



Stigma: Why It Matters



If we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful.

-Edward Cameron, Constitutional Court Justice, South Africa

Stigma Is a Roadblock to Reaching Global Targets and Goals

Sustainable Development Goals: Target 3.3: Ending AIDS by 2030

Stigma Manifestations

Experienced

Perceived

Anticipated

Internalized

Intersectional

HIV Care Continuum

Prevention

Testing

Linkage to Care

Retention

Adherence

Viral Suppression

2025 Targets

95% of PLHIV know their HIV status

95% of PLHIV who know their status initiate treatment

95% of PLHIV on treatment are virally suppressed

95% use combination prevention

95% coverage of services for eliminating vertical transmission

95% of women access HIV and sexual/reproductive health services

Quality of Life

Removing Societal and Legal Barriers to HIV services

Less than 10% of countries have punitive laws and policies

Less than 10% experience stigma and discrimination

Less than 10% experience gender inequality and violence

Stigma Can Undermine Clinical Research

- Bias in recruitment:
 Who feels safe to join a study
- 2. Retention/Follow-up: Who stays in
- Adherence to the protocol:e.g., study drugs
- 4. Stress & inflammation
- 5. Translation of science into action: policy uptake of efficacious results

Participant safety:

Risk of marking participants for stigma



People seeing us from outside will not know about us. They may not know we are [MSM]. But they might think that these people [trial volunteers] are at high risk and that is why they participate. They may look down upon us...look at us in a different manner

(Kothi, FG2, Mumbai)

Chakrapani et al (2012). Willingness to participate in HIV vaccine trials among men who have sex with men in Chennai and Mumbai, India: a social ecological approach. PloS one, 7(12), e51080.



In IDIs, many participants reported fears of being labelled and criticized by community members and people around them, including relatives. They stated that people might point fingers at them if they participate in the HIV vaccine efficacy trial because they believed that the participants are infected with HIV

Iseselo et al (2020). What motivates or demotivates injecting drug users to participate in hypothetical HIV vaccine efficacy trials? A qualitative study from urban Tanzania. *The East African health research journal*, *4*(2), 128–139

Health Facilities: A Good Place to Start

Why Focus on Stigma in Health Facilities?

Stigma is pervasive across the globe:

- Manifestations vary, from longer wait times to denial of care, to verbal abuse and unauthorized disclosure of stigmatized status
- It is perpetrated by both clinical and non-clinical health facility staff & other clients
- Intersecting stigma deepens the challenge & impact

Stigma undermines access to health care and health outcomes for clients.

Stigma undermines the health workforce.

Health workers can be powerful changes agents within and beyond the health facility.

YET, stigma reduction in health facilities is rarely a routine aspect of service delivery or training of health workers.

Definitions and Types of Stigma

Stigma: A Social Process that Occurs within the Context of Power

1. Distinguishing and Labeling Differences

(e.g., people women living with HIV, unmarried pregnant adolescent, people who use drugs, people who engage in sex worker))

2. Associating Negative Attributes

(irresponsible, immoral, promiscuous, untrustworthy)

3. Separating "Us" from "Them" (physical and social isolation)

4. Status Loss and Discrimination

(denial of health care, verbal & physical abuse, loss of respect)

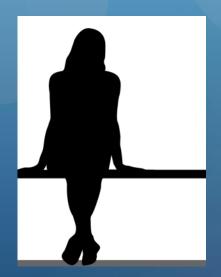
Types of Stigma

Experienced	Stigma that is enacted through interpersonal acts of discrimination How often has a health care worker refused to serve you because you sleep with men? (Ghana PRISM study)	
Perceived	Perception of the prevalence of stigmatizing attitudes in the community or among other groups (e.g., health care providers) People in my community think taking PrEP means you have HIV. (PrEP stigma, Kenya)	
Anticipated	Fear of stigma, whether or not it is actually experienced Do you think you would be treated badly by health workers or be rejected by family if others found out about your HIV status? (Turan et al., 2011)	
Internalized (self)	Acceptance of experienced or perceived stigma as valid, justified I sometimes feel worthless because I am HIV positive. (Kalichman et al., 2009)	
Secondary	Stigma by association, extended to family or other caregivers of stigmatized individual People made negative remarks about nurses involved with HIV and AIDS care. (Uys et al., 2009)	
Intersectional	When multiple social and structural factors that generate stigma intersect and create	

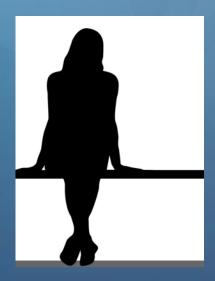
intersecting stigmas for individuals who are part of multiple marginalized groups

Intersectional Stigma





Adolescent Girl #1:
 Acquired HIV
perinatally, not sexually
active, in school



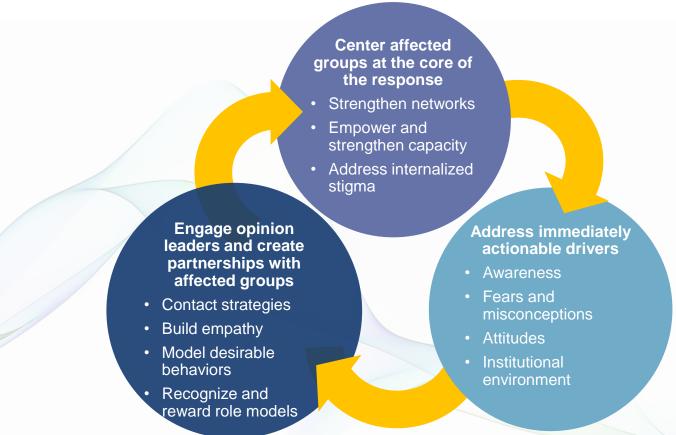
Adolescent Girl #2: Recently acquired HIV, pregnant, sex worker

Of course, to those who [were] born with it, sometimes some people they might think it is fine, let's give this the priority even those who have been raped but those who acquired maybe sexually...the feeling might be different.

(Health Worker, Zambia)

Taking Action: Key Principles for Stigma Reduction Interventions

Three Key Principles for Reducing HIV Stigma



Initial Research & Stigma Reduction Tools Development



2000-2003: Foundational multi-country study (Tanzania, Zambia and Ethiopia)



2003: Co-development by 50+ organizations in Tanzania, Zambia, Ethiopia



- Successfully used with a wide range of audiences
- 40+ Countries
- 7 Languages
- Addressing multiple stigmas



2005-2008: Multiple Toolkit Adaptations

Health facilities, key population stigma



2013-2015: HPP Comprehensive package for stigma reduction in health facilities

Taking Action: Examples of Implementing Key Principles for Stigma Reduction in Health Facilities



The HP+ Total Facility Approach to HIV Stigma Reduction







The HP+ Total Facility Approach to Stigma Reduction: Three Phases

Sociological Levels Addressed Individual **Formative Research** Adapt global assessment tools **Integration into Facility** Structures and Quantitative surveys Capacity-Building Facility staff **Processes** Clients living Adapt global training Interpersonal Early and continuous with HIV tools involvement of management Participatory dissemination Training of facilitators Creation and official workshop sanctioning of stigma Training of staff reduction champion teams Facility/ Development and implementation of stigma-Institutional reduction activities by staff, led by the champion teams Grounded in social cognitive theory principles and interpersonal or intergroup contact theory

How HP+ has Generally been Implemented

Training of Trainers

- Delivered by master trainers
- Facilitators: Facility staff and community members
- Five-day offsite training in:
 - Participatory methods
 - Curriculum content
- Onsite mentoring/coaching for initial step-down training
- Ongoing support checkins

Facility Step Down Training

- Includes both clinical and non-clinical staff
- Equivalent of two days of sessions (10-12 hours) onsite, participatory skills building for facility staff
- Timing is flexible, depending on facility schedule
- Mix of levels and departments works to minimize disruption of service delivery

Champion Teams/Facility Activities

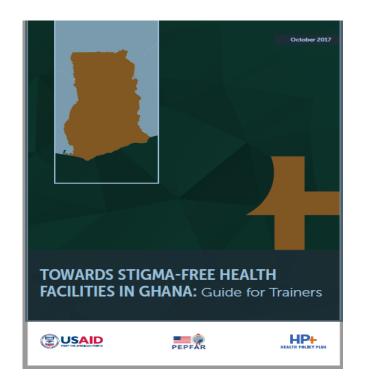
- 8-12 persons per facility
 - Facilitators, management and allies passionate about reducing stigma.
- Developed an action plan
 - Built on ideas generated in training
 - Iterative feedback from study team
- Implementation
 - Small grants to each facility

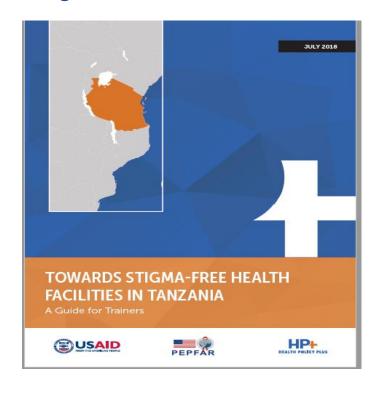
HP+ Participatory Stigma-reduction Curriculum

Topic	Corresponding Exercise
Create awareness of what HIV-related stigma is in concrete terms	Identify stigma and discrimination through pictures; analyze stigma in health facilities
Understand and address fear of contracting HIV in the workplace	Partner work and quality, quantity, route of transmission tool work on non-sexual transmission; role play to review standard precautions
Gender and sexual diversity, stigma and discrimination toward key populations (Ghana)	Sexual diversity education and terminology; learn about and connect stigma to human rights
Understand and address stigma faced by youth seeking HIV and other sexual and reproductive health services (Tanzania)	Use individual reflection, small group work, and plenary discussion to explore stigma experienced by youth, provider comfort/discomfort serving youth, ways to improve service delivery for youth clients
Building empathy and reducing distance (contact strategies)	Listen to first-hand experiences from members of key populations (Ghana), youth (Tanzania), and people living with HIV; discuss experiences in health facilities; self-reflection
Working to create change	Develop realistic strategies and a code of practice and action plan

Final curriculum: 14 participatory exercises (Ghana), 16 exercises (Tanzania)

Ghana and Tanzania Facilitator's Training Manuals





http://www.healthpolicyplus.com/ns/pubs/102 55-10465_GhanaSDFacilitatorsGuide.pdf

http://www.healthpolicyplus.com/ns/pubs/10238-10428_TZStimgaFreeFacilitiesTrainerGuide.pdf

Additional Tailored Stigma Reduction Interventions Designed and Implemented by Facility Staff



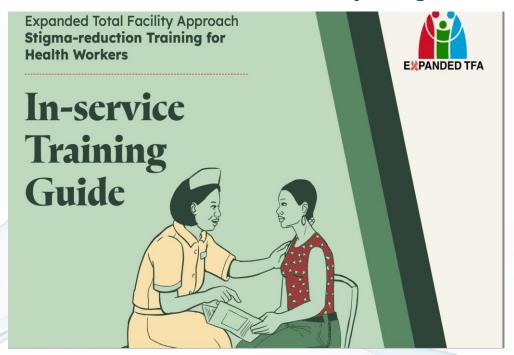
Local Solutions

- Champion teams
- Public declarations to stigma-free care
 - Banners, posters, community TV and radio spots, loudspeaker announcements
- Codes of conduct
- Complaint and compliment system

Sustainable

- Integrated in existing structures and processes
- Small seed grants provided for stigmareduction activities

Most Recent Health Facility Stigma Reduction Facilitators Guide



Available on-line:

https://doi.org/10.17037/PUBS.04673429



Key Elements of the Total Facility Approach

- Utilizes data to catalyze action, tailor approach & evaluate progress
- Strengthens capacity for facility-owned and driven stigma-reduction
 - Early and continued engagement of facility management
 - Trainers: both facility staff and clients
 - Champion teams that design and implement activities

- Uses participatory approaches to learning and behavior change
- Creates new opportunities for contact outside the providerclient power relationship
- Recognizes that all staff at a facility have a role to play to reduce stigma

If You Invest in Stigma Reduction...

The ripple effects will impact across the care cascade

