



**WHAT WORKS?**

# **ADDRESSING SELF- STIGMA AMONG PEOPLE AFFECTED BY HIV**

# ABOUT FRONTLINE AIDS

Frontline AIDS wants a future free from AIDS  
for everyone, everywhere.

Around the world, millions of people are denied  
HIV prevention, testing, treatment and care simply  
because of who they are and where they live.

As a result, almost 2 million people were infected  
with HIV in 2017 and almost 1 million died  
of AIDS-related illness.

Together with partners on the frontline, we work  
to break down the social, political and legal barriers  
that marginalised people face, and innovate  
to create a future free from AIDS

## ACKNOWLEDGEMENTS

The research presented here was supported by the  
Partnership to Inspire, Transform and Connect the  
HIV response (PITCH). The programme strengthens  
community-based organisations' capacity to  
uphold the rights of people most affected by HIV  
by engaging in effective advocacy, generating  
robust evidence and developing meaningful policy  
solutions.

PITCH is a strategic partnership between  
Aidsfonds, Frontline AIDS and the Dutch Ministry of  
Foreign Affairs, and is funded by the Dutch Ministry  
of Foreign Affairs as part of their "Dialogue and  
Dissent" programme.

**Supported by:**



Ministry of Foreign Affairs

### Frontline AIDS

91-101 Davigdor Road  
Hove, East Sussex  
BN3 1RE  
United Kingdom

Tel: +44 1273 718 900  
Fax: +44 1273 718 901  
Email: [mail@frontlineaids.org](mailto:mail@frontlineaids.org)

Registered charity number  
1038860

[www.frontlineaids.org](http://www.frontlineaids.org)

**Authors:** Dr Marija Pantelic,  
Dr Janina Steinert, Shaun Mellors  
and Fungai Murau

**Copy editors:** Jenny Berg and  
Jane Coombes

**Coverphoto:** Peaches from  
Guyana Trans United - © Jason Florio  
for Frontline AIDS

## SUMMARY

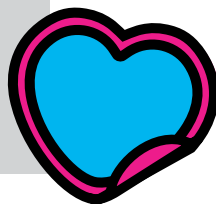
Every year, nearly two million people worldwide are newly diagnosed with HIV, and almost one million people die of AIDS-related illnesses.

Self-stigma among people affected by HIV significantly contributes to this ongoing crisis. Not only does self-stigma affect people's mental health, but it also impacts on uptake of HIV testing, prevention and treatment services. Crucially, for people living with HIV, self-stigma often means that they don't access life-saving antiretroviral treatment, that they become unwell or die.

We must therefore urgently invest in developing evidence-based programmes that reach those most at risk of self-stigma. To do this, we need to know what works.

Frontline AIDS has carried out a systematic review of available evidence on what works to reduce self-stigma. The review found a number of promising approaches: empowerment, economic strengthening, cognitive behavioural therapy, and ensuring access to antiretroviral treatment. However, more than a quarter of evaluated programmes were ineffective in reducing self-stigma; and marginalised populations, that may be most at risk of discrimination and self-stigma, have largely been excluded from research.

*This brief presents a summary of the article from the British Medical Journal: Pantelic, M., Steinert, J., Park, J., Mellors, S. and Murau, F. (2019), 'Management of a spoiled identity': Systematic review of interventions to address self-stigma among people living with and affected by HIV. British Medical Journal Global Health 2019; 4: e001285.*



WHAT IS  
SELF-STIGMA?








Stigma refers to negative public attitudes or discrimination towards a group of people. Self-stigma occurs when a person who belongs to a stigmatised group, for example a sex worker or person living with HIV, internalises negative public attitudes and accepts them as valid. Self-stigma is characterised by profound feelings of shame, worthlessness and, at times, thoughts of suicide. Various forms of marginalisation can contribute to self-stigma, including discrimination, poverty, punitive laws and policies, and violence.

WHERE IS THE  
EVIDENCE?

Our comprehensive synthesis of the evidence within low- and middle-income countries identified a total of 20 unique studies examining what works to address self-stigma. These studies represented the experiences of 9,426 people in Uganda, Lesotho, Malawi, Ethiopia, South Africa, Swaziland, Tanzania, Kenya, Thailand, China, Vietnam, India and Nepal.

➔ We found a stark under-representation of marginalised communities in self-stigma research (as shown in the table below).

Populations represented in  
self-stigma intervention research

Adults living with HIV	12 studies	
Pregnant women living with HIV	5 studies	
Young people living with HIV	0 studies	
Men who have sex with men	1 study	
Sex workers	1 study	
People who inject drugs	1 study	
Transgender people	0 studies	





## CASE STUDY

### DREAM BUILDING IN THE SONAGACHI RED LIGHT DISTRICT

Of the three studies that aimed to address self-stigma among marginalised populations, only one was shown to be effective: the 'Dream Building' programme implemented by Durbar, a sex worker collective in the Sonagachi red light district of Kolkata, India. Dream Building consists of eight group sessions focusing on building aspirations and self-esteem; recognising sex work as a legitimate profession; creating economic security; recognising and acting on gender-based violence; and planning steps to reach one's dreams. The programme highlights the importance of sex worker collectivisation, building aspirations for sex workers' children, and includes a visit to a sex worker community project.

**Importantly, all the sessions are led by and for sex workers, with the exception of the session focusing on children, which is led by the child of a sex worker.**



The programme demonstrated substantial improvements in self-worth and reductions in shame associated with sex work. In addition, the programme improved sex workers' ability to save, and increased their health-seeking behaviour, even though health-related issues were not covered in any of the sessions.

# WHAT WORKS AND WHAT DOESN'T WORK?



## WHAT HAS WORKED CONSISTENTLY?



### EMPOWERMENT INTERVENTIONS

Empowerment interventions consistently resulted in reductions in self-stigma, with moderate to large effects.<sup>1,2,3,4</sup> In empowerment interventions, people living with HIV and sex workers were offered skills-building and opportunities to mobilise, assert their rights, and develop and implement their own anti-stigma interventions.

Importantly, in all of these studies, marginalised populations played a critical role in the design and delivery of the intervention.




### ECONOMIC STRENGTHENING

All interventions that had an economic strengthening component also resulted in significant reductions in self-stigma, with mostly moderate to large effects.<sup>5,6,7</sup> Economic-strengthening interventions offered schemes for savings, housing and nutrition support, as well as income-generating activities. Food assistance had a small positive effect on self-stigma reduction.

### ART PROVISION

All studies that examined the effects of ART provision resulted in small to moderate reductions in self-stigma.<sup>9,8,10,11,12</sup> Of course, ART provision is a necessity for averting deaths, irrespective of its effects on self-stigma.



## WHAT MIGHT WORK IN SOME CONTEXTS

### COGNITIVE-BEHAVIOURAL THERAPY

One small-scale study (with 20 participants) focused solely on providing cognitive-behavioural therapy, which resulted in a significant reduction in self-stigma.<sup>13</sup> However, to inform scale-up we need more research in this area.

Another study used cognitive behavioural therapy and health education, for both women living with HIV and their male partners (separately), combined with psychological support for the women.<sup>14</sup> The aim was to reduce intimate partner violence, improve communication skills and anger management, and enhance health-seeking behaviours. This intervention resulted in a significant reduction in self-stigma, suggesting that it may be beneficial to strengthen people's support systems by providing psychological support to people closest to those at risk of self-stigma.

## WHAT DIDN'T WORK?

### FOCUSING ONLY ON PEOPLE'S BEHAVIOURS

Three studies that focused on behaviour change for people living with HIV, or other marginalised populations, showed no significant reductions in self-stigma. Their main aim was to alter behaviours that make individuals more vulnerable to acquiring or transmitting HIV. This included interventions focusing on reducing sexual risk behaviours and alcohol use through motivational interviewing; and those aiming to improve ART adherence and HIV testing uptake through peer counselling.

### FOCUSING ONLY ON AWARENESS RAISING

The three studies focusing solely on education related to stigma and/or health did not result in significant self-stigma reductions. This applies to both interventions that aim to raise awareness among individuals who have internalised stigma, as well as among the broader community, and suggests that neither individual nor community level knowledge about HIV and stigma are sufficient to combat self-stigma. These findings are in line with systematic review-level evidence of interventions to reduce self-stigma among people living with mental health difficulties, which suggests that psycho-educational interventions are largely ineffective or reducing self-stigma.



## CALL FOR ACTION



### → By policy makers, funders and programme managers

**We need funding, programmes and effective interventions to address self-stigma. In particular, we need to:**

1. Invest in interventions we know are effective, such as those promoting social inclusion through empowerment and economic strengthening, as well as those that improve access to health care.
2. Invest in interventions that are designed and delivered by representatives of the communities that we aim to support.
3. Ensure that programmes reach those most at risk of self-stigma and scale them up through active and meaningful partnership with communities.
4. Invest in more research to better understand what works in reducing self-stigma, and in turn in improving self-worth and health-seeking behaviour.
5. Factor the complexities of self-stigma into research and programming, including intersectional stigma and stigma related to other communicable diseases that are common among communities affected by HIV.

### → By researchers

**We need to know more about what works to address self-stigma. In particular, we need research to respond to the following questions:**

1. **What works for marginalised populations?** The vast majority of research has focused on people living with HIV. Of the three studies focusing on marginalised populations, only one effectively reduced self-stigma.<sup>1</sup> Only one study focusing on young people was identified, despite evidence of high levels of self-stigma in this group. The intervention focused on behaviour change for Thai young men who have sex with men through motivational interviewing. It resulted in significant reductions in sexual risk behaviour, but no changes in self-stigma, adherence to antiretroviral treatment, alcohol and drug use, or general mental health.
2. **How to address 'intersectional' stigma**, which occurs among people who belong to more than one stigmatised group. None of the studies examined this.
3. **What works to reduce self-stigma related to communicable diseases** that are common among people living with or affected by HIV, for example tuberculosis (TB) and viral hepatitis?



Mariam, 20, a peer educator  
with the Frontline AIDS-run  
Link Up project in Uganda.



## METHODOLOGY


### What is a systematic review?

A systematic review is a method used to synthesise a large body of literature into a comprehensive, easily accessible and succinct summary of the state-of-the-art evidence related to a specific research question.

It begins with a comprehensive search of the literature, including academic outlets as well as policy reports and unpublished papers ('grey literature'). It defines inclusion and exclusion criteria, outlining which primary studies should be taken into account, and then presents a narrative or quantitative summary of the aggregated evidence, and assesses the quality of included primary studies.

### About this systematic review

As part of this systematic review, the authors searched eight databases and contacted experts in the field of HIV stigma research to identify relevant published or unpublished studies evaluating effectiveness of interventions that aimed to reduce self-stigma in low- and middle-income countries. The authors screened 5,880 potentially eligible studies, of which 20 studies were included in the review. Two independent authors extracted information from these 20 studies and appraised their quality using rigorous assessment tools. For each included intervention, the researchers appraised the quality of the evaluation methods used and summarised its impact on self-stigma by calculating standardised effect sizes, indicating whether a programme a) had the desired effect on self-stigma reduction (and to what extent); b) did not reduce self-stigma; or c) was harmful in that it increased self-stigma.



## REFERENCES

- 1 Ghosal S., Jana S., Mani A., et al (2016), Sex workers, self-image and stigma: Evidence from Kolkata Brothels. Competitive Advantage in the Global Economy (CAGE) Online Working Paper Series 302.
- 2 Bhatta D.N. and Liabsuetrakul T. (2017), Efficacy of a social self-value empowerment intervention to improve quality of life of HIV infected people receiving antiretroviral treatment in Nepal: a randomized controlled trial. *AIDS and Behavior* 2017; 21:1620–31.
- 3 Chidrawi H.C., Greeff M., Temane Q.M., et al. (2016), HIV stigma experiences and stigmatisation before and after an intervention. *Health SA Gesondheid* 2016; 21:196–205.
- 4 Uys L., Chirwa M., Kohi T., et al. Evaluation of a health setting-based stigma intervention in five African countries. *AIDS Patient Care STDS* 2009; 23:1059–66.
- 5 Lifson A.R., Workneh S., Hailemichael A., et al. (2017), Implementation of a peer HIV community support worker program in rural Ethiopia to promote retention in care. *Journal of the International Association of Providers of AIDS Care* 2017; 16:75–80.
- 6 Nyamathi A., Ekstrand M., Salem B.E., et al. (2013) Impact of Asha intervention on stigma among rural Indian women with AIDS. *Western Journal of Nursing Research* 2013; 35:867–83.
- 7 Maluccio J.A., Wu F., Rokon R.B., et al. Assessing the impact of food assistance on stigma among people living with HIV in Uganda using the HIV/AIDS stigma Instrument-PLWA (HASI-P). *AIDS and Behavior* 2017; 21:766–82.
- 8 Wagner G.J., Ghosh-Dastidar B., Garnett J., et al (2012). Impact of HIV antiretroviral therapy on depression and mental health among clients with HIV in Uganda. *Psychosomatic Medicine* 2012; 74:883–90.
- 9 Turan B., Stringer K.L., Onono M., et al. (2014), Linkage to HIV care, postpartum depression, and HIV-related stigma in newly diagnosed pregnant women living with HIV in Kenya: a longitudinal observational study. *BMC Pregnancy and Childbirth* 2014; 14:1–10.
- 10 Tsai A.C., Bangsberg D.R., Bwana M., et al. (2013), How does antiretroviral treatment attenuate the stigma of HIV? Evidence from a cohort study in rural Uganda. *AIDS and Behavior* 2013; 17:2725–31.
- 11 Peltzer K. and Ramlagan S. (2011), Perceived stigma among patients receiving antiretroviral therapy: a prospective study in KwaZulu-Natal, South Africa. *AIDS Care* 2011; 23:60–8.
- 12 Makoae L.N., Portillo C.J., Uys L.R. et al. (2009), The impact of taking or not taking ARVs on HIV stigma as reported by persons living with HIV infection in five African countries. *AIDS Care* 2009; 21:1357–62.
- 13 Tshabalala J. and Visser M. Developing a cognitive behavioural therapy model to assist women to deal with HIV and stigma. *South African Journal of Psychology* 2011; 41:17–28.
- 14 Peltzer K., Weiss S.M., Soni M. et al (2017). A cluster randomized controlled trial of lay health worker support for prevention of mother to child transmission of HIV (PMTCT) in South Africa. *AIDS Research and Therapy* 2017; 14:1–12..



**JOIN US. END IT.**

[www.frontlineaids.org](http://www.frontlineaids.org)