Breaking Down Barriers to Care

Reducing Stigma and Discrimination in Health Facilities

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Acknowledgments

• Respondents, facility staff, and management in Ghana and Tanzania, and Thailand

• Governments of Tanzania, Ghana, and Thailand, including ministries of health and national AIDS programs

• Local implementing partners in the three countries

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Presentation Overview

• Definitions and terminology
• Key principles for stigma-reduction programming
• Examples: Bringing measurement and interventions together to reduce stigma in health facilities
• Conclusions
What We Know: HIV Stigma is...

- Universal, Prevalent, and Harmful
  - Undermining each step of the cascade—from prevention to treatment

- Common at its core, while contextually specific
  - Causes
  - Forms
  - Consequences

- Differentially experienced, e.g. by gender, race, socioeconomic status, sexual orientation

- Actionable and Measurable
  - Practical models and tools available for adaptation and scale-up
  - Validated and tested measures
Definitions and Terminology
Stigma: A Fundamental Determinant of Health and Health Equity

• Stigma undermines three key determinants of health:
  – Access to resources
  – Access to social support
  – Psychological and behavioral responses

• Through exclusion, segregation, discrimination, stress and downward socioeconomic placement

(Hatzenbuehler et al. 2013)
Stigma: A Social Process that Occurs within the Context of Power

1. Distinguishing and Labeling Differences
(person living with HIV, person who injects drugs, gay man, 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)

The Soup of Stigma Terminology
<table>
<thead>
<tr>
<th>Types of Stigma</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Experienced</td>
<td>Stigma that is enacted through interpersonal acts of discrimination</td>
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<tr>
<td>Perceived</td>
<td>Perception of the prevalence of stigmatizing attitudes in the community or among other groups (e.g., healthcare providers)</td>
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<tr>
<td>Anticipated</td>
<td>Fear of stigma, whether or not it is actually experienced</td>
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<tr>
<td>Internalized</td>
<td>Acceptance of experienced or perceived stigma as valid, justified</td>
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<tr>
<td>Types of Stigma (Continued)</td>
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<tr>
<td>-----------------------------</td>
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<tr>
<td><strong>Secondary</strong></td>
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<tr>
<td>Stigma by association, extended to family or other caregivers of the stigmatized individual</td>
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<tr>
<td><strong>Observed (Vicarious)</strong></td>
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<tr>
<td>Stigma happening to others that is witnessed or heard about</td>
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<tr>
<td><strong>Structural</strong></td>
<td></td>
</tr>
<tr>
<td>Laws, policies, and institutional architecture that may be stigmatizing (or, alternatively, protective against stigma)</td>
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<tr>
<td><strong>Intersectional</strong></td>
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<tr>
<td>Convergence of multiple stigmatized identities within a person or group/intersecting of stigmas faced by individuals who are part of multiple marginalized groups</td>
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</table>
Measurement and Interventions
What We Know and Key Principles for Stigma-Reduction Programming
Why and Where We Intervene to Reduce Stigma and Discrimination

Immediately Actionable Drivers

1. Fear of contracting HIV
2. Awareness of Stigma
3. Attitudes
4. Institutional Environment

Stigma Manifestations

experienced, anticipated, perceived, internalized, etc.

avoidance, harassment, refusal to treat, etc.

HIV Treatment Cascade

1. Testing & Diagnosis
2. Linkage to care & Retention in care
3. Adherence

Viral Load Suppression

Stigma Measurement and Intervention

Sources: HIV Treatment Cascade Reference Literature:
1. Testing: (Musheke et al., 2013)
2. Linkage to & Retained in care: (Govindasamy et al., 2012, Alvarez-Uria et al., 2013)
3. Adherence: (Katz et al., 2013)
Key Principles for HIV Stigma-Reduction Interventions

- Address immediately actionable drivers
  - Raise awareness
  - Discuss and challenge the shame and blame
  - Address fears and misconceptions about contracting HIV

- Create partnerships between affected groups and opinion leaders
  - Contact strategies
  - Build empathy
  - Model desirable behaviors
  - Recognize and reward role models

- Place affected groups at the center of the response
  - Develop and strengthen networks
  - Empower and strengthen capacity
  - Address self-stigma
A Myriad of Intervention Tools
Training Package for Health Facilities: Health Policy Project

• Based on field application in 9 countries
• Can be tailored for different audiences and timeframes
• Includes 17 sample workshops and 1 refresher
• Has been adapted and used in many places
Global Stigma Measurement Tools: Available for Multiple Populations

• People Living with HIV Stigma Index 2.0
  o Recent revision completed, more focus on health facility and key population stigma

• Health facility
  o Measuring HIV stigma and discrimination among health facility staff: Standardized brief questionnaire (www.healthpolicyproject.com)
  o Adaptations: Thailand, Lao PDR, Viet Nam, Jamaica, Ghana, Tanzania, Zambia, South Africa, Alabama

• General population
  o Revised questions in the most recent round of the Demographic and Health Surveys

• Global indicators approved by the UNAIDS Monitoring & Evaluation Reference Group
  o Population (3 indicators)
  o Health facility (6 indicators)
Example: Assessment Tool for Health Facilities

- Health Policy Project-led consortium of international stakeholders developed, field-tested, and refined a brief measurement tool

- Two tools
  - Comprehensive Brief: 21–24 questions
  - Monitoring Tool: 7 questions

- Available in 6 languages
  - Arabic, Chinese, English, French, Spanish, Swahili
Intervention Examples

Bringing measurement and key principles together to reduce stigma in health facilities
Combating HIV-Related Stigma and Discrimination in Health Facilities
Impressive Results from Ghana and Tanzania
The HP+ Total Facility Approach to Stigma Reduction: Three Phases

Assessment (Baseline)

Steps
1. Adapt global assessment tools
2. Quantitative surveys
   - Facility staff
   - Clients living with HIV
3. Participatory dissemination

Intervention

Steps
1. Adapt global training tools
2. Participatory skills building
   - Training of facilitators
   - Stigma-reduction trainings for all staff
3. Other tailored, facility-led interventions

Evaluation (Endline)

Steps
1. Quantitative surveys
2. Data analysis
3. Dissemination at facilities
Participatory Skill Building

• Training of facilitators: Facility staff and clients living with HIV, including youth (Tanzania)
  o Competitive selection of facilitators (Tanzania)
  o Five-day offsite training and five days of mentoring/coaching (led by master trainers)

• Two days onsite, participatory skills building for facility staff (clinical and non-clinical)
  o Mix of levels and departments minimizes disruption of service delivery
  o Timing is flexible, depending on facility schedule
  o Holding the sessions one week apart deepened learning (Tanzania)
## Participatory, Facility-Based, Two-Day Staff Training

<table>
<thead>
<tr>
<th>Topic</th>
<th>Corresponding Exercise</th>
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<tbody>
<tr>
<td>Create awareness of what HIV-related stigma is in concrete terms</td>
<td>Identify stigma and discrimination through pictures; analyze stigma in health facilities</td>
</tr>
<tr>
<td>Understand and address fear of contracting HIV in the workplace</td>
<td>Partner work and quality, quantity, route of transmission tool work on non-sexual transmission; role play to review standard precautions</td>
</tr>
<tr>
<td>Gender and sexual diversity, stigma and discrimination toward key populations (Ghana)</td>
<td>Sexual diversity education and terminology; learn about and connect stigma to human rights</td>
</tr>
<tr>
<td>Understand and address stigma faced by youth seeking HIV and other sexual and reproductive health services (Tanzania)</td>
<td>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</td>
</tr>
<tr>
<td>Building empathy and reducing distance (contact strategies)</td>
<td>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</td>
</tr>
<tr>
<td>Working to create change</td>
<td>Develop realistic strategies and a code of practice and action plan</td>
</tr>
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</table>

*Final curriculum: 14 participatory exercises (Ghana), 16 exercises (Tanzania)*
More Tailored 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 stigma-reduction activities
## Evaluation Methods

<table>
<thead>
<tr>
<th></th>
<th>Ghana</th>
<th>Tanzania</th>
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</thead>
<tbody>
<tr>
<td><strong>Pre- and post-intervention comparison through baseline-endline surveys</strong></td>
<td>10 facilities (5 intervention, 5 comparison</td>
<td>2 facilities</td>
</tr>
<tr>
<td>District-level health facilities</td>
<td>5 of the highest HIV prevalence regions (Ashanti, Brong Ahafo, Eastern, Greater Accra, and Western)</td>
<td>1 region (Morogoro)</td>
</tr>
<tr>
<td>Regions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health facility staff of all levels (clinical and non-clinical)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>n=1,149</td>
<td>n=233</td>
</tr>
<tr>
<td>Endline</td>
<td>n=1,149</td>
<td>n=278</td>
</tr>
<tr>
<td>Estimated before-after trends</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Estimated difference-in-differences</td>
<td>√</td>
<td>-</td>
</tr>
</tbody>
</table>
Evaluations Found Interventions Effective (Ghana and Tanzania)

• Significant reductions in drivers and manifestations of stigma
  o Difference-of-differences in Ghana strengthen ability to attribute changes to the intervention

• Improved treatment of clients (reported by both clients and staff)

• Benefits for facility staff of stigma reduction

This interaction is different from anything else we have experienced so far—we defined the response; we owned it.

— Dr. Akosua Osei Manu
Tema General Hospital
### What Was Measured and Addressed

<table>
<thead>
<tr>
<th>Ghana</th>
<th>Tanzania</th>
</tr>
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<tbody>
<tr>
<td>HIV-related stigma</td>
<td>HIV-related stigma</td>
</tr>
<tr>
<td>✤ Immediately actionable drivers</td>
<td>✤ Immediately actionable drivers</td>
</tr>
<tr>
<td>• Fear, attitudes, health facility environment/influence of stigma on health facility staff</td>
<td>• Fear, attitudes, health facility environment/influence of stigma on health facility staff</td>
</tr>
<tr>
<td>✤ Stigmatizing avoidance behaviors (self-reported)</td>
<td>✤ Stigmatizing avoidance behaviors (self-reported)</td>
</tr>
<tr>
<td>✤ Observed discrimination (behaviors observed in other staff)</td>
<td>✤ Observed discrimination (behaviors observed in other staff)</td>
</tr>
<tr>
<td>✤ Willingness to care</td>
<td>✤ Willingness to care</td>
</tr>
<tr>
<td>✤ Stigma toward key populations</td>
<td>✤ Stigma toward youth (ages 15–24)</td>
</tr>
<tr>
<td>• Men who have sex with men, sex workers, people who inject drugs</td>
<td>• Men who have sex with men, sex workers, people who inject drugs</td>
</tr>
<tr>
<td>✤ Costing analysis</td>
<td>✤ First adaptation to generalized epidemic setting</td>
</tr>
</tbody>
</table>

**Ghana**

- Stigma toward key populations
  - Men who have sex with men, sex workers, people who inject drugs
- Costing analysis

**Tanzania**

- Stigma toward youth (ages 15–24)
- First adaptation to generalized epidemic setting
Worry about Contracting HIV While Caring for Clients Living with HIV: Composite (Ghana)

- **Intervention Facilities**
  - Pre-Intervention: 54% (n=279)
  - Post-Intervention: 27% (n=137) (p=0.000)

- **Comparison Facilities**
  - Pre-Intervention: 56% (n=270)
  - Post-Intervention: 53% (n=248) (p=0.596)
Stigmatizing Avoidance Behaviors: Composite (Ghana)

Intervention Facilities
- Pre-Intervention: 69% (n=359)
- Post-Intervention: 23% (p=0.000)
- Change: 46% (n=227)

Comparison Facilities
- Pre-Intervention: 74% (n=340)
- Post-Intervention: 66% (n=303)
- Change: 8% (p=0.000)
Provider Understanding of and Interactions with Key Populations Improved (Ghana, Pre/Post)

- Own preference not to treat men who have sex with men (MSM)
  - 15% decline \( (p=0.000) \)
  - Greater change in intervention facilities
    - Difference-in-differences: 14.2% \( (p=0.001) \)

Since the training, we have seen an increase in MSM living with HIV coming for services. We think this is mostly due to the change in our staff and how they interact with key populations. We also see MSM coming freely for their medicines during regular facility hours. Before they preferred coming after hours, to avoid being seen by staff.”

— Mr. Kofi Atakorah-Yeboah Jnr, Champion Team Member, Bekwai Hospital
Stigmatizing Attitudes: Composite (Tanzania)

- **Holds 1+ stigmatizing attitude about people living with HIV**
  - Pre-intervention: 99%
  - Post-intervention: 35% (p=0.000)
  - Change: 64%

- **Holds 1+ stigmatizing attitude about women living with HIV**
  - Pre-intervention: 92%
  - Post-intervention: 33% (p=0.000)
  - Change: 60%

- **Holds 1+ stigmatizing attitude about sexually active adolescents**
  - Pre-intervention: 97%
  - Post-intervention: 23% (p=0.000)
  - Change: 74%
Observed Discrimination: Composite, By Group (Tanzania)

- People living with HIV: Pre-intervention 29%, Post-intervention 7% (p=0.000)
- Sexually active adolescents: Pre-intervention 40%, Post-intervention 9% (p=0.000)
- Unmarried pregnant adolescents: Pre-intervention 41%, Post-intervention 9% (p=0.000)
Influence of Stigma on Health Facility Staff (Tanzania)

- **Own hesitancy to take HIV test in facility due to fear of others' reactions if positive**: Pre-intervention 42%, Post-intervention 34% (p=0.000)
- **Perceived hesitancy of colleagues take HIV test in facility due to fear of others' reactions if positive**: Pre-intervention 61%, Post-intervention 19% (p=0.000)
- **Perceived hesitancy of colleagues to work alongside a person living with HIV, regardless of duties**: Pre-intervention 11%, Post-intervention 7% (p=0.000)
Key Elements of the Total Facility Approach

• Evidence-based, building on two decades of work
  o Immediately actionable drivers
    o Adaptation of validated measurement and participatory training tools

• Recognition that all facility staff have a role to play

• Engagement of facility management

• Data-driven
  o Baseline informs intervention and catalyzes action
  o Endline evaluation

• Strengthens stigma-reduction capacity in facilities
  o Participatory approaches to learning and behavior change
  o Participatory stigma-reduction trainings led by staff and clients
  o Facility champion teams
Thailand: An Example of National Scale-up

“3 By 4” and National Framework for Measuring HIV Stigma and Discrimination

With grateful acknowledgment of the Bureau of AIDS, TB, and STIs, Department of Disease Control, Ministry of Public Health, Thailand
Timeline on Measurement and Interventions on HIV-related Stigma in Thailand

Measurement

- Development of SD measurement tool in health settings (HCP&PLHA) 2009
- SD measurement in general pop in the 5th National Health Exam Survey 2010
- Stigma index survey in PLHA 2011
- SD measurement in general pop in the 5th National Health Exam Survey 2012
- SD measurement in general pop in 3rd MICS 2013
- SD measurement for KP in IBBS 2014
- The 1st SD survey of health settings in 5 sentinel provinces 2015
- The 2nd SD survey for health settings in 13 sentinel provinces 2016
- SD Measuremnt for KP in IBBS 2017
- The 3rd SD survey for health settings in 13 sentinel provinces 2018
- SD measurement for general pop in the 6th NHES 2019

Interventions

- Development of SD reduction participatory training tool for health staff
- Pilot 3*4 SD reduction package in 6 hosp.
- Expand 3*4 package + CQI in 50 hospitals in 16 provinces
- Expand 3*4 stigma-free health facilities in 61 hospitals cover all 77 provinces
- Launch SD E-learning tool
- Launch SD E-learning
- Develop self stigma reduction program (SRP) for PLHA&KP
- Pilot SRP in 3 hospitals

National HIV Strategic Plan 2012-16

- Develop online events based report on SD rights violation

National Strategy to end AIDS 2017-30

- Launch online Rights violation event report
- SD measurement for general pop in the 4th MICS and the 6th NHES
PRINCIPLE: CREATE SAFE SPACE FOR LEARNING S&D REDUCTION / PARTICIPATION OF KPs AND PLHIV

LINKAGE

INSTITUTIONAL

INDIVIDUAL

S&D REDUCTION ADMINISTRATIVE COMMITTEE
- Policy on S&D-free health care hospitals and AIDS-Response Standard Organization

WORKING GROUP

SYSTEM IMPROVEMENT ACTIVITIES
- Bi-monthly meeting
- Case conference
- ASO/ CoP
- Collecting data (quantitative & qualitative method)
- Action plan

HIV COORDINATOR

LEARNING ACTIVITIES
- S&D reduction training (50% of staff with mini-package) + CoP and action plan
- Specific training/ group discussion for certain department
- Refreshing training
- Orientation for new staff
- E-learning

TRAINERS

PROVINCIAL MECHANISM
- Consultative meeting
- Case Conference

KP COMMUNITY
- Case Conference

THREE level within health facilities
1) Individual (health facility staff)
2) System/health facility structure
3) Heath facility-community linkage

FOUR key immediately actionable drivers
1) Lack of awareness
2) Fear of workplace exposure to HIV
3) Social stigma, judgment, shame and blame
4) The health facility environment

Source: Bureau of AIDS, TB, and STIs, DDC, MOPH, Thailand
<table>
<thead>
<tr>
<th>POPULATION (FREQUENCY)</th>
<th>OBJECTIVES</th>
<th>METHOD OF MEASUREMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Population (every 5 years)</td>
<td>Attitudes towards PLHIV</td>
<td>Integrated in the existing household survey</td>
</tr>
<tr>
<td>Key Populations (every 2 years)</td>
<td>Experience of S&amp;D</td>
<td>Integrated in the IBBS</td>
</tr>
<tr>
<td>Health Facility Staff (every 2 years)</td>
<td>Assess key drivers and enacted stigma</td>
<td>Survey in sentinel sites (6–8 provinces)</td>
</tr>
<tr>
<td>PLHIV (every 2 years)</td>
<td>Experience of S&amp;D in a healthcare setting</td>
<td>Survey in sentinel sites (6–8 provinces)</td>
</tr>
<tr>
<td>Event Based Monitoring System (ongoing)</td>
<td>Monitor events relating to violence, abuse, and rights violation towards KAP, people living with or affected with HIV</td>
<td>To be determined</td>
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</tbody>
</table>
Action is Possible

- **Measure: standardized and validated tools exist**
  - Make S&D reduction a key goal in national strategies
  - Integrate S&D indicators into national HIV M&E frameworks
  - Expand and standardize measurement of S&D
- **Make S&D-reduction part of all HIV programs: intervention and programmatic tools are available**
- **Make stigma reduction an explicit component of delivering high-quality health services by:**
  - Integrating S&D-reduction into quality-improvement processes
  - Incorporation into medical training—pre and in-service (for all staff)
  - Licensing and accreditation for individuals & facilities
  - Performance assessment & supervision
  - Reporting and redress mechanisms
- **Leverage synergies for stigma reduction**
  - Combine stigma reduction across stigmatized conditions and groups
Stigma Reduction is a Smart Investment: if You Invest in Stigma Reduction...

The ripple effects will impact across the cascade and contribute to reaching 95-95-95 targets...

Coverage across community served

- Willingness to seek testing
- Disclosure of HIV status
- Ability to practice prevention
- Pre-exposure prophylaxis (PrEP)

- Willingness to seek care and treatment
- Ability to access care and treatment
- Retention in care
- Quality of services

- Improved treatment adherence and retention
- Improved treatment effectiveness
- Increased viral load suppression

Prevention and Testing
Linkage and Retention in Care
Adherence and Viral Load Suppression
Action to reduce facility stigma is possible!

Global measurement and intervention tools are easily adaptable across diverse contexts