg [INTUIT](#) ongoing research on QoL assessment using PROMS measurements – Patient-Related Outcome Measures) and this article by [AIDSMAP](#).

Here are some links:

Use of appreciative inquiry to work with young men in gangs in Cape [Town](#).

Use of appreciative inquiry to build resilience among children living with or affected by HIV and their caregivers (*Stepping Stones with Children* [programme](#))

Measuring experiences of quality of care in healthcare [settings](#).

WHO Guideline on SRHR of women living with [HIV](#).

UNAIDS et al ALIV[H]E Framework – case [studies](#).

Addressing environmental racism in Nova Scotia health and socio-economic [contexts](#).

Using appreciative inquiry in our Stepping Stones with [Children](#) and Stepping Stones for Peace and [Prosperity](#) programmes.

Language matters

- See eg Salamander Trust [website](#), with links to several articles / documents; UNAIDS terminology guidelines [2015](#)
- **Use of religion / spirituality / mindfulness to address stigma, including self-stigma**
Gray Alison J, *Stigma and Stigmata*, nd. Article on Royal College of Psychiatrists website about the “Time to Change” campaign, talking about Contact, Educate, [Protest](#), and religion, spirituality and health.
 - **Kristen Neff** has done a lot of research on self-compassion as a means of working on and overcoming self-stigma, using mindfulness [practices](#).

Canada toolkits

Here is a webpage about these with links to [them](#). There is a forthcoming article in JIAPAC about the whole process.

How to move on from stigma and discrimination in research:

a) Research on lack of women living with HIV in AIDS conference abstracts

We have been tracking this for a while. See here for [details](#).

b) Article in the BMJ about ensuring that perspectives of women living with HIV are included in research

“Our meaningful involvement in research is both an intrinsic right, and a logical necessity, in order to produce policies and programmes which more closely align with and address women’s lived experiences. We thought the world would change.... How naïve we [were](#).”

Restorative Justice

Sometimes the justice system itself can be a stigmatising process for people seeking redress. They can be ostracised and blamed for bringing someone or an institution to court. Restorative justice programmes and involvement of mediators can be a more useful approach. See eg here for domestic [violence](#); although there clearly needs to be more [documentation](#) of their effects. See here for an article about mediation in healthcare [contexts](#): *“With emphasis on listening and empathy rather than legal wrangling, patients and physicians can willingly reconstruct or dismantle their relationship in a manner and fashion wherein they retain control of the outcome with some mutual respect or recognition of needs.”*