“…. 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
Definitions

Key principles for stigma-reduction

How: An example applying those to health facility stigma-reduction

TB stigma Resources & emerging research agenda
What we Know About TB Stigma

- **Harmful**
  - To the individual, public health, human rights

- **Universal & common at its core, yet**
  - Locally shaped (context matters)
  - Often differentially experienced (e.g. by gender)

- **Actionable**
  - TB stigma can be reduced if deliberately addressed
  - Yet a gap remains in evaluated interventions

- **Measurable**
  - Growing number of tools
  - Drivers, manifestations and consequences

- Often co-occurs with/intersects with other stigmas
Growing Global Recognition of the Need to Act

- Zero suffering
  - One of the three aims of the WHO’s End TB strategy
- Identified by the Global Fund as one of the most common barriers to fighting the TB epidemic
- UN agencies global call for an end to discrimination in health care
- Recognition of the potential for interventions to simultaneously reduce multiple stigmas
  - Common drivers, manifestations and consequences
  - Co-morbidity of stigmatized diseases
  - Intersectional
  - BMC Medicine collection on stigma research and global health
Definitions, Terminology & General Intervention Principles
Stigma is a Fundamental Determinant of Health and Health Inequity

- 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 socio-economic placement (Hatzenbuehler et al. 2013)
Stigma: a Social Process that Occurs within the Context of Power

1. Distinguishing & Labeling Differences
   (TB patient, Person living with HIV, Immigrant, Adolescent)

2. Associating Negative Attributes
   (dirty, irresponsible, dangerous, 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)

# Terminology of Stigma

## Types of Stigma

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experienced</td>
<td>Stigma that is enacted through interpersonal acts of discrimination</td>
</tr>
<tr>
<td>Perceived</td>
<td>Perception of the prevalence of stigmatizing attitudes in the community or among other groups (e.g. healthcare providers)</td>
</tr>
<tr>
<td>Anticipated</td>
<td>Fear of stigma, whether or not it is actually experienced</td>
</tr>
<tr>
<td>Internalized (self)</td>
<td>Acceptance of experienced or perceived stigma as valid, justified</td>
</tr>
</tbody>
</table>
### Terminology of Stigma Continued

#### Types of Stigma

<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary</td>
<td>Stigma by association, extended to family or other caregivers of stigmatized individual</td>
</tr>
<tr>
<td>Observed or Vicarious</td>
<td>Stigma occurring to others that is witnessed or heard about</td>
</tr>
<tr>
<td>Structural</td>
<td>Laws, policies, and institutional architecture that may be stigmatizing or alternatively protective against stigma</td>
</tr>
<tr>
<td>Intersectional</td>
<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>
</tr>
</tbody>
</table>
Key Principles for HIV Stigma-Reduction Interventions

Address immediately actionable drivers
- Raise awareness & understanding of stigma
- Attitudes: Discuss/challenge the shame and blame
- Address transmission fears and misconceptions

Institutional Environment
- Affected groups at the center of the response
  - Develop and strengthen networks
  - Address internalized stigma
  - Foster Resiliency & Resistance
  - Empower and strengthen capacity

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

Foster Resiliency & Resistance
- Empower and strengthen capacity
An example of a facility-focused HIV stigma reduction intervention
Why and Where We Address Stigma in Health Facilities

Combating HIV-related Stigma and Discrimination in Health Facilities
Acknowledgments

**Tanzania**
- Respondents, facility staff, and management
- Government of Tanzania
  - National AIDS Control Programme
  - Office of the Morogoro regional medical officer
  - Mvomero and Kilosa districts
- Local implementing partners
  - Muhimbili University for Health and Allied Sciences (Research)
  - Kimara Peer Educators (Intervention)
- USAID and PEPFAR

**Ghana**
- Respondents, facility staff, and management
- Ghana AIDS Commission
- National AIDS Control Programme
- Educational Assessment Research Center (local implementing partner)
- USAID and PEPFAR
- The Global Fund to Fight AIDS, Tuberculosis, and Malaria
The HP+ Total Health Facility Approach to Stigma Reduction: Three Phases

**Assessment (Baseline)**
1. Adapt global assessment tools
2. Quantitative surveys
   - Facility staff
   - Clients living with HIV
3. Participatory dissemination

**Intervention**
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)**
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
  • Competitive selection of facilitators
  • 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)
  • Mix of levels and departments minimizes disruption of service delivery
  • Timing is flexible, depending on facility schedule
# Participatory, Facility-Based, Two-Day Staff Training

<table>
<thead>
<tr>
<th>Topic</th>
<th>Corresponding Exercise</th>
</tr>
</thead>
<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 workplace HIV transmission</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>
</tbody>
</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
### What Was Measured and Addressed

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

Intervention Facilities

- Pre-Intervention: 54% (n=279)
- Post-Intervention: 27% (n=137)

Comparison Facilities

- Pre-Intervention: 56% (n=270)
- Post-Intervention: 53% (n=248)

StatisticalSignificance:
- Pre-Intervention to Post-Intervention in Intervention Facilities: 27% (p=0.000)
- Pre-Intervention to Post-Intervention in Comparison Facilities: 3% (p=0.596)

Sample Sizes:
- Intervention Facilities: N=514
- Comparison Facilities: N=480
Stigmatizing Attitudes: Composite (Tanzania)

- Holds 1+ stigmatizing attitude about people living with HIV: Pre-intervention 99%, Post-intervention 35% (p=0.000)
- Holds 1+ stigmatizing attitude about women living with HIV: Pre-intervention 92%, Post-intervention 33% (p=0.000)
- Holds 1+ stigmatizing attitude about sexually active adolescents: Pre-intervention 97%, Post-intervention 23% (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
Key Elements of the Total Facility Approach

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

- Builds ownership of the response by facilities
  - Recognition that all facility staff have a role to play
  - Early and ongoing engagement of facility management

- Strengthens stigma-reduction capacity in facilities
  - Participatory approaches to learning and behavior change
  - Participatory stigma-reduction trainings led by staff and clients
  - Facility champion teams
Participation leads to ownership and lays foundation for success and sustainability

“Training facility staff as facilitators led to much better results… Because they were our own staff, they were able to go and learn and then prepare sustainable trainings for their colleagues … Trainings were easier to understand and better received, because the facilitators know their fellow staff members and understand the facility context and were able to plan the content accordingly”

—Joseoh Ngimba, Medical Officer-In-Charge, Turiani

“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
TB Stigma Focused Resources
TB Stigma Reduction Intervention Tools

Understanding and challenging TB stigma
Toolkit for action

- Introduction to TB and stigma
- More understanding and less fear about TB

Tuberculosis Stigma Reduction
for Health Care Institutions

INTERVENTION PACKAGE
Allies Approach
The KNCV Stigma Reduction Tool Box

From the Inside Out:
Dealing with TB-related Self-stigma and Shame
A pilot toolkit for people with TB to deal with self-stigma and shame

Version 1.3 - September, 2018
www.ced-self-stigma.com
TB Stigma Measurement Toolkit

- Companion Curriculum:
Defining the research agenda to measure and reduce tuberculosis stigmas  Macintyre et al

1) Drivers: what are the main drivers and domains of TB stigma(s)

2) Consequences: how consequential are TB stigmas and how are negative impacts most felt?

3) Burden: what is the global prevalence and distribution of TB stigma(s) and what explains any variation?

4) Intervention: what can be done to reduce the extent and impact of TB stigma(s)?
Stigma-Reduction: A key ingredient to finding and treating the estimated 4 million missing TB cases?

The ripple effect will impact across prevention and treatment, contributing to better health outcomes across populations & TB control.

Coverage across communities served:

- Prevention & Diagnosis
- Linkage to Care
- Treatment adherence
- Strengthened Health Outcomes

Stigma-reduction interventions