HIV/AIDS Research Results

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Research Around Stigma and Discrimination in Jamaica

IMPLICATIONS FOR KEY AFFECTED POPULATIONS

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C-Change Jamaica

- Two-year project
- Three key areas of work:
  - SBCC capacity strengthening
  - Material development
  - Research
    - Formative research directly impacting program
    - As requested by USAID Mission/Ministry of Health, across levels of the socio-ecological model, including service provision
HIV Context in Jamaica

- Concentrated HIV epidemic, with HIV prevalence:\n  - 1.7% general public
  - 4.1% female sex workers (SW)
  - 31.2% men who have sex with men (MSM)

- 2012 incidence: 30% new infections among MSM; 7% their female partners; 7% among SW and clients

- Sex work and sexual acts between men illegal and highly stigmatized

1 UNAIDS 2012
Layered Stigma Among Health Facility and Social Services Staff Toward Key Affected Populations in Jamaica
Layered Stigma

Quantitative study with three components:
1. 165 health facility workers (25 facilities)
2. 63 social service workers (12 organizations)
3. 450 male and female SW

Locations: Kingston, Montego Bay, Ocho Rios

PLHIV not a primary interest group, but questions administered to differentiate stigma and discrimination
Findings: Training

% Staff Untrained

0 20 40 60 80 100

HIV Prevention
HIV Care & Treatment
Psychosocial Support - HIV
Psychosocial Support - MSM
Psychosocial Support - SW
Interpersonal Communication
Key Affected Populations

Health Facility  Social Services
Fear and Avoidance Desires: Casual Contact

- Discomfort sharing a bathroom:
  - 32% health facility; 21% social service for PLHIV colleague
  - 45% health facility, 19% social service (.05) for MSM colleague

- Fear (HIV)/desire to avoid (MSM, SW) touching sweat or saliva:
  - 31% health facility; 30% social service—PLHIV
  - 45% health facility; 33% social service—MSM
  - 35% health facility; 23% social service—SW
Fear and Avoidance Desires: Clinical Contact

- Clinical health facility staff:
  - 47% feared giving an injection or IV for PLHIV
  - 44% feared dressing wounds of PLHIV; 10% wanted to avoid doing this for MSM
  - 50% feared suturing or conducting surgery on PLHIV
## Association of Training on Fear Measures

<table>
<thead>
<tr>
<th></th>
<th>% Health facility staff trained</th>
<th>% Health facility staff untrained</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>No fear/avoidance desire of sweat or saliva</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLHIV</td>
<td>76%</td>
<td>51%</td>
<td>.004</td>
</tr>
<tr>
<td>MSM</td>
<td>66%</td>
<td>37%</td>
<td>.001</td>
</tr>
<tr>
<td>SW</td>
<td>70%</td>
<td>51%</td>
<td>.032</td>
</tr>
<tr>
<td>Comfort sharing bathroom with colleague suspected as</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLHIV</td>
<td>79%</td>
<td>56%</td>
<td>.002</td>
</tr>
<tr>
<td>MSM</td>
<td>80%</td>
<td>48%</td>
<td>.000</td>
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</tbody>
</table>
Moral Judgments

- Most believed PLHIV and key affected populations deserved quality of care (90%–98%, depending on group and sector).

- Females more likely (.001) to believe that SW deserved the same level of care as others (94% females vs. 79% males).

- Other moral judgments were high.
Moral Judgments

- Women prostitutes spread HIV
  - SSO: 34
  - HF: 30
- Sex work is immoral
  - SSO: 61
  - HF: 75
- MSM spread HIV in community
  - SSO: 40
  - HF: 35
- Homosexuality is immoral
  - SSO: 63
  - HF: 83
- PLHIV should be ashamed
  - SSO: 10
  - HF: 10
- HIV due to immoral behavior
  - SSO: 46
  - HF: 53
- HIV punishment for bad behavior
  - SSO: 7
  - HF: 14
Components 1 & 2 (continued)

• Enacted stigma = Unlawful discrimination, as well as a wider set of stigmatizing actions

• Predominantly gossip about status:
  • as PLHIV (10%)
  • as MSM (13%)
  • as SW (8%)

• Followed by reports of HIV testing without consent
## Vignettes

<table>
<thead>
<tr>
<th>Characters</th>
<th>Highest Stigma Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Four HIV positive</td>
<td>X is responsible for illness</td>
</tr>
<tr>
<td>Four HIV negative</td>
<td>You would allow your kids to visit X in their home</td>
</tr>
<tr>
<td>Two SW</td>
<td>You would attend a party where X prepared food</td>
</tr>
<tr>
<td>Two MSM</td>
<td>X is dangerous to other people</td>
</tr>
<tr>
<td></td>
<td>X deserves sympathy</td>
</tr>
</tbody>
</table>
Mean Stigma Score by Character

- No SW, HIV-
- Non MSM, HIV-
- SW, HIV-
- MSM, HIV-
- No SW, HIV+
- Non MSM, HIV+
- SW, HIV+
- MSM, HIV+

Mean Stigma Score
Component 3 Findings

- Nearly half SW disclosed to health worker
  - One-third regretted doing so

- SW who disclosed significantly more likely to report poorer quality services or denial of services

- SW worried clinic workers would tell others (61%) or would judge them (52%)
Component 3 Findings

- In the past six months:
  - 22% gossiped about (health care)
  - 14% gossiped about (health activities)
  - 13% rushed/hurried during exam
  - 11% poorer quality health care services
  - 4% denied services

- **Gender**: Male SW reported highest proportion of stigma and discrimination (past 6 months) across almost all measures—significant for gossip in health activity and being hurried.
Using a Socio-Ecological Model as a Framework to Analyzing Stigma and Discrimination Toward MSM
Purpose and Methods

- Aimed to put a ‘virtual’ face on quantitative data and provide findings useful for SBCC campaigns
- Qualitative study using hearsay ethnographic approach
- 24 MSM data collectors trained to identify actions, words, behaviors, and attitudes experienced or observed
- Data collected through written journals and weekly debriefings
Findings: Types of Stigma and Discrimination

- Incidents pervasive
- Verbal insults most frequent (88%), but physical incidents reported (5%).
- Directed at specific individuals; occurred most when alone
- Largely perpetuated by males (73%); 18-45 years of age (65%)

A man shouts “batty man” at a group of young men. They ignore him. He returns later with two other men and harasses them.

They respond, cursing their abusers. The three men go to their car and get machetes and sticks and chase the suspected young homosexuals.

The young men retaliate by throwing acid on their attackers. They say “Mi nah run, mi ago burn up somebody. Mi tired, mi nah run nuh more.”
Interpersonal Level: The Family

- 9% of incidents occurred within the home and among family members
- Fear and anxiety about their sexuality being ‘found out’ and ostracized

One ethnographer reported that his mother said: “If I ever find out that you are gay, I will poison you to death myself.”

Another ethnographer reported overhearing a man say to another man that he would “… pour kerosene oil all over his son and light him on fire personally, if he ever found out his son was gay…”
Interpersonal—Within MSM Community

- Divisions between:
  - More effeminate vs. masculine MSM
  - Gay-identified vs. non-gay, straight-identified MSM

- Expressed frustration and concern for the safety of fellow MSM who behave effeminately in public, as well as their own self-interest

- I have gay friends that I only communicate with by phone. I will not go out in public with them because they behave too feminine. I am well known in my community and so I can’t afford to be seen with them, cause then people would know I’m gay too (KSA).
Community Level

- 60% occurred in very public spaces
- Elicited a response from other persons within the vicinity
- Incidents would become the focal point of activity

Female customer in a shoe store commented to another customer that she was reluctant to purchase from the outlet as it was owned by a suspected homosexual and staffed with homosexuals:

“It is owned by a battyman, and is only faggots and battyman who work there.... Me no support battyman living” (Outside KSA).
Institutional Level

- Incidences of stigma and discrimination took place in educational institutions (10% of cases; n=14).
- Reluctance to utilize some health facilities due to stigma and discrimination displayed by some staff.
- Often resulted in seeking health care outside own parishes, which cost more than accessing local public clinics.
- Churches functioned as a source of stigma.
- Some congregants used nonverbal behavior to isolate or shun MSM or suspected MSM.
Impact

Depression
Suicidal thoughts
Fear
Frustration
Anger/desire for retribution

I couldn’t stay there anymore, I would have died. I am gay and I am HIV positive ...I have been through a lot. This infection has changed my life forever. And, never will I ever wish this to happen to anybody else. I was so disappointed for I was expecting better from people who are ‘educated’ and ‘Christians’ too.
## Limitations

<table>
<thead>
<tr>
<th>Layered stigma</th>
<th>Stigma and discrimination toward MSM</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Staffing shortages</td>
<td>• Hearsay methodology</td>
</tr>
<tr>
<td>• Lack of social service organizations outside Kingston</td>
<td>• Demographic details</td>
</tr>
<tr>
<td>• UK threat of sanctions</td>
<td>• Time period of reports</td>
</tr>
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</table>
Conclusions from Two Jamaican Studies

- Findings consistent with literature that show MSM, SW, and PLHIV are the target of stigma and discrimination.
- Widespread evidence found in health facilities and social service organizations, including layered stigma.
- HIV-prevention training in health facilities and social service organizations significantly associated with decreased stigma and discrimination.
- For MSM, stigma and discrimination found across several environments, implying a pervasive social norm.
Recommendations

- Strengthen training in HIV prevention, interpersonal communication, and stigma and discrimination and work with key affected populations.

- Use a multilayered approach to address stigma and discrimination, based on a socio-ecological model.

- Conduct greater advocacy within key affected populations and the wider community to address stigma and discrimination.

- Use the C-Change study on layered stigma as a baseline for PEPFAR and National Programme work in Jamaica.
Perspectives of PLHIV on HIV Prevention: A Study in Three African Countries

OPPORTUNITIES AND CHALLENGES FOR STRENGTHENING RESPONSE

C-CHANGE COMMUNICATION FOR CHANGE
PEPFAR U.S. President's Emergency Plan for AIDS Relief
USAID FROM THE AMERICAN PEOPLE
Background

- The past decade has seen marked shifts in health and life opportunities of PLHIV in Africa.

- Changes largely attributable to strong commitment and availability of ART.

- Shifts in life circumstances and outlook allow for expanded emphasis on HIV prevention in relation to living with HIV.
Terminology and conceptual framework for HIV prevention among PLHIV varied over time: Positive Prevention, Prevention with Positives, Positive Living... Positive Health Dignity and Prevention (PHDP)

PHDP concept includes
- ‘We are more than patients’
- ‘We are not vectors of transmission’
- ‘We are all responsible for HIV prevention’
- ‘We have needs and desires’
- Values: rights, dignity, equitable access, inclusion, economic wellbeing
## Participants

### Quantitative PLHIV Survey

<table>
<thead>
<tr>
<th>Total</th>
<th>Ethiopia</th>
<th>Moz</th>
<th>Uganda</th>
<th>Male</th>
<th>Female</th>
<th>18–29 years</th>
<th>30–49 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>862</td>
<td>392</td>
<td>218</td>
<td>252</td>
<td>377</td>
<td>485</td>
<td>332</td>
<td>530</td>
</tr>
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### Qualitative Assessment (PLHIV and non-PLHIV)

- **FGDs:** 20 per country
- **IDIs:** 25 per country

### Situational Assessment (organizations)

<table>
<thead>
<tr>
<th>Total</th>
<th>Ethiopia</th>
<th>Moz</th>
<th>Uganda</th>
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</thead>
<tbody>
<tr>
<td>49</td>
<td>37</td>
<td>20</td>
<td>22</td>
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</table>
Understanding of HIV Prevention

• PHDP was not a known term—concept referred to as ‘positive prevention,’ ‘positive living,’ or not translated

• Prevention in context of living with HIV seen as:
  - prevention of transmission/prevention of reinfection
  - protected sex/less risky relationships/sero-sorting
  - ART adherence/healthy living

• Links to rights, dignity; economic support less emphasized
Communication and Knowledge

- Most PLHIV rate knowledge as adequate to very good and most actively seek information on HIV

- Key aspects of PHDP well communicated (mass media), but limited print materials—few/none for sex workers and MSM.

- Health workers are a main source of information

- Religion and spirituality very important to living with HIV
Disclosure

- Disclosure much easier in era of ART availability; stigma has declined—recognized as a key/transformative step
- Difficult to contain radius of disclosure and the negative consequences of unintended disclosure
- Only two-thirds of PLHIV disclosed to sexual partners, but imbalanced by gender (75% vs. 56%)
- Negative consequences more likely for women relationship or marriage ended for one in six
- Disclosure <50% to children, employers, colleagues, landlords
Stigma and Discrimination

- Two out of five PLHIV say they work hard to keep HIV status secret; one in three worry about discrimination
- One in ten experience rejection by friends and family
- One in fifteen lost jobs or accommodation after disclosure; petty trade, esp. food preparation, unsustainable; some discrimination in health-care settings, birth/delivery
- Children of PLHIV stigmatized
High proportion of PLHIV are not in relationships: over two-thirds of women and a quarter of men had not had sex in the past year

- Reasons given for abstinence/celibacy:
  - I do not have a partner (34%)
  - Not interested in sex (25%)
  - Abstaining because of HIV status (26%)

Among sexually active, 80% had only one partner; 20% had two or more partners in past year; 11% had partner overlap in past 3 months
Sexuality and HIV Prevention (2)

- Most PLHIV (70%) made proactive changes in response to their positive status: condom use; less risky relationships; abstain from sex; use ART to reduce viral load; sero-sort for positive partner.

- With positive or negative partner, >80% used condoms; those not using condoms had ‘gentle sex;’ relied on reduced viral load from ART; or ‘did nothing.’
HIV Discordancy

- HIV discordancy a key challenge for PLHIV—confusion and disharmony in relationships follows discovery of discordancy.

- Blame, relationship break-up, and violence flow from discordancy—women more likely to be negatively affected.

- For partners who stay together, commitment to the relationships is ambiguous. Some seek outside partners or report ‘prevention fatigue.’
Managing ART

- Most PLHIV in survey (79%) reported high adherence to ART.
- Managing ART was not a uniformly easy process; some took ART secretly, including those who had not disclosed to partners.
- One in eight experienced not having adequate food to take drugs or no transport to access drugs.
- Although stock-outs were uncommon, three in five PLHIV on ART were worried about sustainability of ART supply.
PMTCT and Children

- One-third of women had babies after learning of positive HIV status; about nine out of ten followed PMTCT process.
- A third did not have support of partner/father.
- One in five among all PLHIV experienced death of a child from HIV; a third wanted children in future.
Support Groups and Associations

- PLHIV support groups and associations include important benefits, such as enhanced knowledge, emotional support, spiritual support, disclosure support, economic support, referral.

- Only a third were members of support groups.

- Managing/sustaining such groups difficult; guidance lacking in training, governance, income-generating activities.
Voluntarism

- Voluntarism included important benefits for PLHIV: enhanced knowledge; training; improved self-esteem; affirmation from others.

- Volunteers provide support to PLHIV and non-PLHIV.

- Around half were volunteers—had given testimonials and provided care to others.

- Little or no remuneration; poor recognition; limited inclusion of insights and perspectives of PLHIV.
Support Services

- Service providers were addressing elements of PHDP.
- Communication materials lacking on some themes/issues.
- Challenges included:
  - funding and resource limitations (sporadic funding)
  - unequal distribution of services, especially in rural areas
  - limited collaboration/coordination between organizations
  - limited human resources and skill deficiencies
  - limited inclusion of PLHIV
  - evaluations under-resourced
Conclusions

- Positive HIV status impacts on sexuality, includes diverse consequences and responses.
- Disclosure and discordancy includes negative consequences, with limited access to support.
- ART transformative, but implemented as ‘stand alone.’
- Economic support could enhance adherence.
- ‘Treatment as prevention’ may have limited impact in discordant couples.
- Support groups/associations/voluntarism empower PLHIV, but are inadequately supported. PLHIV not adequately integrated into response.
- Evaluation under-utilized for guiding PHDP.
Recommendations

- Address challenges of sexuality of PLHIV.

- Provide support to disclosure (rights/dignity) and also disclosure in context of discordant relationships.

- Expand ART programming to include economic support and draw on support groups and other structures to strengthen response.

- Foster and holistic response to PHDP with stronger emphasis on empowerment of PLHIV and their integration into response and leadership.

- Expand indicators and evaluate critically.
Preventing HIV Among Adult Women in African contexts

OPPORTUNITIES FOR SOCIAL AND BEHAVIOR CHANGE COMMUNICATION
Background

- HIV prevalence is highest among adult women ages 25–34 in many African countries.
- High HIV prevalence among adult women has not declined over time.
- Higher HIV incidence among adult women demonstrated in a South African study.
- Dynamics of risk and vulnerability are not clear.
Research Design

- Study comprises FGDs and IDIs in three countries: South Africa, Namibia, (Ethiopia)

- Around 40 FGDs and 40 IDIs in 4 to 5 rural and urban communities per country

- Key questions included understanding community perspectives:
  - Why adult women remain vulnerable to HIV
  - Ways to reduce vulnerability to HIV among adult women
  - Opportunities for communication to address vulnerability and risk
Approach to Analysis

- Data coded to derive broad themes
- C-Change socio-ecological model provided a basis for interpretation
- Additional models developed to aid analysis
Main Findings

- Participants in all communities evidenced sound in-depth understanding of HIV vulnerability and risks that make adult women vulnerable to HIV.

- Although socio-economic and geographic contexts differed, perspectives on problems and solutions were similar across communities and between countries.
A Continuum of Risk Among Women

- Economic inequality and gender-power disparities drive a continuum of HIV infection risk.

- Transformations in gender empowerment for women have taken place, including access to education and employment and later marriage, but have not transformed their vulnerability to HIV.
Transition and Risk

- Family and social expectations: Women focus on education first, then work, then establishing a family

- Vulnerabilities embedded in:
  - seeking and enjoying freedom, post-education
  - not finding employment or being sought out by poorer men, if employed
  - avoiding long-term commitments, as marriage is seen as stifling
  - having children early on, who have been abandoned by their father(s)
Commodification

- The commodification of sex as a means to address a range of economic needs and wants is well understood by both men and women.

- Alcohol consumption is established as a social practice that provides opportunities for ‘entertainment’ and escapism. Men and women are conscious of the fact that exploitative sexual interactions occur that include risks of HIV exposure and sexual violence.
Factors Sustaining HIV Prevalence

INTERPERSONAL

SOCIO-CULTURAL

INDIVIDUAL

STRUCTURAL

SUSTAINED HIGH HIV PREVALENCE AMONG ADULT WOMEN
Is change possible in a context where the underlying conditions appear to be intractable?
Opportunities for Change and SBCC

- Motivation
- Ability to Act
- Information
- Norms

SBCC to reduce high HIV prevalence among adult women
Challenges & SBCC Opportunities

INFORMATION

- Mass media communication has wide reach and increases knowledge.

_There is a lot of information out there. It depends on the individual’s seriousness of the issue and in life (FGD, Khayelitsha)_

MOTIVATION

- Knowledge not readily translated into action. Behavior of some community educators and leaders contradict prevention messages.

_The very same people who educate are the ones who misbehave...They are the ones who excel in sexual misbehavior more than the ordinary people (FGD, Nongoma)_.

- A range of individual strategies have evolved to counter vulnerability and risk among adult women.

_I made a decision of testing every six months... I noticed that this guy was also seeing other girls and the girls were getting sick... I decided to abstain or the guy must do an HIV test (FGD, Peddie)._  

- Motivations to act lie in self-value, plotting a pathway forward, considering one’s children.

_If a woman has a set of goals – even if she is unemployed – her chances of being infected are less (FGD, Keetmanshoop)._
Challenges & SBCC Opportunities

ABILITY TO ACT

- Communities not taken on board to problem-solve or lead response, despite interest. Men marginalized.

- If you want to help people, you have to talk to people who are affected. Rather than sitting in the offices and boardrooms, they should focus on the grassroots. Then you will know what the perfect solution would be. (FGD, Keetmanshoop).

NORMS

- Leaders and communities not drawn in to response. Focus on individual behavior, not relationships nor community action.

- I think that they are not involving the community in the decision-making, and that might be the cause of the problem (IDI, Moretele).

- The power of working together through community-level groups with a focus on problem solving is seen as an urgent means to intensify response.

- We are sick and tired of our sisters being infected... We tend to forget that if we get the HIV, it’s for life ... But if the ten of us can join us and we call other men and we say okay, come, we have a support group, whether you are infected or not. Maybe we get a name. We say okay, we are fighting for HIV in this community. Maybe it can make a difference (FGD, Robertson).

- There is a place for new norms that mobilize action and re-center values in sexual relationships.

- We need to advise each other to slow down. We are the ones that have the power to have as many women as we like... We can stop this (FGD, Nongoma).
A range of individual strategies have evolved to counter vulnerability and risk among adult women.

Motivations to act lie in self-value, plotting a pathway forward, considering one’s children.

The power of working together through community-level groups with a focus on problem-solving is seen as an urgent means to intensify response.

There is a place for new norms that mobilize action and re-center values in sexual relationships.
SBCC for Change

SBCC to reduce high HIV prevalence among adult women

- Information
- Motivation
- Ability to act
- Norms
- Individual
- Interpersonal
- Socio-cultural
- Structural

Reduced HIV vulnerability and risk among adult women
Way Forward (1)

- Shift from a focus on individuals as the unit of change to building healthy relationships located in community-based mobilization

- Move from top-down ‘vertical’ interventions to an integrated approach that includes ‘horizontal’ dimensions and local leadership
Way Forward (2)

- Harness indigenous voices and indigenous strategies across the four domains of change
- Foster and intensify change through SBCC, focusing on translating knowledge into action through ownership of change processes at community level