

# **Finding Respect and Ending Stigma around HIV (FRESH): An Intervention for Change in Public Health Settings**

## **Appendices to Facilitators' manual**

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## Appendix I.a. Understanding Stigma

### Definitions of Stigma and HIV-Related Stigma

One of the numerous definitions of Stigma is by Erving Goffman, who described stigma as an occurrence where an attribute creates a “deeply discrediting gap between who we think we are – our actual social identity – and how we are seen by others – our virtual social identity.” (Stangl, Lloyd, Brady, Holland, & Baral, 2013) Another definition of stigma is by Link and Phelan. They described stigma as “a harmful societal phenomenon – enabled by underlying social, political and economic powers – that begins when a difference is labelled, then is linked to negative stereotypes, leading to a separation of “us” from “them”, and finally to status loss and discrimination for those carrying the trait.” (Stangl et al., 2013)

Health-related stigma is defined as “a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem.” (Weiss & Ramakrishna, 2006)

HIV-related stigma occurs when negative meanings are attached to HIV resulting in avoidance, partial acceptance, and discrimination of people living with HIV (PLHIV). (Bogart et al., 2008)

### Different Dimensions of Stigma

- Anticipated stigma (fears)
- Normative stigma (perceptions of community norms)
- Experienced or enacted stigma (discrimination)
- Internalized or self-stigma
- Disclosure concerns
- Observed stigma / vicarious stigma

**Anticipated stigma** refers to the extent to which PLHIV “expect they will experience prejudice and discrimination from others in the future.” (Earnshaw & Chaudoir, 2009)

**Felt normative stigma** “refers to the subjective awareness of stigma.” (Steward et al., 2008) This type of stigma is expected to motivate individuals with a stigmatized condition e.g. HIV to take actions to protect against enacted stigma (see definition below). Such actions could include attempting to pass as someone who is HIV negative. (Steward et al., 2008)

**Enacted stigma**, also known as **experienced stigma** is defined as the degree to which PLHIV believe “they have actually experienced prejudice and discrimination from others in their community.” (Earnshaw & Chaudoir, 2009)

**Internalized stigma**, also known as **self-stigma** refers to the degree to which PLHIV “endorse the negative beliefs and feelings associated with HIV about themselves.”(Earnshaw & Chaudoir, 2009)

**Disclosure Concern:** PLHIV may decide whether or not/ how to disclose their HIV status, depending on the perceptions of social support they feel that they have. The ability of PLHIV to cope with the “physical, psychological, and social aspects of HIV may be affected, in part, by decisions made about whether, when, and how to disclose the HIV diagnosis to significant others.” (Derlega, Winstead, Greene, Serovich, & Elwood, 2004) Studies have found that the perception of social support are positively associated with the number of friends and family members to whom diagnosis are disclosed. Also, the perception of negative emotional reactions are inversely related to HIV disclosure. (Derlega et al., 2004)

According to (Berger, Ferrans, & Lashley, 2001), disclosure concerns are evident in factors that involves PLHIV controlling information, keeping HIV status secret, or worrying that others who are aware of a person’s HIV status would disclose it. Some of these factors include; “I am very careful who I tell,” “I work hard to keep my HIV secret” etc.

**Vicarious Stigma:** This type of stigma is a channel for transmitting information about enacted or experienced stigma. With this type of stigma, participants do not need to actually experience stigma (enacted stigma) to fear its social consequences. An example of stories/ information transmitted includes stories of discrimination against others PLHIV. (Steward et al., 2008)

### **Stigma in Healthcare Settings**

PLHIV may have frequent contact with healthcare providers. Fear of stigma, discrimination, and lack of confidentiality in health facilities can discourage people from;

- accepting HIV testing
- linking to HIV care after receiving an HIV-positive test result
- adhering to HIV visits and treatment, and getting other kinds of healthcare that they need.

According to (Parker, Aggleton, Attawell, Pulerwitz, & Brown, 2002), many studies have published reports from health care settings of “HIV testing without consent, breaches of confidentiality, and denial of treatment and care.” (Parker et al., 2002). Others are “failure to respect confidentiality by clearly identifying patients with HIV/AIDS, revealing serostatus to relatives without prior consent, or releasing information to the media or police appear to be problems in some health services.” (Parker et al., 2002)

Other studies have documented various stigmatizing practices in health care settings toward PLHIV. Some of these practices were described in “*Training Kit for a Stigma Free Health Facility*” (Laura Nyblade, 2014) This includes:

- Keeping Clients waiting a long time
- Gossip and verbal abuse e.g. name calling
- Differential treatment e.g. asking clients to take an HIV test before providing care
- Marking files of PLHIV or isolating clients in separate waiting areas or wards
- Excessive use of barrier precautions e.g. using multiple gloves and masks during routine tasks.

### **Manifestations of HIV/STI Stigma in Healthcare Settings in the US (Dr. Bronwen Lichtenstein, UA)**

General problems:

- Visibility when entering the clinic or in the waiting area – “patient spotting” is a local sport

What men fear:

- Being named by vengeful partners
- Being labeled as gay
- Being pursued by Disease Intervention Specialists (DIS)

What women fear:

- Being portrayed as dirty or promiscuous

### **Drivers of Stigma in Healthcare Settings**

Researchers have identified some factors driving these stigmatizing and discriminatory behaviors, and some of these factors include lack of adequate knowledge of HIV, “moral attitudes, and perceptions that caring for PLHA [PHLIV] is pointless because HIV/AIDS is incurable”, etc. (Parker et al., 2002)

There are three main drivers of stigma and discrimination in healthcare settings (Laura Nyblade, 2014):

1. Limited recognition of stigma: This occurs when health workers do not realize

that their actions and behaviors are stigmatizing towards PLHIV.

2. Fear of getting HIV through casual contact: This occurs when health workers have insufficient knowledge about HIV transmission, and are afraid of getting HIV through everyday interactions with clients in an hospital setting.
3. Moral judgement and values: This occurs when health workers hold judgmental attitudes towards PLHIV. These could affect the services that they render to these clients.

### **Examples of dimensions of HIV-related Stigma**

Examples presented below have been taken from data collected as part of the FRESH Study in Alabama, or from research conducted in other parts of the US South. (Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011). As part of the FRESH study, two focus group discussions (1 male group and 1 female group) were conducted with PLHIV at Birmingham Aids Outreach (BAO) to seek their views on stigma and ways to adapt a stigma reduction intervention for healthcare settings in Alabama.

#### **Experienced or Enacted Stigma:**

PLHIV may face discriminatory behaviors in all aspects of their lives, from people in the community, family, and/or friends. Discrimination can be in form of blame and gossip. (Miles et al., 2011) Enacted stigma can take other forms such as mistreating and disrespecting PLHIV, attempting to humiliate or physically harm PLHIV, denial of housing or economic opportunities, etc. (Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009)

The following examples illustrate this type of stigma:

- *“They talk about you like a dog. People are just uncaring, insensitive . . . point their fingers and look down on PLWH [PLHIV] [like] modern day leprosy.” (man/woman living with HIV, North Carolina, (Miles et al., 2011))*
- *“People say she got AIDS . . . just stay away from that person.” (man/woman living with HIV, Alabama, FRESH Study focus group)*
- *“They look at you funny . . . they scared to touch behind you, sit behind you.” (man/woman living with HIV, Alabama, FRESH Study focus group)*
- *“When I go take me a bath in the tub . . .they keep saying, ‘You need to clean that tub*

*out,' . . . and someone will say, 'I ain't bathing behind [after] so and so.'"* (man/woman living with HIV, Alabama, FRESH Study focus group)

- *"She wouldn't let her [the friend with HIV] back in the house . . . spoons and dishes she ate off, she threw them away."* (man/woman living with HIV, Birmingham, FRESH Study focus group)

### **In healthcare settings:**

- *"I remember a long time, it's been a long time ago though, I went to X to the dentistry, to they dentistry school and um, uh when I went in to the dentistry, the lady, when she found out, this was before the dental clinic at the X. .... But when I went in there, the lady, I was filling out the paper work and stuff and on the HIV, I put that I was HIV positive, Man before I knew it, the lady came and said (covers he mouth and leans to her neighbor like she is whispering) "she HIV positive". Then I saw another one (covers he mouth and leans to her neighbor like she is whispering) "she HIV positive."* (man/woman living with HIV, Alabama, FRESH Study focus group)
- *"Once the young lady realized that I was HIV through my chart and stuff, her whole attitude changed. In the beginning she was friendly and nice and everything. When she realized that I was HIV, it looked like a shade came down in a sense."* (man/woman living with HIV, Alabama, FRESH Study focus group)
- *"It was a weekend and I had a bad case of flu or something similar ... and of course X was not open and there weren't any doctors that I know of open, and there's one of those X healthcare places open a couple of blocks from where I live and I went there. It was obvious they didn't even wanna talk to me, much less, the minute they asked me if I was HIV-positive and I said yes, they were through with me. At one point he said 'we're not trained to deal with HIV'" and I said 'I'm not here to be treated for HIV, I'm here to be treated for some kind of infection, like flu or something, so what does that have to do with anything?' – and that's when he got really nasty"* (man/woman living with HIV, Alabama, FRESH Study focus group)

**Perceived community stigma:** Perceptions of high levels of HIV-related stigma in the community can have negative effects on PLHIV, and also discourage people from getting tested for HIV or seeking treatment. Some examples from the South:

- *"They think people with HIV should live in separate houses."* (man/woman living with HIV, Alabama, FRESH Study focus group)

### **Anticipated stigma:**

- *"In [town], you might get jumped on if they find out."* (man/woman living with HIV,

*Alabama, FRESH Study focus group)*

- *“Most employers would not employ me because I am HIV + [positive]” (man/woman living with HIV,(Earnshaw & Chaudoir, 2009))*
- *“My neighbors would not like living next door if they knew I had HIV” man/woman living with HIV,(Earnshaw & Chaudoir, 2009))*

**Disclosure concerns:** Concerns about how they will be treated in their community have led many PLHIV to live lives of secrecy in which their diagnosis was revealed to only a few people, and sometimes to no one.

- *“My family and friends and church family . . . are unknowledgeable of it [lack knowledge about HIV], so I keep it hid[den].” (man/woman living with HIV, North Carolina, Miles et al. 2011)*
- *“So you keep your mouth shut. If you tell, you’ll be ostracized and left alone. If you don’t tell you are alone.” (man/woman living with HIV, North Carolina, Miles et al. 2011)*
- *“I keep it all balled up inside me. I just keep it to myself. Sometimes I feel I need to talk but I don’t know who I can talk to.” (man/woman living with HIV, North Carolina, Miles et al. 2011)*
- *“I lay up there and think, suppose I get bad, was sick. Ain’t got nobody to call. I just lay there and die, right? That bothers me but I just stick to myself. I’ll battle this all myself.” (man/woman living with HIV, North Carolina, Miles et al. 2011)*

**Internalized Stigma:** PLHIV may feel devastated about being diagnosed with HIV and may internalize negative attitudes towards PLHIV that exist in their communities:

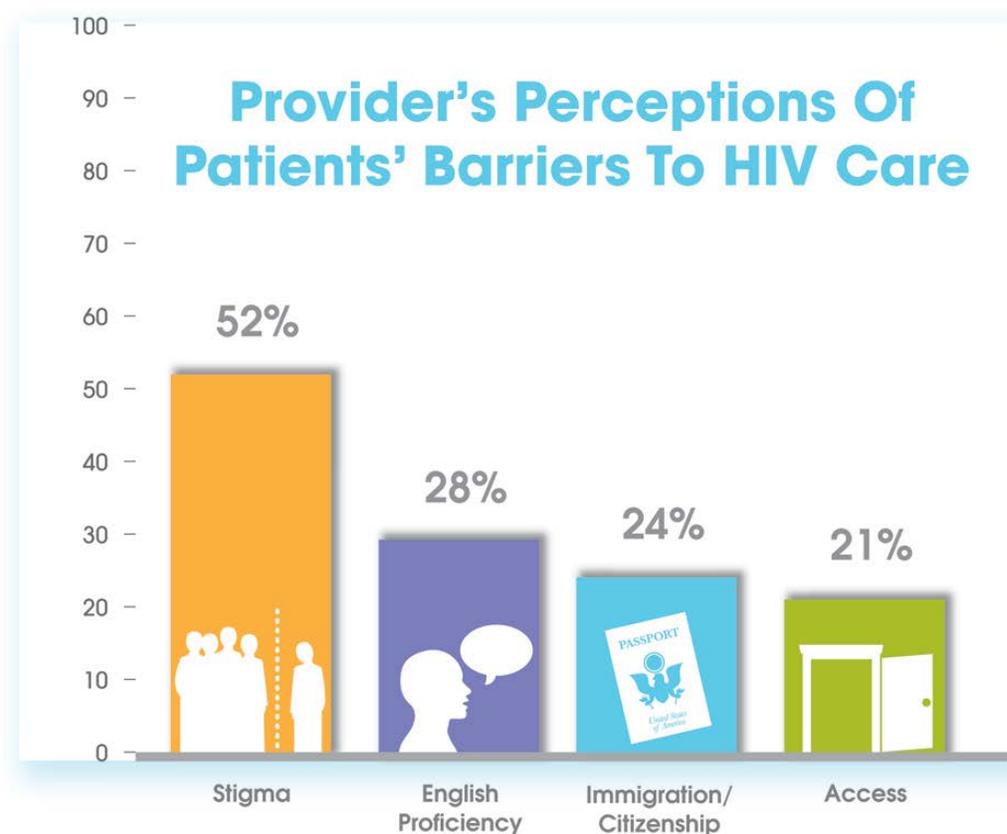
- *“I’ll never forget it. I just wanted to die. I just felt like I was useless and I shouldn’t live, and I felt real disgraced, shamed. I just felt bad. Other than feeling bad mentally I felt bad physically. I just, it took me a long time. I stayed in denial for a long time.” (man/woman living with HIV, North Carolina, Miles et al. 2011)*
- *“Feel like nobody wants you, very alone, lonely.” (man/woman living with HIV, Alabama, FRESH Study focus group)*

## **National Data on Stigma**

According to the study by Herek, et al, (2002), many Americans still express fear and discomfort about people living with HIV. By comparing findings from three national surveys conducted in 1991, 1997, and 1999, they discovered that 30.3% of those polled in 1999 would feel uncomfortable having their children attend school with another child who has HIV, compared to 26.6% in 1997. 22.4% of those polled in 1999 would feel uncomfortable around an office co-worker living with HIV, compared to 24.7% of those polled in 1997. (Herek, Capitano, & Widaman, 2002)

On the other hand, these researchers also found a 40% increase between 1991 and 1997 in the number of Americans who believed that people who contracted HIV through sex or drug use deserve their illness. 20% expressed this view in 1991, and this number increased to 28% in 1997. By 1999, the number had declined to 25%, a number still higher than the 1991 figure. (Herek et al., 2002)

There was a shrinking percentage of Americans who expressed stigmatizing few towards PLHIV. A smaller percentage of Americans said they would actively avoid people living with HIV. Only 9% said they would avoid a co-worker with HIV/ AIDS in 1999, compared to 19% in 1991. 29% of those surveyed in 1999 would avoid shopping at a neighborhood grocery store whose owner has AIDS, compared to 45% in 1991. (Herek et al., 2002)



Source: 2nd Annual HealthHIV State of HIV Primary Care Survey, January 2012

Figure 1 above shows health care provider’s perceptions of patients’ barriers to HIV care (as published in the *Second Annual HealthHIV State of HIV Primary Care Survey Results*). This figure was based on 1,806 U.S. based responses received by *HealthHIV* between July 20 and October 28, 2011. Stigma was seen as the biggest barrier to HIV care, followed by English proficiency. Other key findings from this survey are concerns over rising HIV caseloads among specialist who are already overworked, and insufficient reimbursement for HIV services. (HealthHIV, 2012)

### Brief Overview of the FRESH Study Participants

To increase our knowledge about levels and effects of HIV-related stigma in the south, we studied the following population:

1. At-risk populations
2. Health care providers

### 3. Persons living with HIV

For the at-risk population, questions on fears of stigma and values/attitudes were added to baseline data collection for 3 HIV prevention projects implemented by the Health Services Center in North East Alabama:

- **Project Vortex:** This project focused on young adult females (19-24 years) and their partners at local colleges and universities (especially persons of color)
- **Project Real:** This project focused on the re-entry population (those coming back to their community after being incarcerated) in this region.
- **Project Revolution:** This project focused on young adult females (19-24 years) and their partners in a community setting (especially persons of color).

## **Appendix I.b. Results of FRESH Data Collection from Public Health and Primary Healthcare Workers**

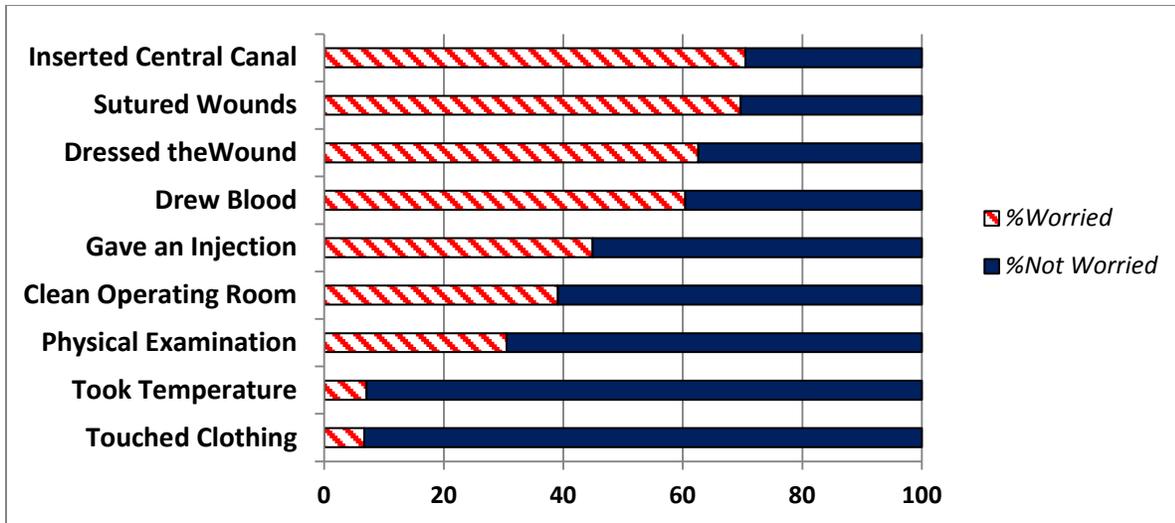
The survey for the FRESH study data collection from public health and primary healthcare workers was developed by an international expert group on HIV stigma. The result of this international effort is a brief, standardized stigma measurement tool that can be used to measure stigma among all levels of health facility staff. This stigma measurement tool has been tested in six different sites – China, Dominica, Egypt, Kenya, Puerto Rico, and St Christopher & Nevis. (L. Nyblade et al., 2013) Some of the measurements in this survey instrument include health workers worry about HIV transmission, their attitudes towards PLHIV, their work environment and policies in this environment, and questions on enacted stigma. (L. Nyblade et al., 2013)

For the FRESH study, online survey links were sent out to employees/ members of 4 different public health/primary health care organizations by email, fax or regular mail in the state of Alabama. There were 950 total attempts, of which 147 cases were removed in cleaning. We ended up with 803 surveys with usable data, and 702 completed cases.

Below are a few other preliminary results on transmission worry, attitudes and values, and the groups often affected by stigma

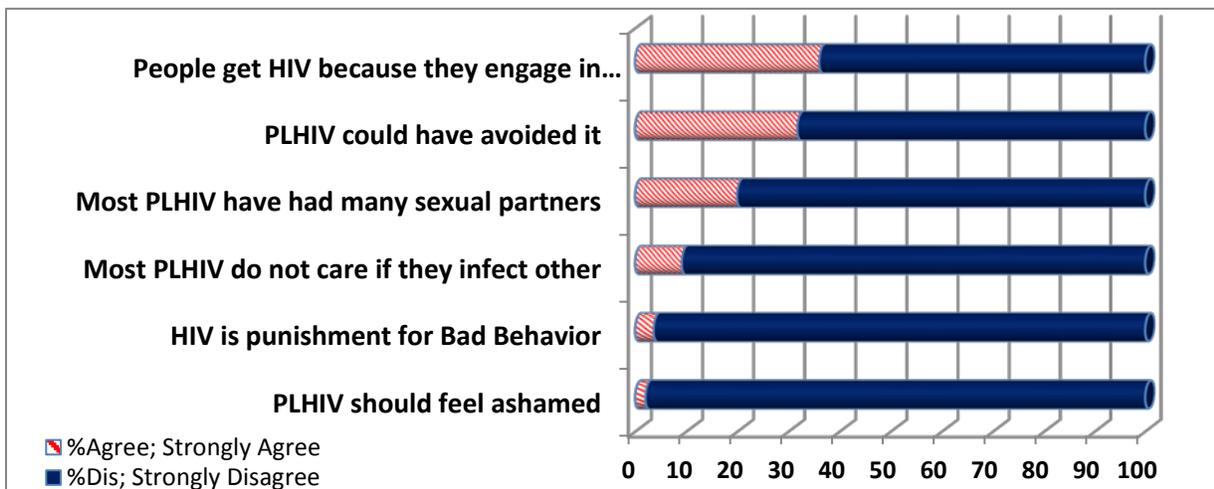
### **Transmission Worry**

**How worried would you be of getting HIV if you did the following?**



### Attitudes and Values

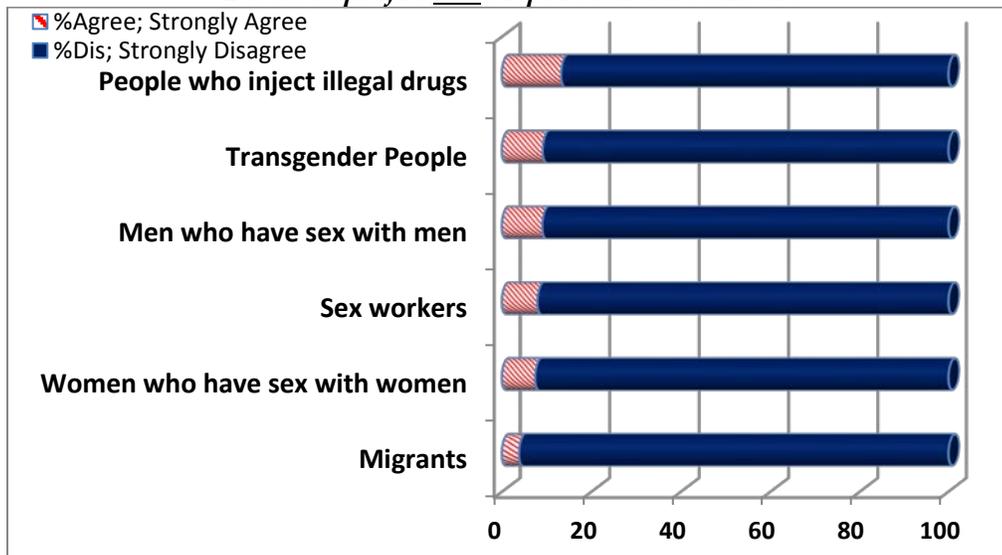
Do you strongly agree, agree, disagree or strongly disagree with the following statements?



### Groups often Affected by Stigma

Do you strongly agree, agree, disagree or strongly disagree with the following statements?

*I would prefer not to provide services to:*



Observed Stigma

<u>In the past 12 months, how often have you observed the following in your health facility?</u>	<u>% Never</u>	<u>% Observed</u>
<u>Health care workers disclosing a patient's HIV status without the patient's permission</u>	<u>94.8</u>	<u>5.2</u>
<u>Health care workers referring patients with HIV because workers do not want to treat them</u>	<u>94.0</u>	<u>6.0</u>
<u>Health care workers using extra infection precautions (like wearing extra gloves) when caring for a person living with HIV</u>	<u>78.5</u>	<u>21.5</u>

Shame

	<u>% Yes</u>	<u>% No</u>

<b><u>People living with HIV should be ashamed.</u></b>	<b><u>2.0</u></b>	<b><u>98.0</u></b>
<b><u>I would be ashamed if someone in my family were infected with HIV.</u></b>	<b><u>17.8</u></b>	<b><u>82.2</u></b>
<b><u>I would be ashamed if I were infected with HIV.</u></b>	<b><u>41.4</u></b>	<b><u>58.6</u></b>

In summary, we find that the majority feel that it is their responsibility to protect the confidentiality of people living with HIV (98%). 60% of those who take blood samples were worried about drawing blood from people living with HIV. Although only 2% said that people living with HIV should feel ashamed, 41% would be ashamed if they became infected with HIV themselves. 62% felt that stigma is an important barrier to accessing health services for people living with HIV

### **Preliminary Results from the At-Risk Population**

Anticipated Stigma  
Some Preliminary Results (n=141)

*How likely do you think it is that any of the following things might happen to you, if you were to test positive for HIV and others found out about your HIV-positive status?*

*How likely do you think it would be that you would? . . . . .*

	<b>Very likely or Extremely likely</b>
Lose friends	16%
Be rejected by family	8%
Be treated badly by health workers	6%
<b>Be an outcast in community</b>	<b>37%</b>
<b>Experience breakup of your relationship</b>	<b>58%</b>
Experience physical partner abuse	14%
Lose job	7%
<b>Be treated badly at work/school</b>	<b>30%</b>

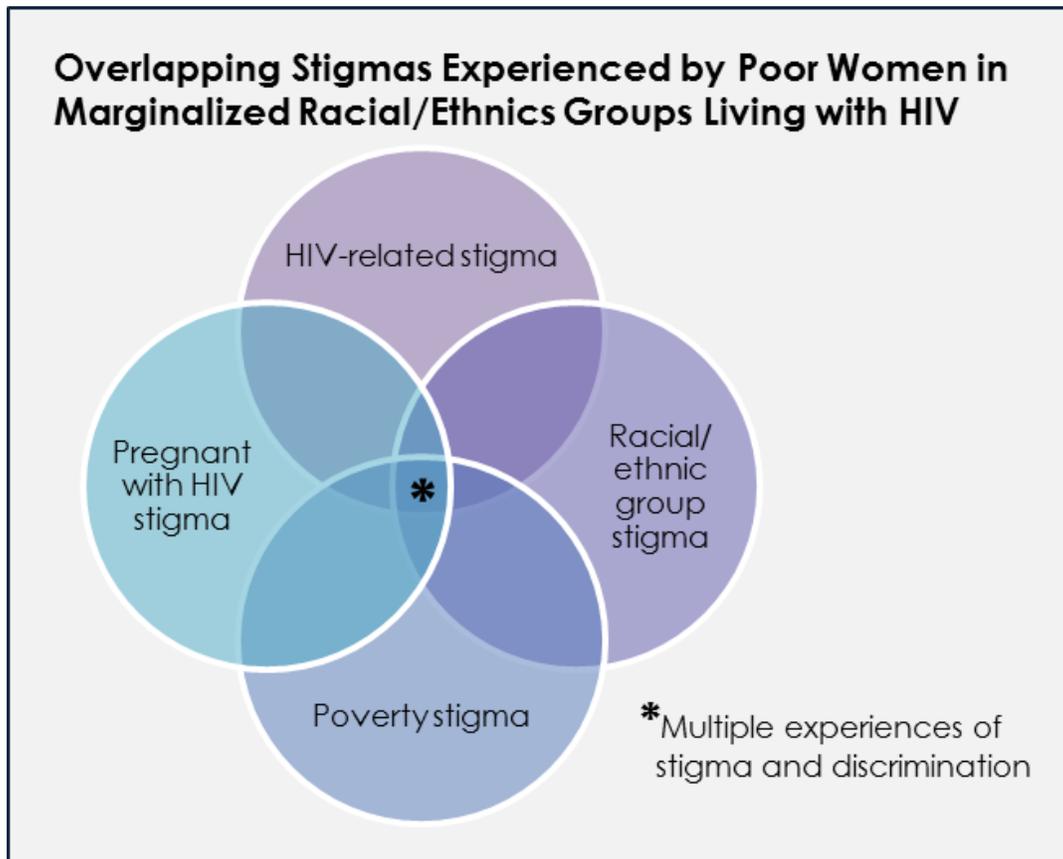
Values and Attitudes  
Some Preliminary Results (n=141)

*The following statements are opinions that some people in the community have about people living with HIV. Please indicate if YOU strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree with these statements.*

	<b>Strongly agree or agree</b>
PLHIV should be ashamed	12%
PLHIV deserve compassion	63%
Could have avoided HIV if they wanted to	48%
HIV is punishment for bad behavior	14%
Most PLHIV are homosexuals	11%
<b>PLHIV should be treated with respect</b>	<b>89%</b>
Most PLHIV have had many sex partners	19%
<b>Most people are uncomfortable w/ PLHIV</b>	<b>65%</b>
<b>PLHIV are negatively judged by others</b>	<b>80%</b>
Most PLHIV have used illegal drugs	15%

## Appendix II Intersecting Stigma

Intersectionality describes a theoretical framework for understanding how multiple social identities e.g. race, gender, sexual orientation, socio-economic status, and disability intersect at “the micro level of individual experience” to reflect systems of privilege or oppression (e.g. classism, racism, and stigmatization) at the “macro social structural level.” (Bowleg, 2012) The most important element of intersectionality relevant to public health is that “social identities are not independent and unidimensional, but multiple and intersecting.” (Bowleg, 2012) Therefore, behaviors contributing to HIV should not be examined in isolation. Instead behaviors (including HIV stigma and discrimination) should be understood and addressed in broader contexts of social identities. (Wyatt et al., 2013) HIV-related stigma may interact with pre-existing stigma and discrimination associated with race/ ethnicity, social-economic status, sexual orientation, and gender. PLHIV may be faced with multiple sources of stigma and discrimination, due to their membership in multiple marginalized identities.



Source: (Turan & Nyblade, 2012)

Figure 2 above showing how stigma experienced by poor women living with HIV and are in marginalized racial/ ethnic groups intersect.

## **HIV-Related Stigma and Sexual Orientation**

Among all the pre-existing stigmas that interact with HIV-related stigma, HIV-related stigma is most closely associated with sexual stigma. The reason being that the primary way HIV is transmitted in most areas of the world is sexually. Also, HIV epidemic initially affected those whose sexual practices and identities are different from what is considered “normal.” The belief that homosexuals are to blame for the HIV epidemic or that they are the only group at risk of HIV infection is still common (Parker et al, 2002). HIV-related stigma has therefore “appropriated and reinforced pre-existing sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution, and sexual deviance.” (Parker et al., 2002)

## **HIV-Related Stigma and Gender**

“Gender is part of a “societal codebook” for how men and women should act in their respective roles in their communities.” (Wyatt et al., 2013) HIV-related Stigma also interacts with gender-related stigma. The impact of HIV-related stigma on women reinforces pre-existing stigma and discrimination that women face due to their gender. Gender serves as an important organizational structure, in the sense that it helps define “gendered activities” and access to power and resources. (Wyatt et al., 2013) Women are known to experience inequality in the areas of economic empowerment, access to education (especially in low resource settings), cultural and social disadvantages, and unequal access to information and services (Parker et al, 2002). In settings where heterosexual transmission is the main method of contracting HIV, the spread of the disease has been associated with female sexual behavior that is not consistent with gender norms, e.g. prostitution. Men are also blamed, in many settings for heterosexual transmission, because of the assumptions that some men have the need for multiple sexual partners. (Parker et al., 2002) Furthermore, there is a level of stigma associated with being transgendered. Transgender persons are those with gender identity and gender expression that differs from the sex they were born as. (Wyatt et al., 2013) Therefore, gender is a social identity that is also a social determinant of health. Social determinant of health contributes to inequitable experiences e.g. social and psychological that can lead to differences in health outcomes and risks. (Wyatt et al., 2013)

## **HIV-Related Stigma and Race/ Ethnicity**

HIV-related stigma also interacts with stigma associated with race/ ethnicity. HIV epidemic has been characterized “both by racist assumptions about “African sexuality” (Parker et al, 2002), and in some settings by perceptions in the African-American community of “immoral behavior” of the White community. What was once a disease that mostly affected the affluent, White, gay men has now become a disease that is concentrated in non-affluent populations of color, especially within the black

population. (Wyatt et al., 2013) Black men accounts for 42% of new HIV infections among men and Black women accounts for 64% of new infections among women, despite the fact that the black race is only approximately 12% of the U.S. population. (Wyatt et al., 2013) Racial/ ethnic stigma contributes to the marginalization of minorities, increasing their vulnerability to HIV, which in turn worsens stigmatization and discrimination. (Lichtenstein, 2004)

### **HIV-Related Stigma and Socio-Economic Status**

According to Parker et al, (2002) the HIV/ AIDS epidemic developed “during a period of rapid globalization and growing polarization between rich and poor.” (Parker et al, 2002). Pre-existing social inequalities include the stigmatization of the poor, homeless, jobless, etc. thereby increasing the vulnerability of these groups to HIV. Also, HIV exacerbates poverty in a lot of settings in the world. HIV-related stigma interacts with pre-existing stigma that is associated with being marginalized economically. In other settings/ context, HIV epidemic has been characterized by assumptions about the rich, and HIV has been associated with affluent lifestyles. (Parker et al, 2002)

In the United States, the national HIV/ AIDS Strategy noted that HIV disproportionately affects those who have less access to prevention and treatment services - the most vulnerable in the society. (Earnshaw, Bogart, Dovidio, & Williams, 2013)

### **Examples of how intersecting stigmas affect people**

There is still a perception by many that HIV only affects “others,” especially those who are already stigmatized because of their sexual orientation, gender, race, or socioeconomic status. The pre-existing sources, such as those related to gender, sexuality, and socio-economic status, often intersect and reinforce one another. This interaction has contributed to the deep-rooted nature of HIV-related stigma, making it more difficult to develop effective responses. HIV worsens the stigmatization of individuals and groups who are already marginalized, which increases their vulnerability to HIV, and in turn causing them to be further stigmatized and marginalized. (Parker et al, 2002)

## Examples of intersecting stigmas:

### HIV & Homosexuality:

- *“ Well you know, speaking of church, I was in a church that I had been in for years. They didn't have a problem with me being HIV. I even cooked for the church so I know they didn't have any problem with that. I was still who I was. But, when it started kinda looking like I was gay. Awe man, I can't remember a subject to a sermon, not one, but I can remember that every sermon was almost closed with the phrase “ God created man and woman.”, Adam and Eve, not Adam and Steve. So, you can accept me HIV, but you can't accept me gay? So that's why I said I dealt with overlapping. And finally, I just left the church” (man/woman living with HIV, Alabama, FRESH Study focus group)*
- *“In a sense the community doesn't care. They don't care. First of all, AIDS is a gay man disease. That's what they say. ...It's not talked about. And, and when you do talk about it, you hear, 'Well, if people were doing what they were supposed to do, they wouldn't get HIV'. You know? And, 'they're nasty, and they must be gay.'” (HIV Positive Jamaican Man in Toronto (Lawson et al., 2006))*

### HIV & Gender:

- *“I lost my job because my manager stalked me. You know, just being a woman in general and then working in the sex trade – you can't demand respect in the health care system or in the employment system.” (HIV positive sex worker in Ontario, Canada (Logie, James, Tharao, & Loutfy, 2011))*
- *“Most of these ASO [HIV programs] do not cater specifically for women. I think that comes from the fact that long back HIV and AIDS was well known to be a white gay man's disease.” (HIV positive woman in Ontario, Canada (Logie et al., 2011))*
- *“I find because there's a tendency to kind of glamorize male promiscuity, men who are affected with it are not as stigmatized as women because women the promiscuity is more demonized. ... So, I mean, both would experience stigma. But I think it's way more heavily against the woman.” ( A Jamaican Man in Toronto (Lawson et al., 2006))*
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### HIV & Race:

- *“The African community, for example, we are not informed about anything. Nothing at all.” (African Caribbean HIV positive woman in Ontario, Canada (Logie et al., 2011))*
- *“Research is all about the White folks and what the White folks want to get from the Black people” (African Caribbean HIV positive woman in Ontario, Canada (Logie et al., 2011))*

- *“The key association to AIDS and the Caribbean or the Black, you know, macho thing, you know, like, battyman, and that whole kind of stuff is very much alive, you know, so anybody who has AIDS in the community, I mean, maybe he would have got it from a blood transfusion or maybe some other way, but without even knowing, you’re stigmatized. That’s how the community looks at it, and that is a big, big problem.”( A Trinidadian Man in Toronto (Lawson et al., 2006))*

### **HIV & Sex Work:**

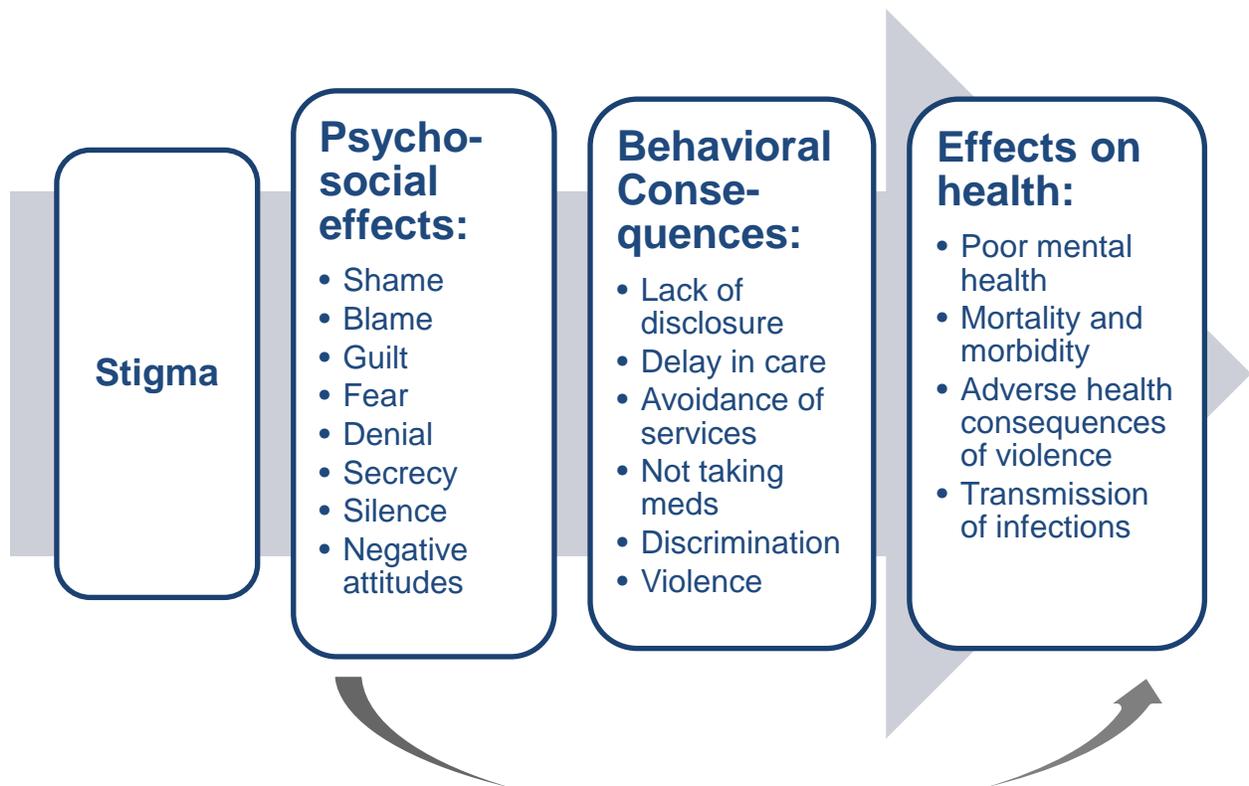
- *“We all know that most people think that prostitutes are disease-carrying people. And if they really educated themselves around prostitution, they would know that prostitutes are pretty well-educated on protecting themselves on not getting diseases.” (Sex Worker & HIV Positive Woman in Ontario, Canada) (Logie et al., 2011))*
- *“Because you got it (HIV), you're careless. You're irresponsible. You're seen that way. But you're not.” (Sex Worker & HIV positive woman in Ontario, Canada) (Logie et al., 2011))*
- *“The commercial sex workers, how do we view them as a community? As spoiled and outcasts. So when you get the disease AIDS, you have been interacting with those outcasts. So you’re also an outcast. So if somebody has HIV, he keeps it to himself” ( A Kenyan Man in Toronto (Lawson et al., 2006))*

## Appendix III - Outcomes of Stigma

There is a need for increasing global awareness of the importance of addressing HIV stigma in halting the spread of HIV. This is Reflected in the UNAIDS goal for 2015 “Getting to Zero Discrimination”. The objectives include:

- Zero tolerance for gender-based violence related to HIV.
- Reducing number of countries with punitive laws/practices around HIV transmission, sex work, drug use, or homosexuality that block effective response by half.

### Framework for effects of stigma on health behavior and health outcomes



Adapted from (Kumar, Hessini, & Mitchell, 2009) (Turan & Nyblade, 2012)

### Examples from the literature of the effects of stigma

Many studies have documented the deleterious effects of stigma on PLHIV. For example, PLHIV who anticipate or experience stigma may experience psychological distress and lowered well-being. (Earnshaw & Chaudoir, 2009) HIV stigma is cited as a major barrier for PLHIV to accessing health care, including prevention and treatment. (Mahajan et al., 2008) The effects of stigma on health behaviors include the following:

- Anticipations of stigma were strongly associated with HIV test refusal by pregnant women in Kenya (Adj OR=2.1). *Turan et al., AIDS Behav, 2011*
- Internalized stigma was strongly associated with poor access to care among persons living with HIV in Los Angeles (Adj OR=4.4). *Sayles et al., J Gen Intern Med, 2009*
- In Seattle, higher levels of stigma were associated with poorer ART adherence ( $p<.01$ ). *Rao et al., AIDS Behav, 2012*
- In Los Angeles, HIV-infected study participants who reported perceived stigma from health care workers had more than 2 times the odds of reporting low utilization of HIV care. *Kinsler, AIDS Patient Care STDs, 2007*

## Appendix IV Coping with Stigma

### Dealing with Stigma - Coping strategies

Coping can be defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.” (Kotze´, Visser, Makin, Sikkema, & Forsyth, 2013) Coping could be categorized as either active or avoidant. (Kotze´ et al., 2013) Active coping is a behavioral and cognitive way of dealing with a stressful situation and changing this situation, while avoidant coping is a behavioral and cognitive way of avoiding and dealing with a stressful situation by e.g. disengagement, denial and distractions. (Kotze´ et al., 2013)

Aside from the two broad ways of coping with stigma mentioned above, there are hundreds of sub-ordinate coping mechanisms that have been identified in the literature. (McIntosh & Rosselli, 2012) Some of these examples include; through spirituality/ faith (religious-based practices e.g. prayer are shown to provide psychological relief), talking about it, rationalization, letting it be, seeking social support which could be classified based on the source of support (e.g. from, friends, family, loved ones or extended social network), type of support (tangible or based on information), and the perception of the quality of support received). (McIntosh & Rosselli, 2012) (Makoae et al., 2008)

### Examples of coping strategies for living with HIV:

#### Talking about it:

- *“For me, when I first got diagnosed, I went up there and told the people I had HIV, I aint ashamed of it.” (man/woman living with HIV, Alabama, FRESH Study focus group)*

#### Spirituality/ faith:

- *“You know and so, so, what I did is I, I asked God to heal me. And as I, as time went on and stuff I started believing that God had healed me, and so you know, I don’t know if it was just better. It’s kinda like, out of sight, out of mind. If I’m not taking the medicine, then I don’t have to worry about it. I been healed” (man/woman living with HIV, Alabama, FRESH Study focus group)*
- *“There is only one person to put it back in control, God. But, I’m only one person, I got children, I got grandbabies, everybody (short pause) we out of control. It’s hard but I’m here today.” (man/woman living with HIV, Alabama, FRESH Study focus group)*
- *“Cause, I was, back then, oh I was something else (all participants laugh). I was off the chain. When they say off the chain, I was off the chain! It took me to go through a lot of*

*programs to motivate myself. Know what I'm sayin? Because, girl, let me tell you something. God, God, It's just God above that got me here today, cause I been through hell and back but I'm here. It's like an upside down smile. I have to keep on laughing to keep from crying." (man/woman living with HIV, Alabama, FRESH Study focus group)*

### **Rationalization:**

- *"I told myself that all of us are dying. There is no one who will remain in the world." (man/ woman living in an urban city in Southern Africa (Makoae et al., 2008))*
- *"I expect two things - people will talk about me or they will not. If they do not talk about me, I am not human. "A human being cannot talk to a horse," people talk about people." (man/ woman living in an urban city in Southern Africa (Makoae et al., 2008))*
- *So I just told myself that this illness is just like TB, ulcer, and so on. It didn't really hurt me that much. (man/ woman living in an urban city in Southern Africa (Makoae et al., 2008))*

### **Letting it Be:**

- *"I just become patient with them, and I tried to avoid confrontations with them. There was nothing else I could do." (man/ woman living in an urban city in Southern Africa (Makoae et al., 2008))*
- *"My children made me sit down. They begun to tell me everything that was said there about me, but I did not say anything. I just said, "Leave it because this disease is an epidemic, it has spread throughout the world." We also do not know where he (spreading the gossip) has heard this from because if he is young he cannot know about these things, but he must have been told by somebody who is older (pause), and my children asked me what we were going to do with them? I said, "No, you just leave it (pause), when you leave it like that they will feel guilty." Since then they never spoke those words again because my children did not approach them to ask or talk it over with them." (man/ woman living in an rural city in Southern Africa (Makoae et al., 2008))*

### **Seeking Social Support:**

- *"I told my sister that, if it was that "thing" (AIDS) for as long as I lived, I was going to beat it ." (man/ woman living in an urban city in Southern Africa (Makoae et al., 2008))*

### **Developing a Routine:**

- *"I wanted to make sure I developed a routine that would help me. So my routine every day was to take my meds, have breakfast, take a walk down the hall a few times, then take my shower. It was important for me to do things to make myself feel good – to make myself active as much as I could." (male patient at the San Francisco General Hospital (Christopoulos, Massey, Lopez, Geng, & Johnson, 2013))*

- *“Dr. H. who became my primary care physician, he told me if you do the right things you can live a long time, you know, by taking your meds and everything. So that was quite reassuring. I was hoping he would say that because I didn’t want to die.” (male patient at the San Francisco General Hospital (Christopoulos et al., 2013))*

## **Appendix V Why is Stigma Hard to Change?**

While it is known that stigma is a major barrier to effective responses to the HIV epidemic, the efforts to reduce stigma is usually consigned to the bottom of HIV program priorities. (Mahajan et al., 2008) One of the primary reasons cited for the limited responses to reducing HIV stigma is the complexity of this issue. ((Mahajan et al., 2008) Because stigma is manifested on different levels, it becomes difficult to measure, not only the extent to which stigma exists, but also the effectiveness of the various intervention programs on stigma reduction. (Mahajan et al., 2008) Few studies have been published on programs and interventions to reduce HIV stigma, and majority of these interventions in the literature have focused on reducing stigma at the individual (Mahajan et al., 2008) or community level. (Brown, Macintyre, & Trujillo, 2003) The major strategy used in these interventions was education through the provision of information about HIV. (Ehiri, Anyanwu, & Donath E., 2005) (Kuhn, Steingberg, & Mathews, 1994) Although education is a good strategy, it may not always be effective on all levels. Even when this strategy has worked, it may be hard to accurately measure how much improvement has occurred, and in what areas subsequent reduction strategy should focus. It is believed that an intervention that would work has to be based on an understanding that stigma is a social processes that could only be changed by social action. (Parker et al., 2002) From the literature, a more comprehensive HIV stigma reduction intervention and programs should be developed at the structural or institutional level. (Mahajan et al., 2008) Socio-cultural factors should inform the design of these programs, since prevailing socio-cultural forces that provide dominant groups the power to create stigmatizing and occur at this level. (Parker et al., 2002)

According to (Mahajan et al., 2008), intervention approaches to reducing stigma has to be multifaceted and multilevel. Interventions that do not use these approaches could fail, and this may explain why stigma is hard to change. It is necessary for any HIV stigma intervention to include individual and structural levels of stigma (multilevel), and to account for the different ranges of HIV stigmatizing conditions (multifaceted).

## Appendix VI Intervening in Stigma

### Different types of stigma-reduction interventions

Stigma Interventions adapted from Pulerwitz et al, 2010 include:

- Help institutions recognize stigma
- Address stigma in the service environment
- Respond to the needs of stigmatized populations
- Use the media to show that the condition has a human face (e.g., **South Africa TAC**)
- Involve people living with the condition in service delivery
- Engage the community
- Engage partners and family
- Expand access to treatment

Types of stigma-reduction interventions that have been used around the world can be categorized to include the following intervention categories originally described by (Brown et al., 2003):

1. Information-based approaches:: Examples include HIV educational model for rural nurses in Georgia
2. Skills building: Examples include interactive techniques (role play, games, small group discussions) were used to build skills to among service providers in China to reduce discriminatory practices towards patients.
- 3.
4. Counselling/support: Examples include telephone support groups for patients to increase self-efficacy, decrease social isolation and increase social support and coping related living with HIV
5. Contact with affected groups; Example include panel discussions with patient testimonials

A recent review of intervention studies (Stangl et al., 2013) found that information-based intervention approaches were the most common (38 studies), followed by skills-

building intervention approaches (32 studies) and contact based intervention strategies (14 studies). Only 7 studies included counseling/support, 6 included structural approaches and 4 included a biomedical component. Majority of interventions reviewed in this study used two or more strategies to reduce HIV-related stigma and discrimination. However, majority of the interventions targeted only a single socio-ecological level, and a single stigma domain. (Stangl et al., 2013)

Another systematic review of interventions (Sengupta, Banks, Jonas, Miles, & Corbie-Smith, 2011) provided valuable suggestions on the most efficient ways of designing an effective HIV stigma reduction intervention. According to (Sengupta et al., 2011), HIV stigma interventions could improve by paying greater attention to internal validity and using tested and validated HIV stigma instruments, in order to achieve both statistical and public health significance.

### **Example Interventions for reduction of HIV-related stigma in healthcare settings**

#### **Multi-African Study (Uys et al., 2009)**

The aim of this intervention was to increase acceptance of PLHIV among health care workers and the population at large in five African countries (Lesotho, Malawi, South Africa, Swaziland, and Tanzania), and to increase the willingness of health workers to care for PLHIV. This intervention used three approaches; sharing information, increasing contact with the affected group, and improving coping through empowerment. The intervention steps involved bringing a group of clients and health workers from one healthcare setting together for a two-day workshop. During these two days, the group of clients and health workers were given the task of designing a project to reduce stigma in their own health facility within a month. The project concluded with a one-day workshop to evaluate the intervention that was implemented during the subsequent month. The PLHIV who participated in this intervention experienced a significant decrease in total stigma score, as well as a significant increase in self-esteem. The health workers who participated (nurses) had a significant increase in voluntary testing of HIV. The basis of this intervention has informed our FRESH study HIV-related stigma intervention workshop.

#### **Puerto Rico (Varas-Díaz et al., 2013)**

Varas-Diaz and colleagues (Varas-Díaz et al., 2013) took a different approach to HIV-related stigma intervention by implementing an intervention developed to reduce HIV stigma among medical students in Puerto Rico. This was part of the formal training of future healthcare professionals. According to Varas-Diaz et al, Latino healthcare professionals have been absent from HIV-related stigma intervention efforts, although

the epidemic has affected this population disproportionately. They developed an intervention and randomly assigned 507 medical students to intervention and control conditions. The intervention, “stigma-free spaces in medical scenarios” (SPACES) is a nine-hour workshop divided into three sessions (three hours each). The intervention addressed the sources and functions of HIV stigma, issues that can worsen its consequences, and focused on both instrumental and symbolic stigmas related to HIV. The researchers found statistically significant differences in stigma levels between the intervention and control groups – the intervention group lower HIV stigma levels than the control group, and these differences were sustained for an entire year.

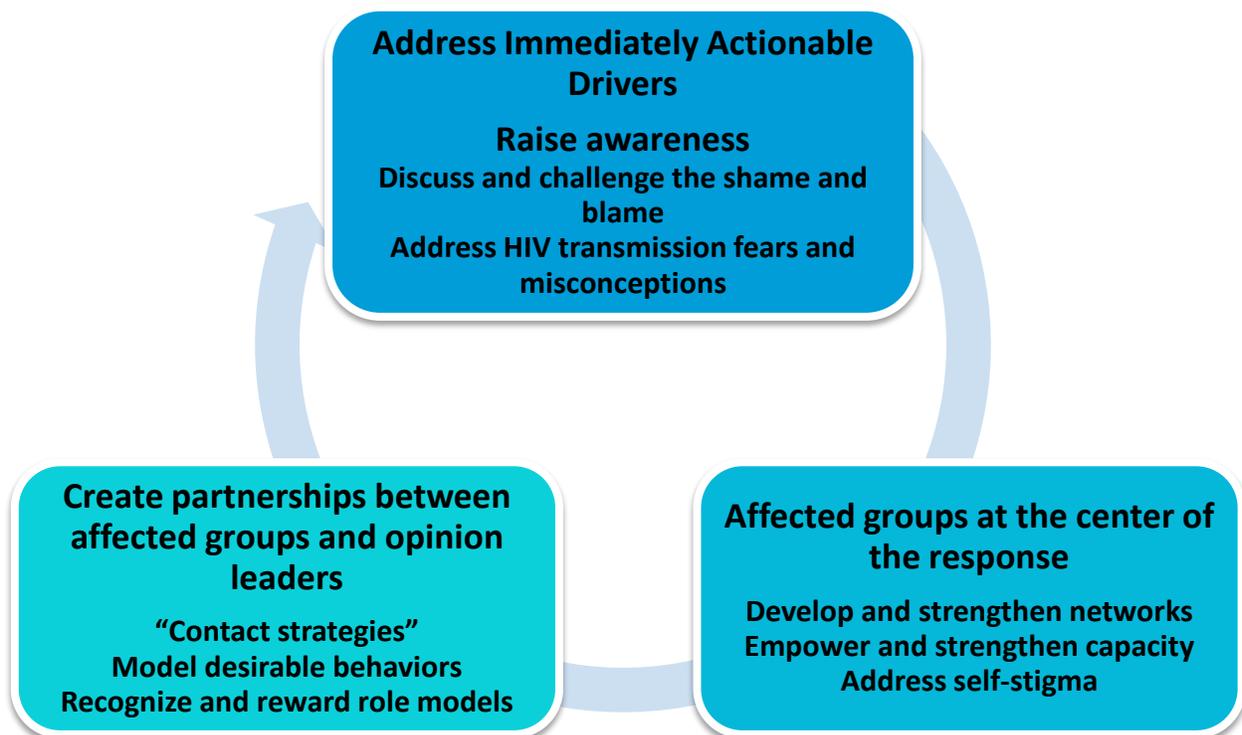
### **China(Li, Lin, Guan, & Wu, 2013)**

Li et al, 2013 sought out to fill a gap that continues to exist between what is known and what is actually delivered in medical settings to reduce HIV-related stigma. They implemented a stigma-reduction intervention trial that involved 1760 health providers in 40 hospitals in China. They followed the diffusion of innovation theory, and the intervention identified and trained about 15-20% providers as popular opinion leaders (POLs) to spread stigma reduction messages in each of the intervention hospitals. Another important part of the intervention was engaging governmental support in the provision of universal precaution supplies to all of the participating hospitals in the trial. They measured the frequency of message diffusion and reception, perceived improvement in universal precaution practices and reduction in the level of stigma in hospitals at 6- and 12-month during follow-up assessments. Among the intervention hospitals, POL providers reported more frequent discussions with their co-workers regarding universal precaution principles, equal treatment of patients, provider-patient relationships, and reducing HIV-related stigma. Health providers in the intervention hospitals reported more desirable intervention outcomes than providers in the control hospitals. The authors believed that the involvement of health authorities in supporting occupational safety was an important element for sustainability of this intervention.

**There are 3 key principles that need to be considered in implementing programs for any target group. These 3 principles are described in the figure below:**

- 1. Addressing “immediately actionable drivers.” This focuses on the content of interventions and what we learn from research and programs. These key causes of stigma are actionable in the short or immediate term and are fundamental to any stigma-reduction program. The following are steps to address the “immediately actionable drivers”:**
  - Raise Awareness: *Close the Intention-Action Gap.* This is to foster understanding and motivation for stigma reduction**

- **Address Transmission Fears and Misconceptions:** This helps us to understand how stigma is and/ or is not transmitted, and how to respond to specific fears related to daily living context
  - **Discuss and Challenge the Shame and Blame:** This helps us to understand the values and beliefs that underlie stigma and discrimination. We aim to understand where they come from and their consequences.
2. The second principle is putting those experiencing stigma at the core of the response to stigma.
  3. The third is creating and sustaining partnerships between those experiencing stigma and those in the community who have the power to shape opinions and model non-stigmatizing behavior.



## Appendix VII Cardstorming

### Introduction

The workshop makes use of a range of facilitation and group work techniques. Cardstorming or participlan as it is also known and rotational brainstorming are two of the essential tools in the facilitators' toolbox for this workshop.

Both techniques offer several advantages over small group discussions and large group discussions. These advantages include:

- Value all contributions
- Minimise power differences between participants
- Minimise domination by some
- Ensure equal participation
- Create opportunities to participate from quieter or shy participants
- Ensure high levels of participation
- All difference and dissent to be easily voiced
- Contentious issues can be safely expressed
- Efficient in time
- Are energizing and mobilizing
- Promote creativity
- Allow good organisation and documenting of contributions and ideas

The methods for each of the techniques are described below. A common set of materials (essential for cardstorming) will be useful for these techniques and for the workshop facilitation process as a whole. These are listed immediately.

### Materials list

1. Flipchart Paper and Large Post-Its .

Have enough flipchart paper and large post-its available for the entire workshop.

2. A<sup>6</sup> writing pads

These pads are easy to have made up at any binding service. A ream of A<sup>4</sup> paper is cut into 4 equal pieces and glue bound along the long side. Participants use the pads to write ideas on and for posting onto the flipcharts. This is essential for the cardstorming technique.

3. Felt tip pens

These should be the large variety, with the large nib and are used throughout.

### Cardstorming - Participlan Description

In this technique participants respond to a task stimulus, usually a specific question and write their ideas, responses, answers down on the post-its provided. After a set amount of time, the facilitator collects all the post-its and starts to “post” them on the flip-charts, reading each one aloud. As similar ideas emerge, they can immediately be positioned alongside each other. Once all the cards are read and posted up a group task of organizing and understanding the outputs occurs. Limit all participants’ verbal contributions whether questions or opinions to 30 seconds only. This rule promotes efficiency in processing the task and the discussion. From here, similar ideas are grouped together. Once the ideas have been arranged into thematic clusters, the group can name the cluster, giving it a higher order category or classification. This yields a set of general themes with detailed content within the cluster. Draw around the cluster with a pen making the cluster visibly clear and write the cluster name on the sheet.

### *Procedure*

At the start of the exercise, it is important to explain the technique to participants and issue several instructions.

1. Explain the basics of how the technique operates as above.
2. Issue a specific set of instructions which are listed below in bullet points, have these pre-printed on cards and post them up on a sheet as you present them. Leave this sheet up and visible throughout the process.
3. Distribute pads and pens. All pads and pens within each sub-group should be of the same colour. Use different colour paper pads for different sub-groups to allow easy distinction between group outputs if needed. The same colour pad and pen is essential to allow participants to post items anonymously. This is key because it allows the anonymous posting of difficult or contentious issues.
4. Describe the question or stimulus for the work-session and the overall objective. Explain it and post it up visibly for the group as reference point throughout the exercise.
5. Ask participants to respond by writing as many responses as they like within a set time limit. They may use as many cards as they like.
6. At the end of the time, collect all the cards, shuffling them up as you go to ensure you separate out individuals’ ideas and protect anonymity.
7. Read each card aloud and post it up on the pre-sprayed sheets
8. Use the opportunity to start grouping similar ideas together, ask participants to agree on the grouping or to suggest what goes together. DO NOT do all this grouping yourself.

9. Once all the cards are posted, invite participants to come up and do the grouping. This is an active part of the exercise, and
10. Stimulate discussion and question on clarity and meaning of items and debate groupings
11. Once the groups/clusters are arranged, give each cluster a name or label that makes sense as a general theme or category, circle the cluster and write the name on the sheet.
12. Some cards are hard to deal with and some may be relevant to other questions or irrelevant. With the participants' agreement, decide whether to discard a card, or whether to "park" it for later use.
13. Parking a card: Have a separate sheet – a parking lot, for cards that have content the group does not wish to lose, but is not immediately useful or relevant.
14. When discarding or parking a card, do so with the groups participation and be sensitive. It's an idea that is being parked, not a person, but participants may feel sensitive about it.
15. Facilitate a concluding discussion that relates the outputs to the objectives of the task at hand.
16. Ensure that the outputs are documented or stored safely for later transcription.

*Instruction List for cardstorming*

- Group process
- Facilitator helps the process
- Everyone can participate
- All are equal
- Anonymity is ensured
- Use the cards to participate
- Write big
- Spelling does not matter
- Use as many cards as you like
- Only one idea per card – no long books
- Use simple language
- No big "suitcase" words (Words that need to be extensively unpacked)
- 2 rules
  - 30 second rule

- rule of 2 feet (participants may get up, leave for short periods, but the process does not wait or go back to accommodate anyone's absence – one can influence the process as long as ones' "two feet" are in the room)
- Use the facilitator as the communication channel

*Adaptation for low or no literacy*

If participants in the group have low literacy skills, the technique can still be used but must be adapted. The adaptation requires pairing people with one literate member in the pair. The pairing must be done through self-selection to ensure that the pair are comfortable with each other and to ensure that the advantages of the technique are not over ridden by withholding ideas and lowering participation. The literate-low/no literate pair will then produce a set of written cards collectively. The one simply writes the cards for the other in addition to their own cards.

Adaptation steps

1. Ask if anyone has any difficulties with writing
2. Ask them to seek a partner in the group they feel comfortable with to do the exercise together
3. Ask the pair to generate ideas and have one of them write all their ideas down on the cards
4. They should not discuss them or evaluate them – **just get them written down**
5. Allow a bit more time for the exercise
6. Ensure the cards are read out clearly and repeated regularly to ensure all participants can follow and participate actively in the process

**Appendix VIII: Exercise on Understanding Stigma: Roots and Leaves**

- **Break into two groups (mixed clients and HWs)**

- You have been provided with a tree trunk with roots and leaves
- Brainstorm on all the things you can think of that are roots or causes of stigma and write those on the roots
- Brainstorm on all the things you can think of that are outcomes or effects of stigma and write those on the leaves
- Choose someone to present your tree back to the larger group.

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