

# The Stigma of HIV/AIDS



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# Outline of Today's Talk

1. What is stigma? A theoretical analysis of four manifestations of stigma
2. Applying this theory to HIV-related stigma
3. Some studies examining the relationship between different manifestations of HIV-related stigma
4. Some examples of stigma reduction interventions
5. Common elements of effective interventions – what works?

# What is stigma?

- The term *stigma* can be traced to the **Ancient Greeks** who used tattoos, scars, or brands to mark slaves, deserters, or criminals as people of reproach and disgrace.
- **Goffman (1963)** described stigma as a sign or mark designating the bearer as spoiled, flawed, or compromised—someone less than fully human.
- More recently, Dovidio, Major, & Crocker (2000) defined stigma as "a social construction that involves at least two fundamental components: **(1)** the recognition of difference based on some distinguishing characteristic, or 'mark'; and **(2)** a consequent devaluation of the person" (p. 3).



# Three Social Psychological Functions of Stigma

(Phelan, Link, & Dovidio, 2008)

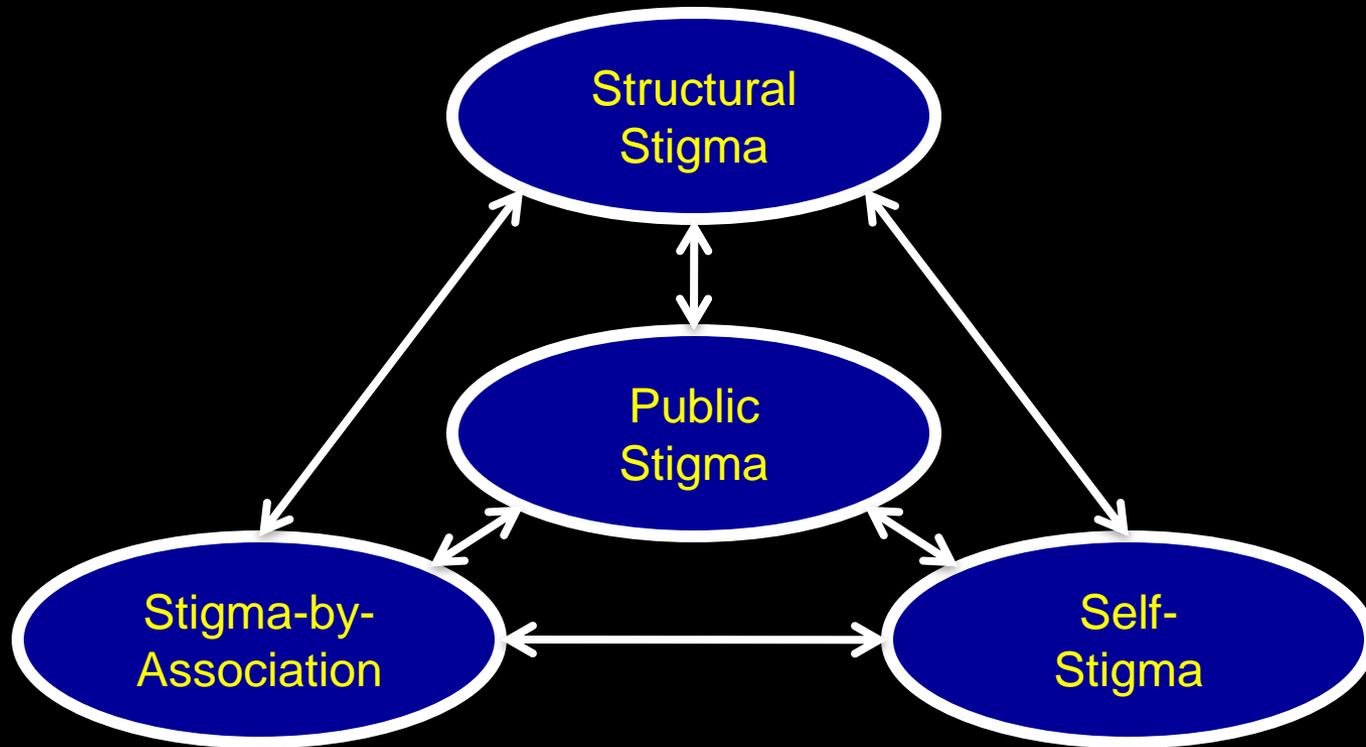
- **To keep people down** – stigmas help to legitimize and perpetuate social inequities (i.e., provide justification for the exploitation and dominance of lower status groups)
- **To make people conform** - stigmas help to enforce social norms by serving as a punishment to those who choose non-conformity
- **To keep people away** – stigmas trigger avoidance responses to a broad class of deviant human characteristics that potentially signal risk of infection

# Four Manifestations of Stigma

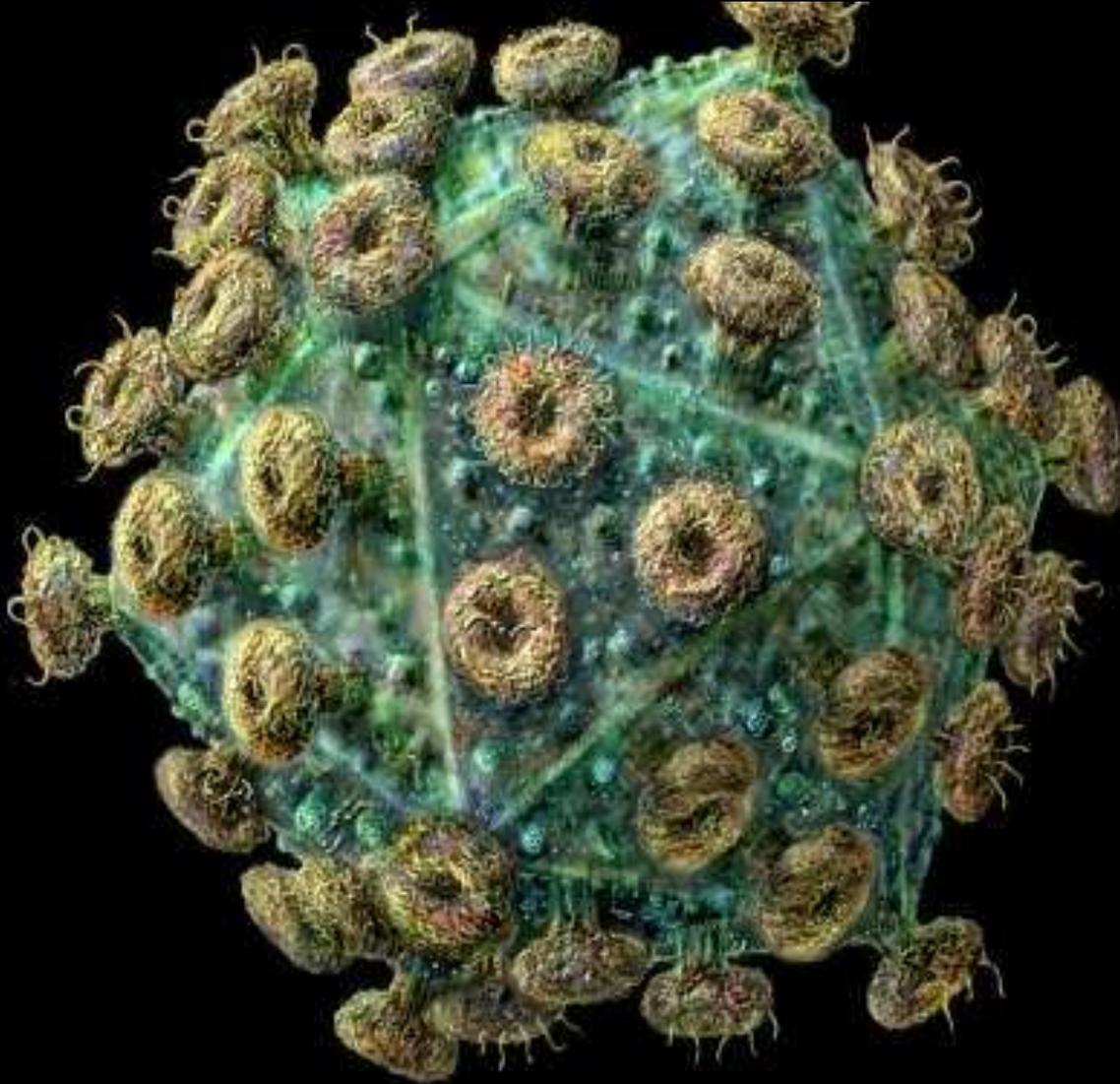
(Pryor & Reeder, 2011)

- 1) *public stigma* – people's social and psychological reactions to someone with a perceived stigma
- 2) *self-stigma* – how one reacts to the possession of a stigma
- 3) *stigma-by-association* – social and psychological reactions to people who are somehow associated with a stigmatized person or how people react to being associated with a stigmatized person
- 4) *structural stigma* – the legitimization and perpetuation of a stigmatized status by society's institutions and ideological systems

# A Dynamic Model of the Four Manifestations of Stigma



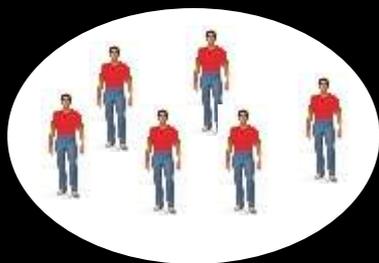
# Applying the Stigma Model to HIV



# Public Stigma

- Social psychologists view negative reactions to a perceived stigma as a form of *prejudice*.
- Prejudice is essentially a negative *attitude* toward people perceived to be members of an out-group.
- Stigmatized out-groups often have less social power than in-groups.

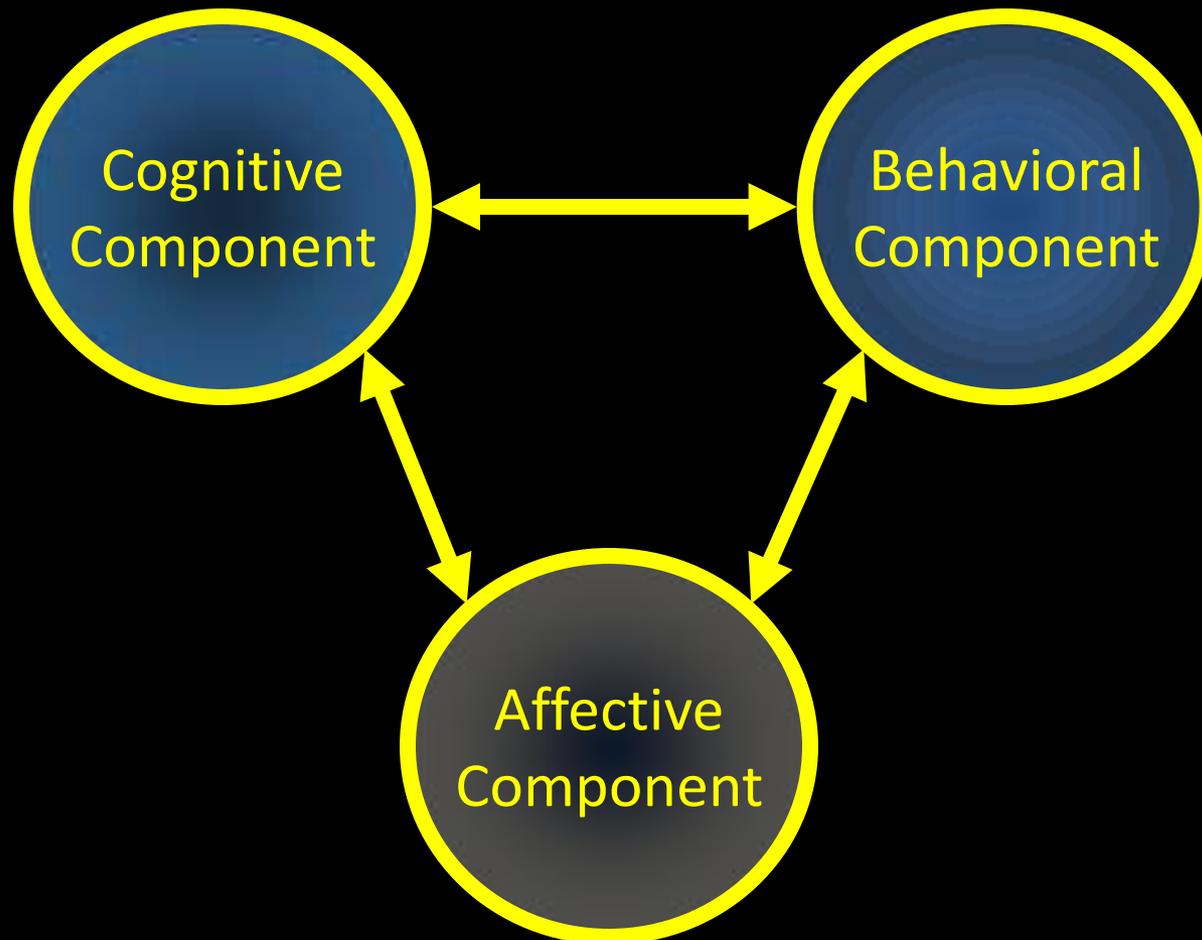
*US*



*THEM*



# Tri-Part Conceptual Model of Public Stigma



# Cognitive components of reactions to perceived HIV-related stigma

- **Stereotypes about PLWHA**
  - Connections to sexual orientation and drug use
- **Beliefs about blame**
  - Belief that bad things happen to bad people
- **Conceptions of risk and transmission**
  - Risks associated with casual contact
- **Beliefs about prejudice**
  - Are negative reactions to PLWHA seen as a form of prejudice?

# **Affective (emotional) components of reactions to perceived HIV-related Stigma**

- Affective reactions can be positive (e.g., compassion, empathy) or negative (e.g., fear, disgust, anger, etc.)
- Affective reactions can be automatic (spontaneous or reflexive) or derived from conscious deliberation

# Behavioral components of reactions to perceived HIV-related stigma

- **Avoidance** (or approach) – a general behavioral tendency
- **Harassment, ridicule, & ostracism**
- **Discrimination**
  - Employment
  - Housing
  - Educational opportunities
  - Access to medical care
  - Insurance
- **Pro-social behavior** – *the flip side of discrimination* – **social support**
- **Support for public policies**
  - Coercive policies
  - Anti-discrimination policies



**What is  
self-  
stigma?**

# **Self-stigma** – *derived from enacted (actual) or perceived (anticipated) social experiences*

- **Related to knowledge of public reactions to stigma** – *reflected appraisals of others*
- **Label avoidance**
  - Avoiding HIV testing
  - Avoiding disclosure of HIV status
  - Avoiding treatment
  - Avoiding safer sex
- **Withdrawal from situations where ill treatment might occur** – *social isolation*
- **Internalization of the negative label**
  - Reduction of self-esteem & self-efficacy
  - Hopelessness and depression
  - Reduced Immune functioning

# Stigma-by-Association

Goffman called this *courtesy stigma*

- To some degree all of the public stigma reactions to PLWHA are also experienced by uninfected people who are somehow associated with PLWHA
- HIV-related stigma affects families – **shame & disclosure concerns**
- Stigma-by-Association contributes to **burnout** among care-givers and health care providers
- Being associated with a PLWHA may contribute to **psychological distress**
- Concern about stigma-by-association contributes to **social avoidance**



# Structural Stigma



Examples of stigmatizing government laws and policies in the U.S.

- Until recently the U.S. government banned individuals with HIV from entering the United States as tourists, workers or immigrants
- The U.S. Foreign Service still refuses to hire applicants with HIV.
- The Transportation Security Administration has refused to hire applicants who are HIV+.
- 34 states and 2 U.S. territories have criminal statutes based on perceived exposure to HIV, and prosecutions for alleged exposure to HIV have occurred in at least 39 states.

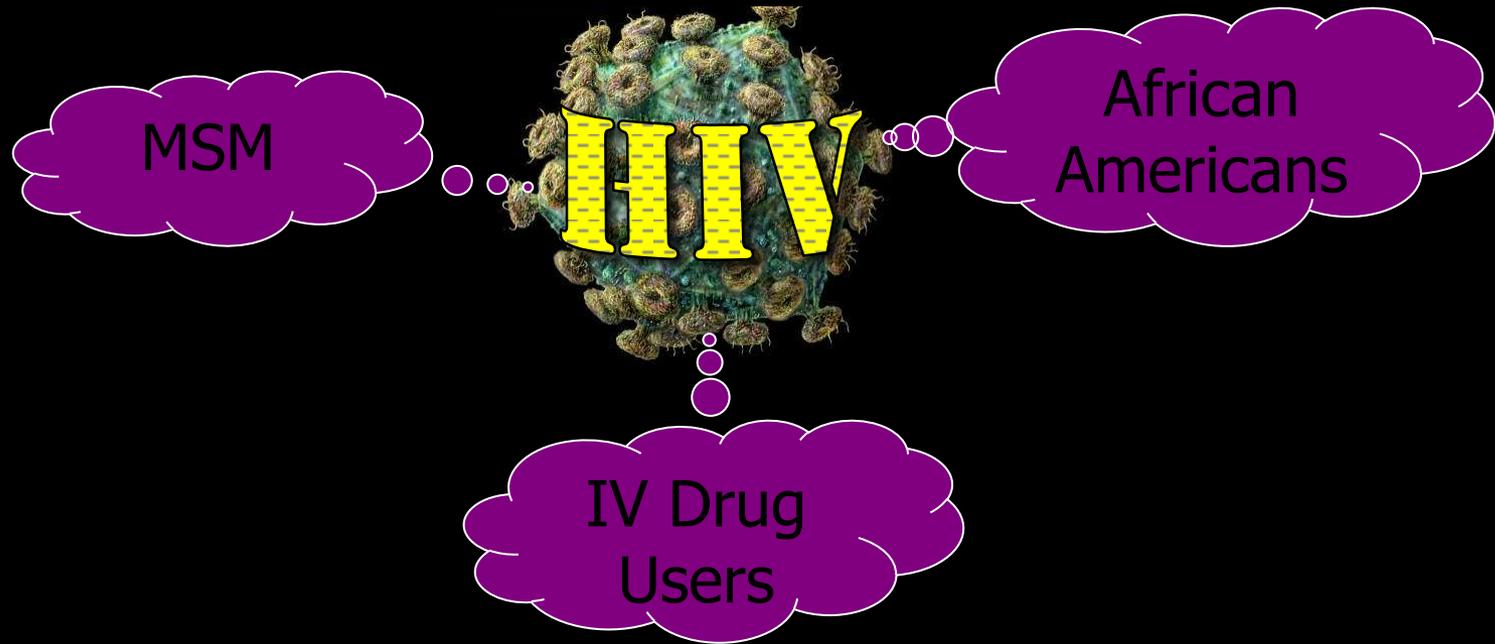


# Structural Stigma

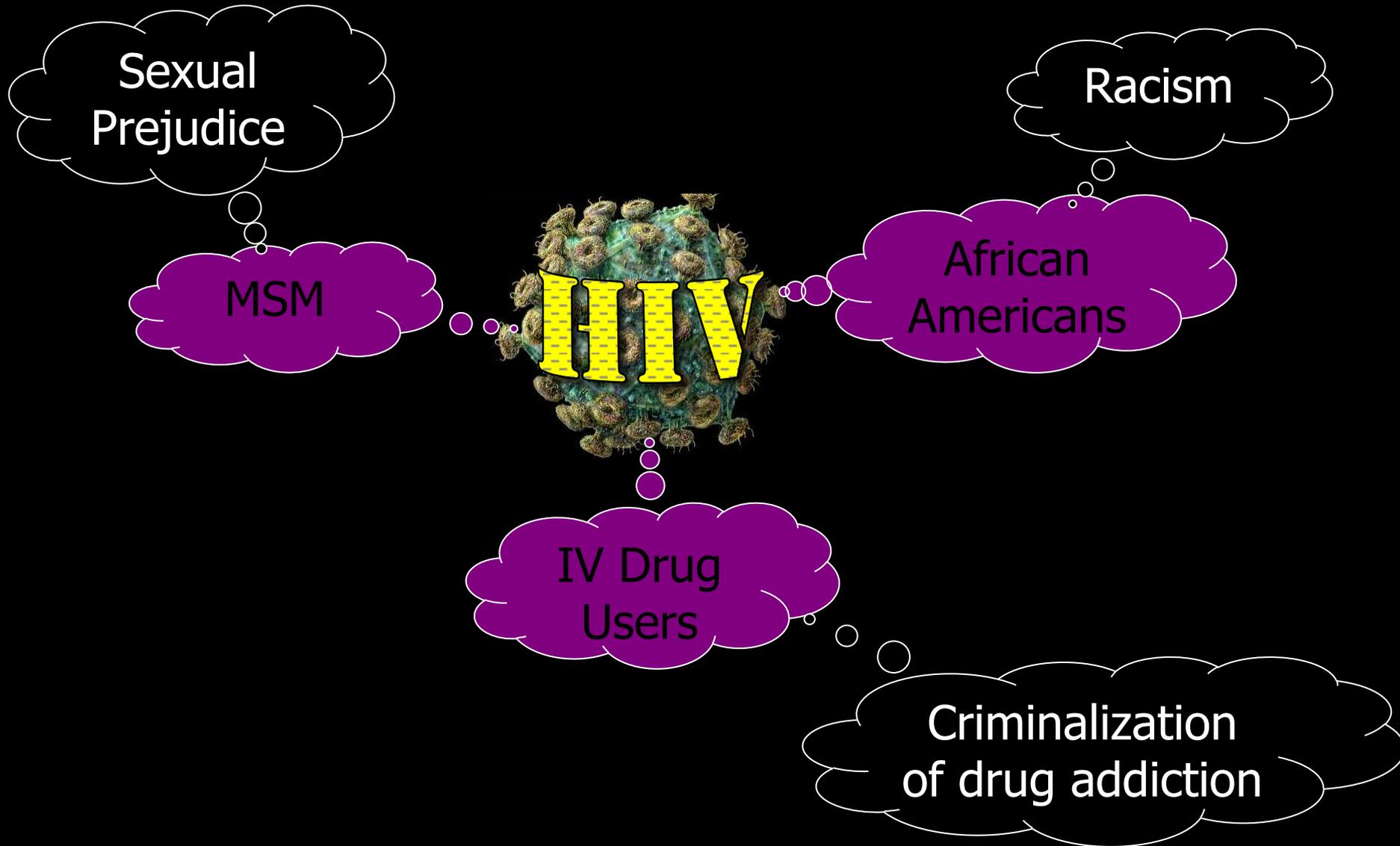


- Public stigma toward persons living with HIV/AIDS is related to the perceived connections of HIV/AIDS to other stigmas (e.g., homosexuality)
- Policies of private and governmental institutions that have a negative impact people with these related stigmas also serve to legitimize and perpetuate HIV-related stigma

# Stigmas related to HIV in the US



# Societal responses to related stigmas in the US





# Related Structural Stigma in the United States



- **Sexual prejudice** – state laws in the US banning gay marriage, Federal Defense of Marriage Act
- **Institutional racism** – 1 in 7 US Black men between ages 25 & 29 are in prison
- **Criminalization of Drug Addiction** - Federal ban on syringe exchange (recently rescinded)



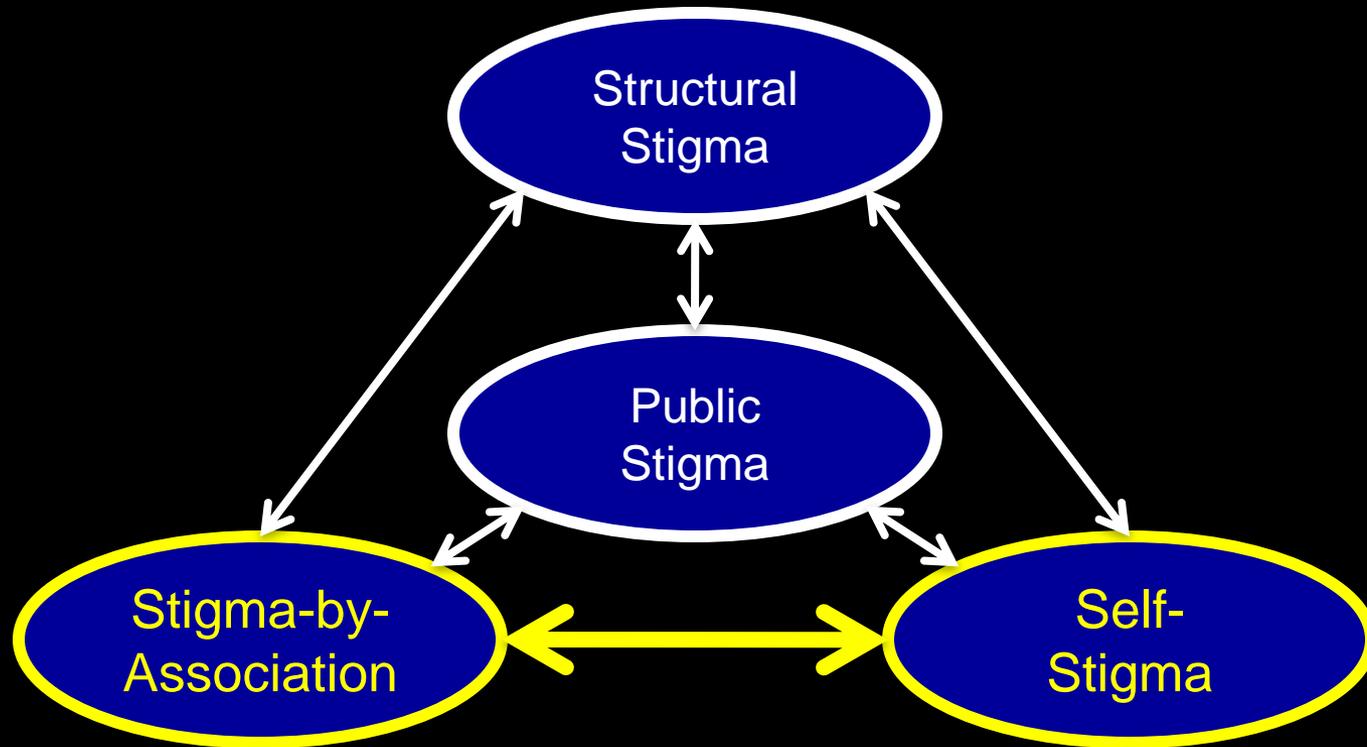
# Related Structural Stigma in Texas



- **Sexual prejudice** – More than half of US states have laws prohibiting discrimination in public workplaces based upon sexual orientation, but not Texas.
- **Institutional racism** – In Texas, there are 4.7 Black people incarcerated for every White person. Over 150, 000 Black Texans have felony disenfranchisement.
- **Humane Treatment of Drug Addicts** – According to a 2012 amFar study, there are only 2 syringe exchange programs in Texas. In contrast, neighboring New Mexico has 29.

**These different manifestations  
of HIV-related stigma are inter-  
related**

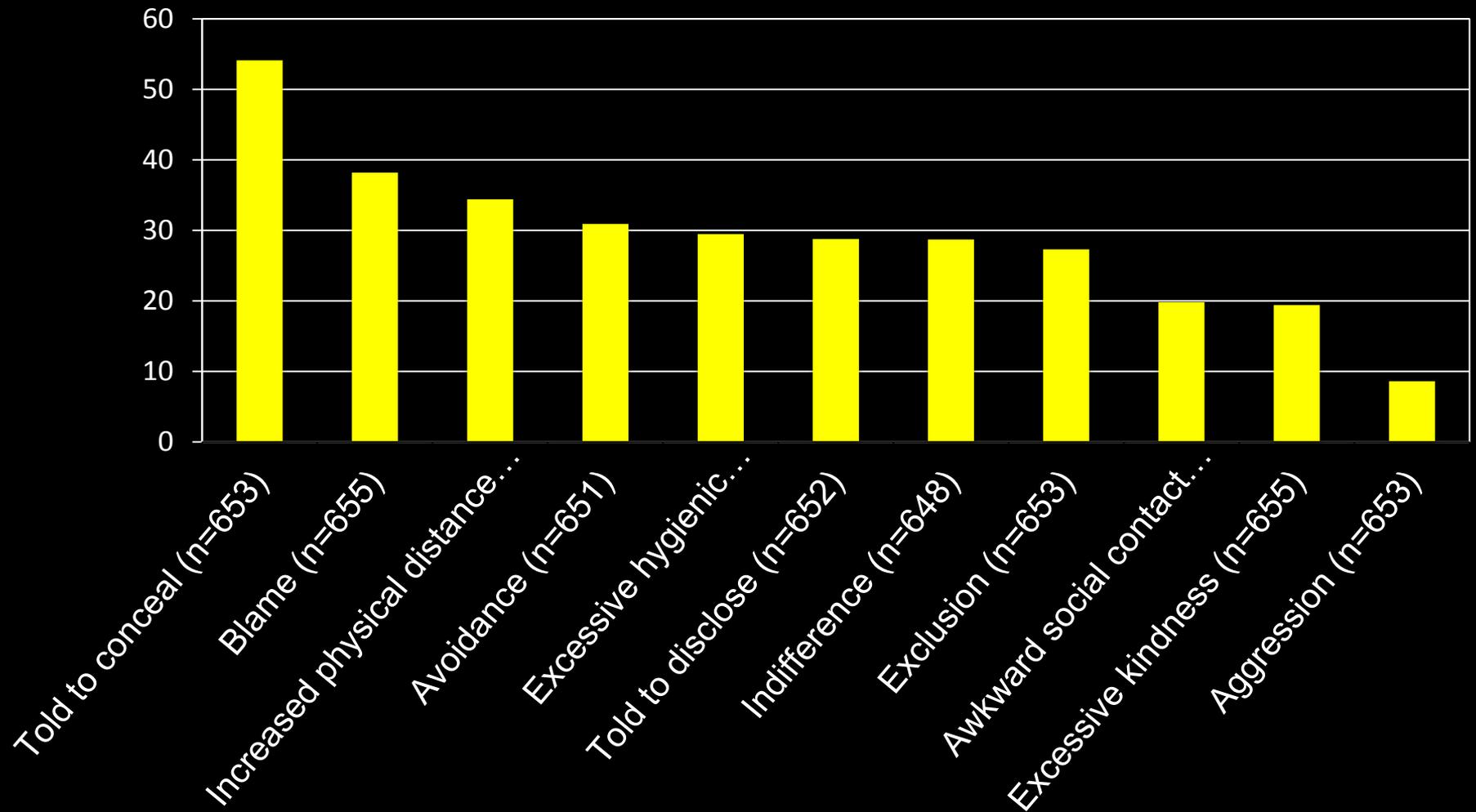
# Research focusing upon one link in the model of stigma



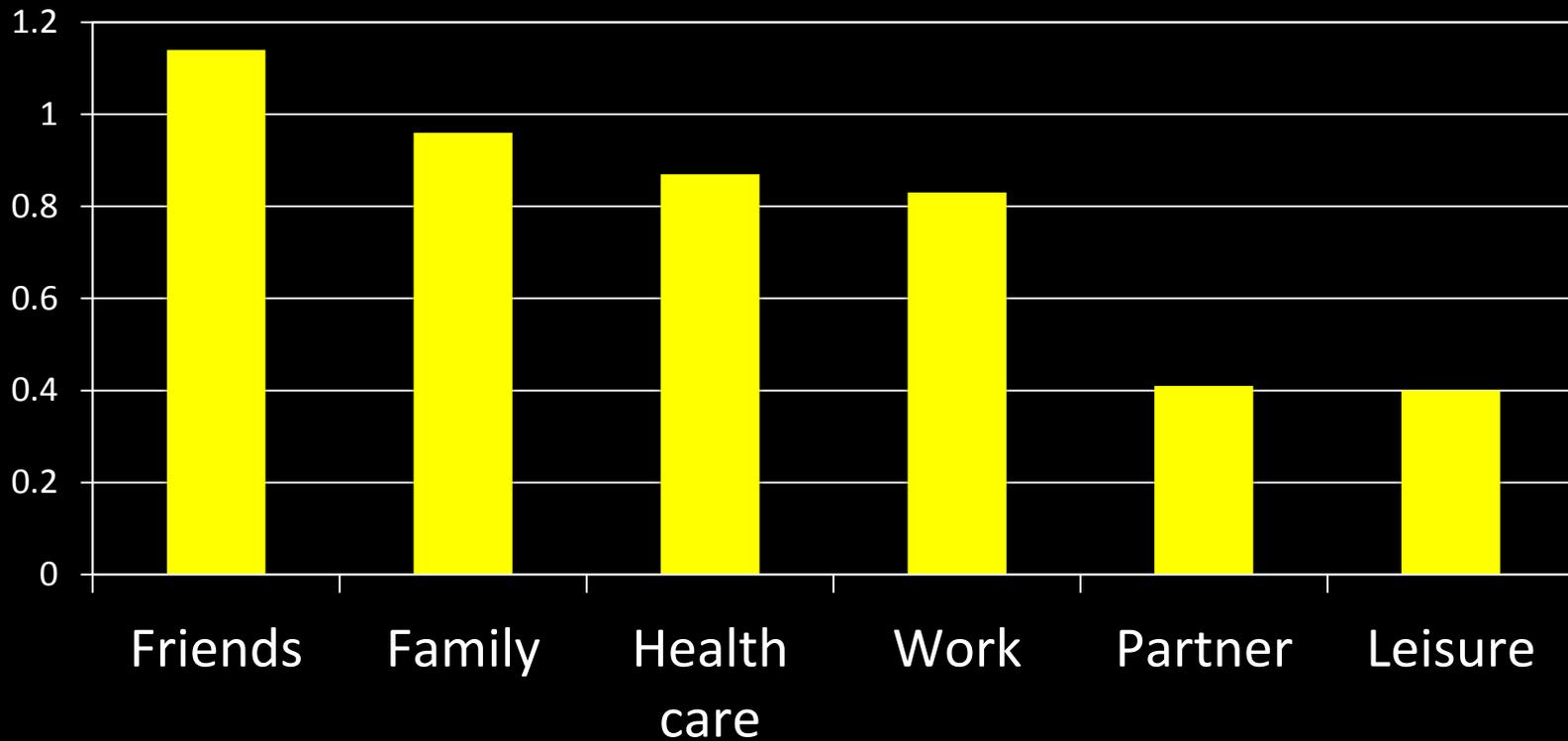
# HIV-Related Stigma in the Netherlands



# Types of Stigmatizing Behavior Experienced



**Mean number of manifestations of  
*enacted stigma*  
across social contexts**



Stigmatizing experiences that uniquely predict psychological distress among 601 Dutch PLWHA

*From Health Care Sector*



$\beta = .09$



$\beta = .08$

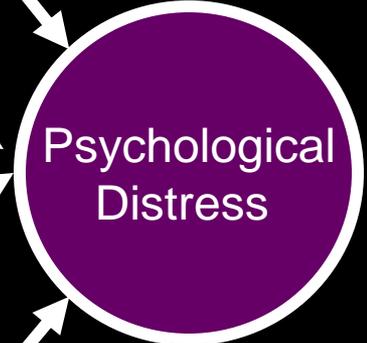


$\beta = .10$

*From Family*



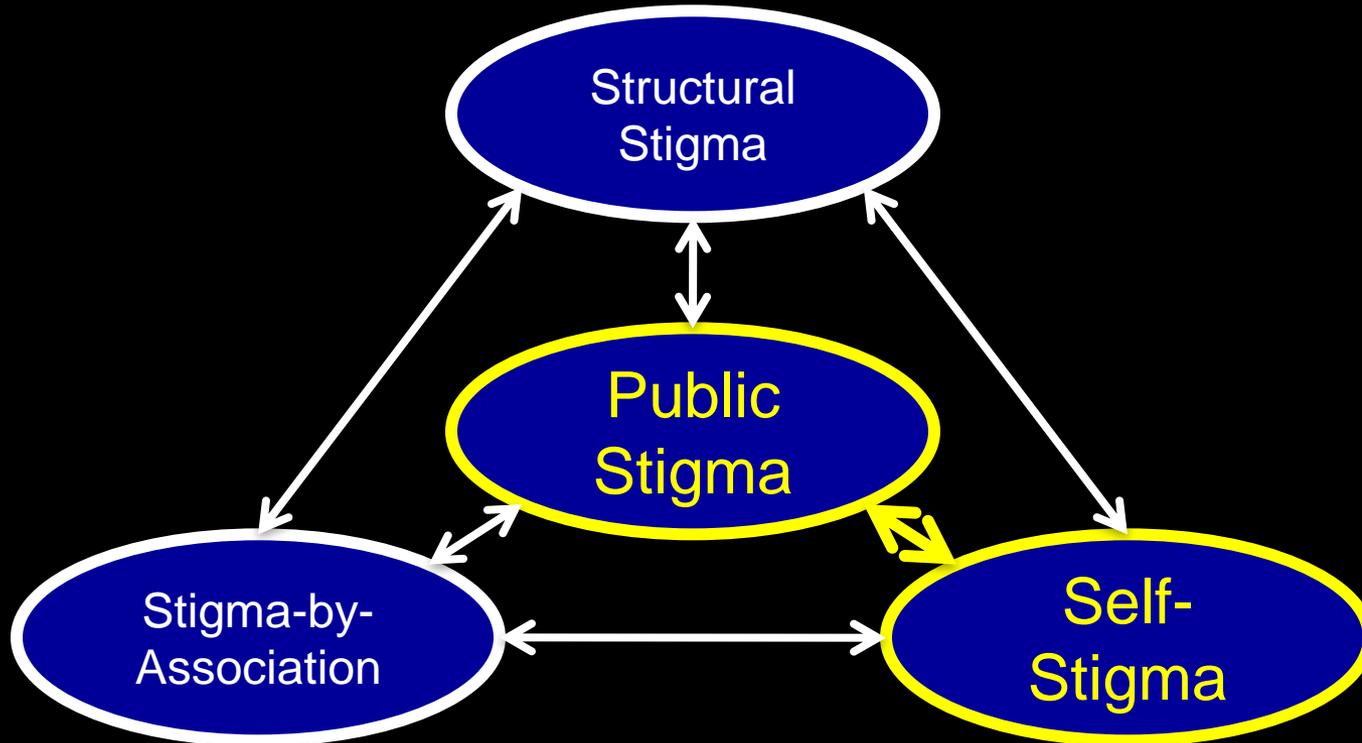
$\beta = .09$



Source: Stutterheim, Pryor, Bos, Hoogendijk, Muris, & Schaalma (2009)

Controlling for partner, educational & health status

# Relationship of Community Public Stigma to Manifestation of Self-Stigma



# PUBLIC STIGMA SELF-STIGMA

## Community Level

2444 community participants  
33 geographic clusters

## Individual PLWHAs

203 participants

### INTERNAL MOTIVATION TO CONTROL PREJUDICE

e.g., I attempt to act in non-**prejudiced** ways towards people with **HIV/AIDS** because it is personally important to me

### EXTERNAL MOTIVATION TO CONTROL PREJUDICE

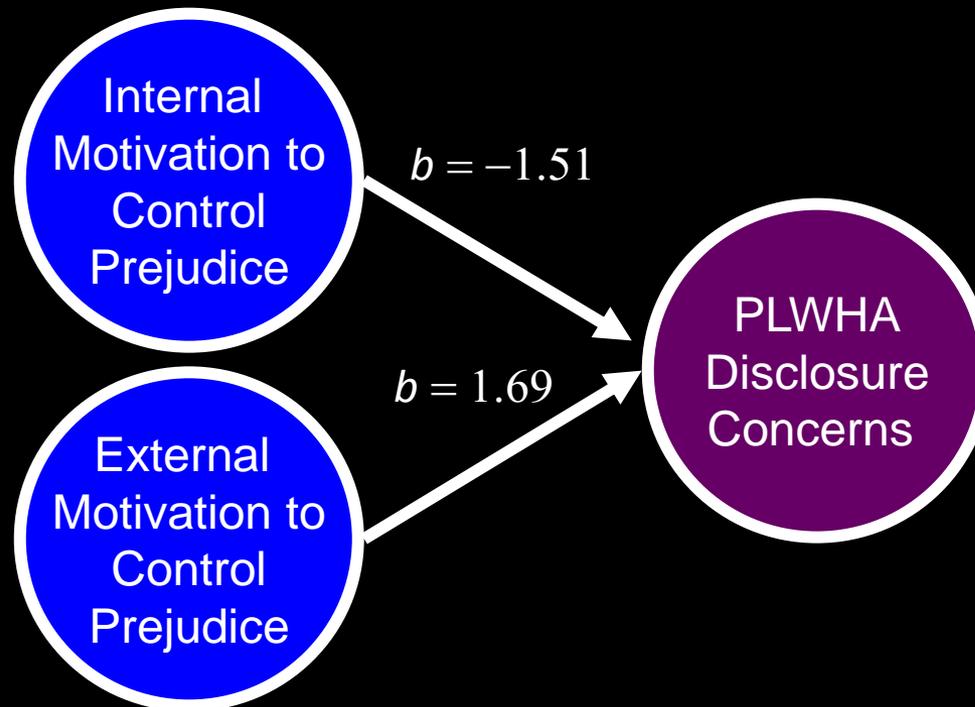
e.g., Because of today's politically correct standards, I try to appear non-prejudiced towards people with HIV/AIDS

### DISCLOSURE CONCERNS

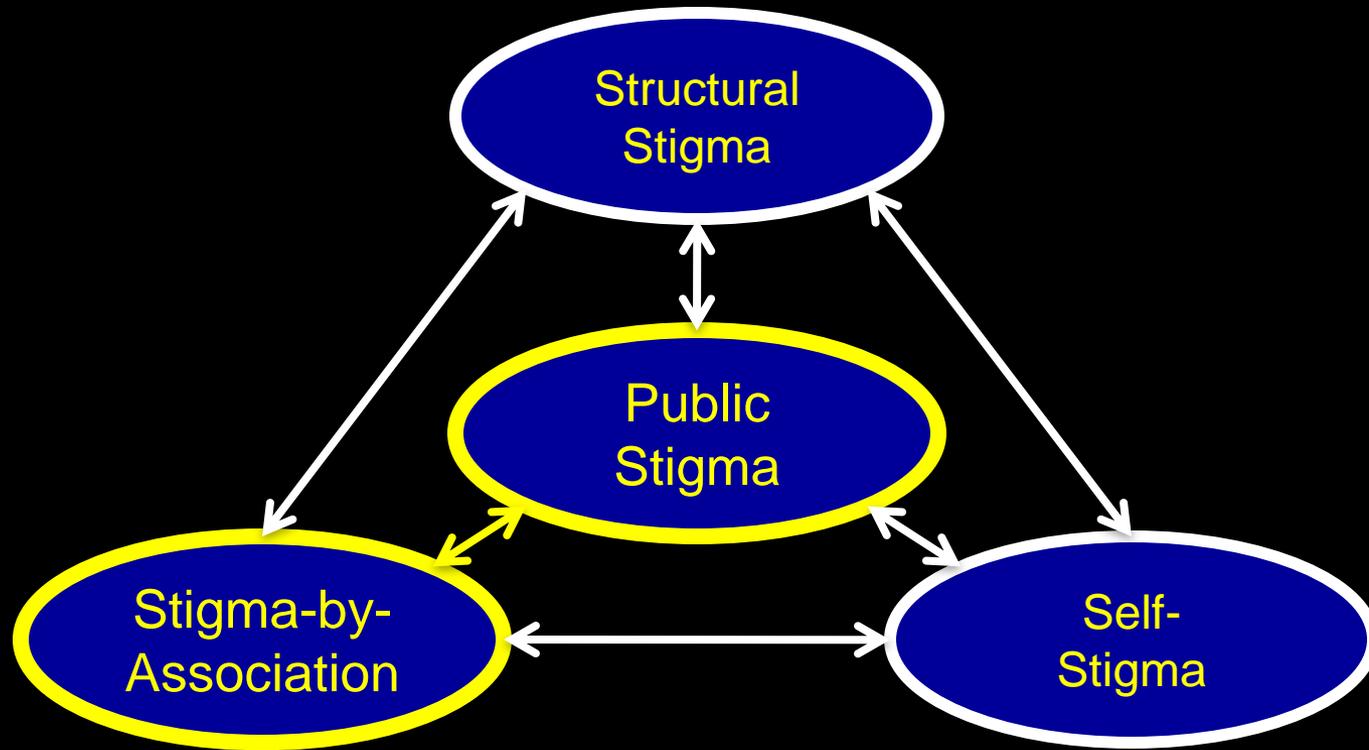
e.g., I worry that people who know will tell others

## Community Level

## Individuals Living with HIV/AIDS



# Relationship of Endorsing Public Stigma to Experiencing Stigma-by-Association



# SBA among South African University students with Relatives who have HIV/AIDS

Bos, Pryor,  
de Vos, Funani  
& Ruiter (2012)

- An estimated 5.7 million people were living with HIV and AIDS in South Africa in 2009, more than in any other country.
- Almost one-in-three women aged 25-29, and over a quarter of men aged 30-34, are living with HIV.
- Sample: 198 HIV- students from Walter Sisulu University in Mthatha who had HIV+ family members



# SBA Sensitivity for Relative with HIV/AIDS

*RMSEA* = .079, acceptable fit

## **COGNITIVE** ( $\alpha = .85$ )

People might treat my family in a negative way because one of my family members has HIV/AIDS

People might look down on my family if they find out

People might avoid me if they discover I am related to someone with HIV/AIDS

People would probably think that I am strange if they discover I am related to a person with HIV/AIDS

People might look down on me if they discover that I am related to this person with HIV/AIDS

People might treat me in a negative way if they find out that my family member has HIV/AIDS

## **AFFECTIVE** ( $\alpha = .80$ )

I am disgusted by the idea of being connected to someone with HIV/AIDS

I am worried that others will find out that someone in my family has HIV/AIDS

I feel disgraced by having someone with HIV/AIDS in my family

I feel offended that I am associated with someone with HIV/AIDS

I am nervous when others find out about my relationship to this person

## **BEHAVIORAL** ( $\alpha = .74$ )

When the person with HIV/AIDS and I are in public, I pretend that we are not related

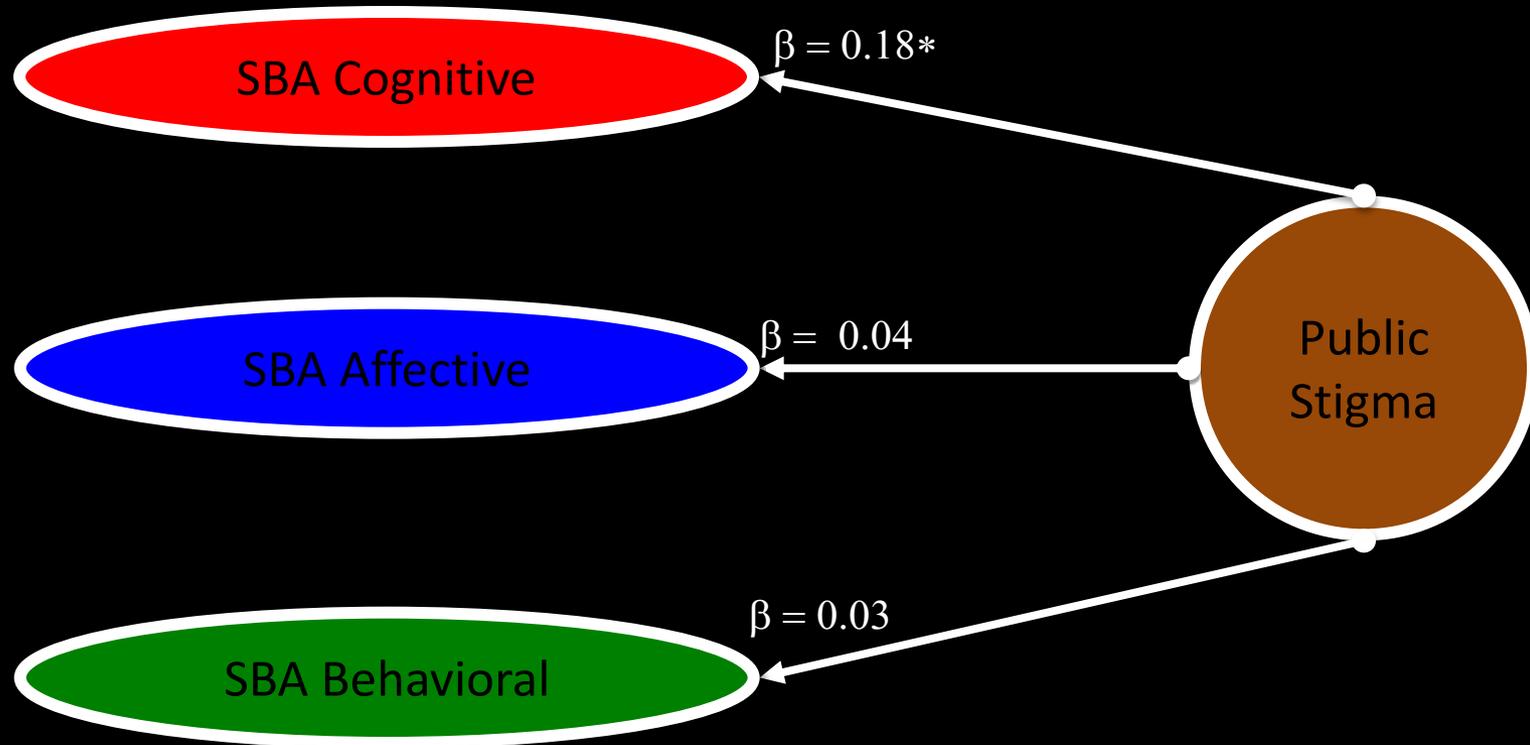
I don't introduce my friends to this person

I try to avoid being seen with the person who has HIV/AIDS

I try to keep my relationship to this person a secret

# Regression model of SBA on Public Stigma Among South African Students with a Relative who has HIV/AIDS

$\Delta R^2 = .07, F(3,181) = 2.89 p < .04$

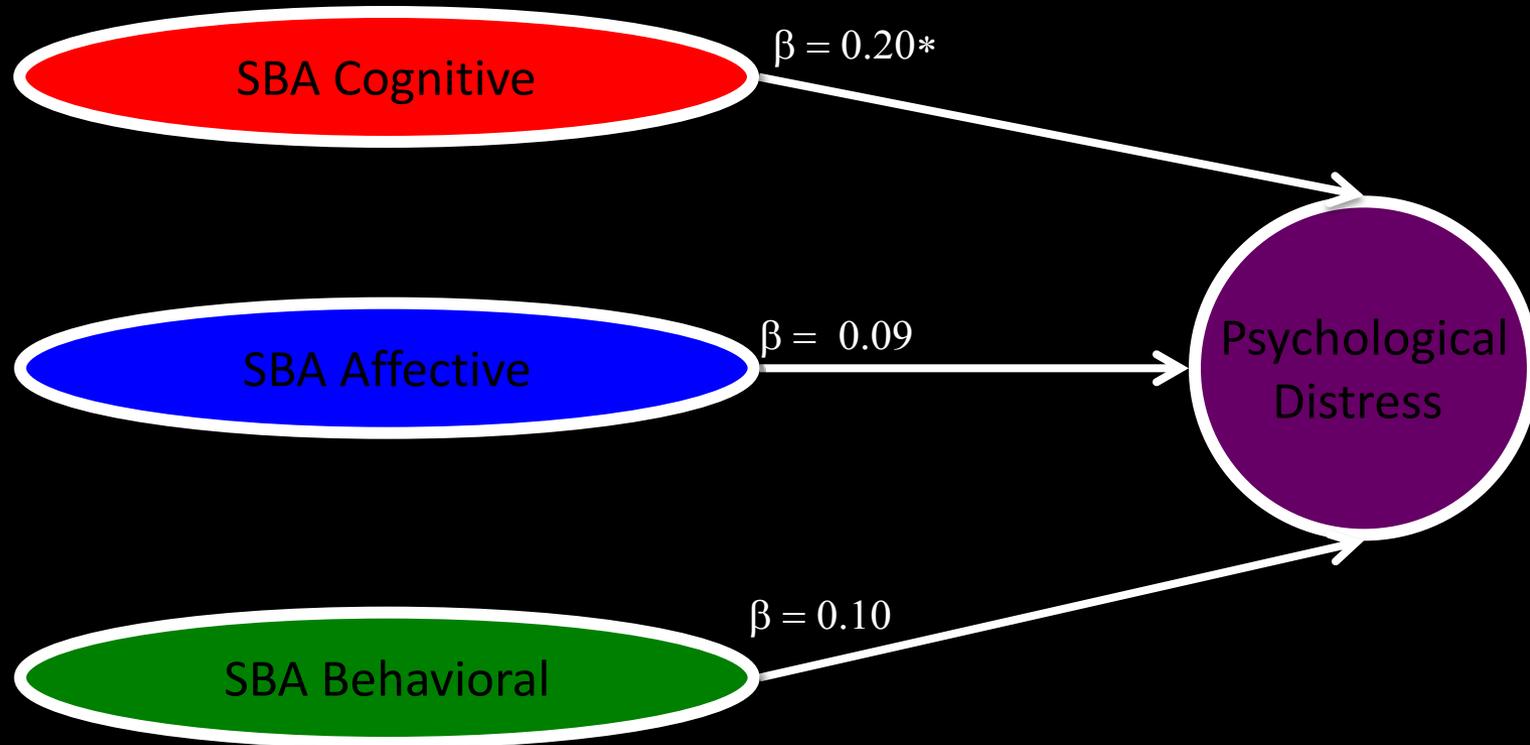


$*p < .04$

Controlling for gender and age

# Regression model of SBA on Psychological Distress Among South African Students with a Relative who has HIV/AIDS

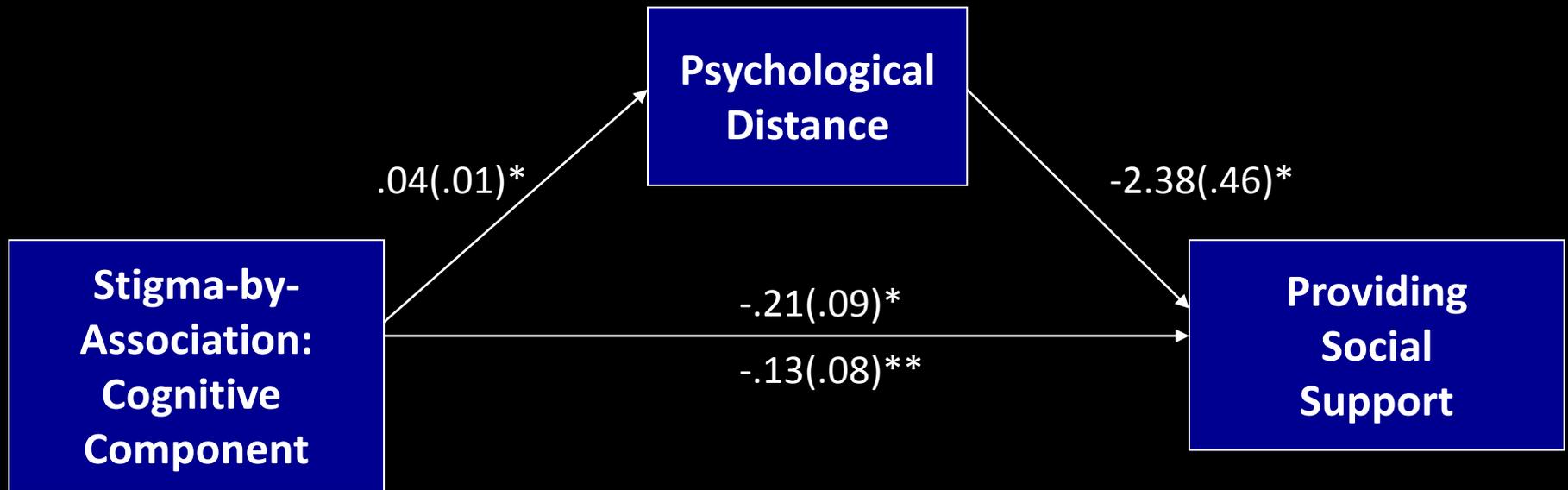
$\Delta R^2 = .10, F(3,181) = 6.15 p < .02$



$*p < .02$

Controlling for gender and age

# Test of Mediation: Psychological Distance to a Family Member with HIV/AIDS Mediates the Relationship between Stigma-by-Association Sensitivity and Social Support



\* $p < .01$

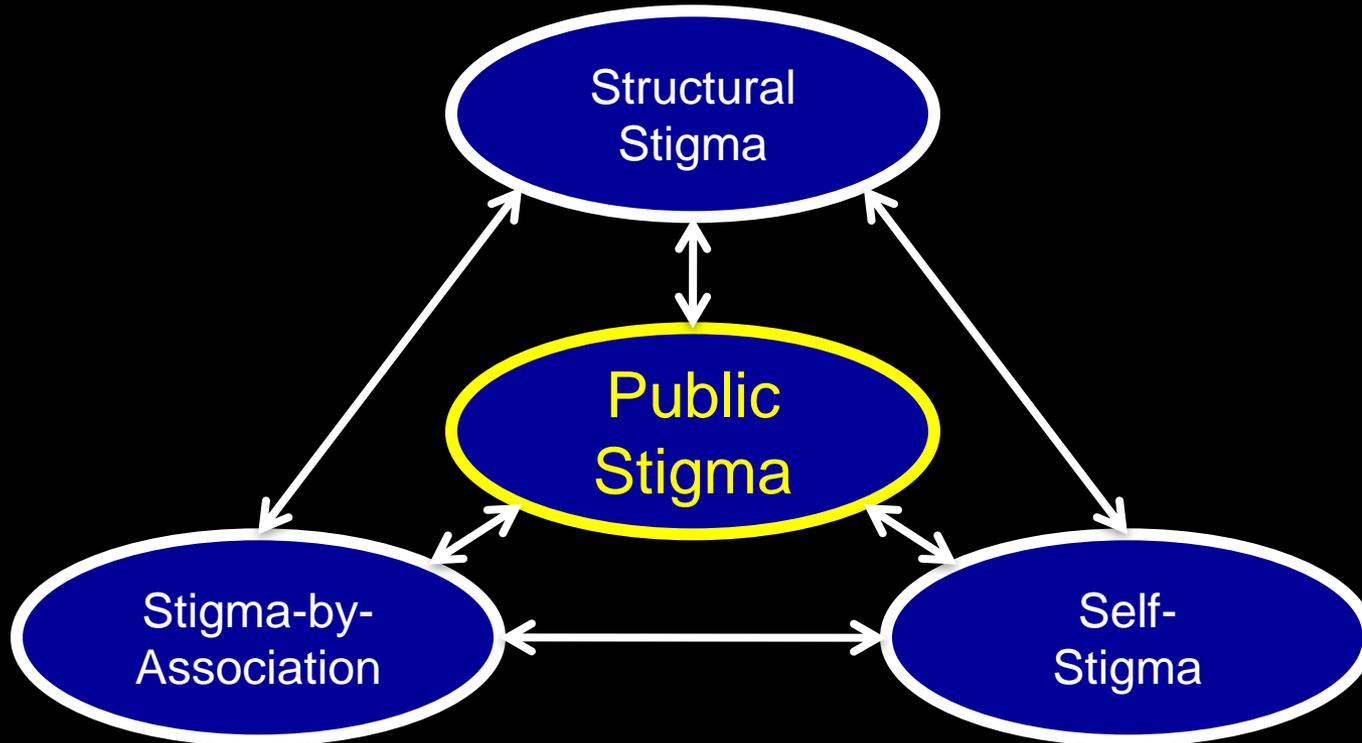
\*\*NS

*Sobel = -2.36, SE = .03,  $p < .02$*

*Evidence for complete mediation*

# Some examples of HIV-related stigma interventions

# Evaluation Research of an Intervention Design to Reduce Public Stigma





Salud Es Cultura  
¡Protégete!  
(Health is Culture,  
Protect Yourself)



Center on AIDS & Community Health

## PRIMARY OBJECTIVE

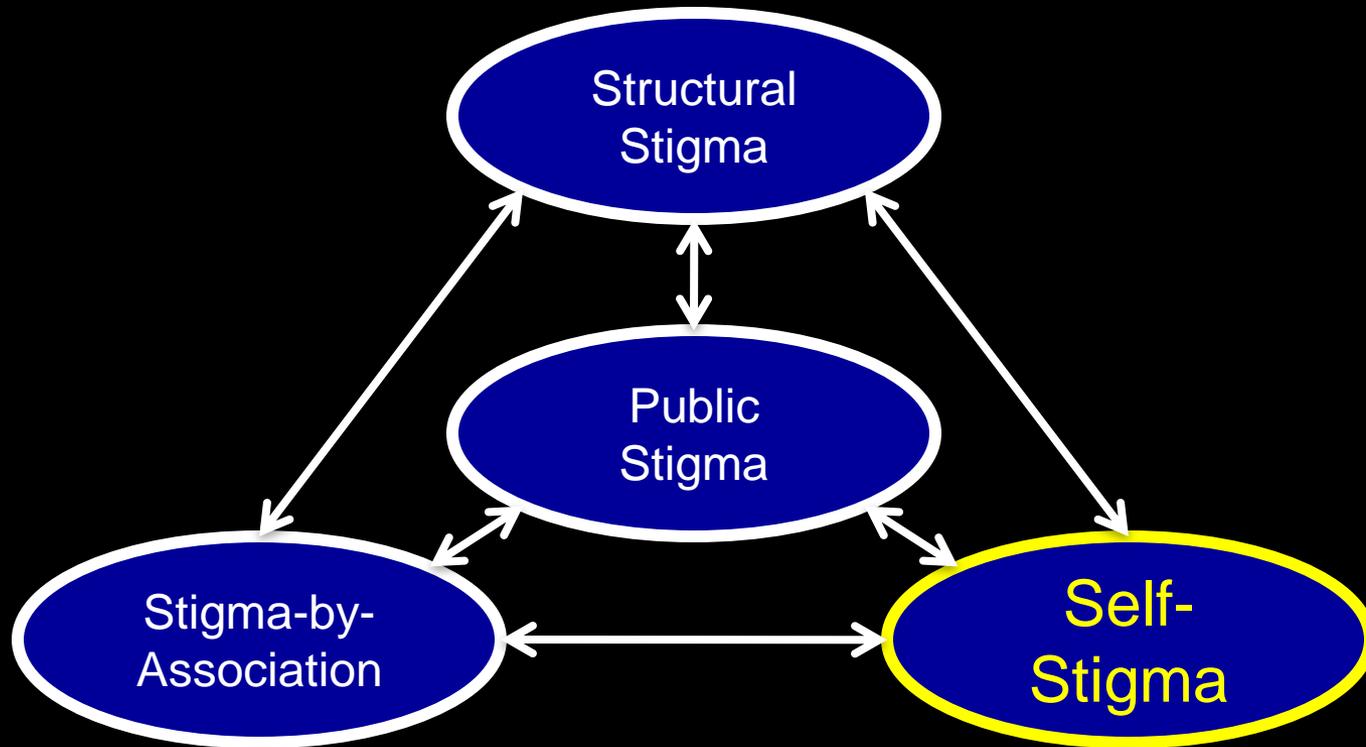
To reduce HIV/AIDS-related stigma within Latino communities through a portable *promotores (peer education) program designed to provide accurate and culturally appropriate HIV prevention and outreach information.*

# Overview of peer education (*promotores*) intervention components

- A group discussion of Latino cultural values that contribute to personal health.
- HIV 101- basic information about HIV and how it is transmitted and can be prevented.
- A discussion of sexuality in Latino culture.
- Common attitudes about homosexuality in Latino communities were explored.
- The concepts of public stigma (*externo* and *comunidad*) and self-stigma (*interno*) were explained. A story or *novelita* about a man whose neighbor was HIV+ was used to illustrate the process of coming to terms with one's own prejudices regarding PLWHA. Discussion following the story focused on stereotypes of PLWHA, how prejudice can impair prevention efforts, and how traditional Latino values can contribute to both prevention and care of PLWHA.
- The roles of Latino cultural values, knowledge of HIV/AIDS, and community leadership and support in overcoming stigma were discussed.

<b>Organization</b>	<b>The National Council of La Raza</b>
Anti-Stigma Focus	Public stigma
Target Audience	Selected Latino communities in California and Texas (N = 574)
Method	Peer education ( <i>promotores</i> ) programs
Evaluation	Quantitative: Pre/post assessment of public stigma in peer education sessions ( <i>charlas</i> )
Results	Improvements in knowledge, communication intentions, testing comfort, & comfort with PLWHA

# Evaluation Research of an Intervention Design to Reduce Self-Stigma





# THRIVE! Weekend

A program developed by  
the **AIDS SURVIVAL  
PROJECT**



Center on AIDS & Community Health

## PRIMARY OBJECTIVE

To reduce HIV/AIDS-related stigma among PLWHA as a barrier to prevention, care, and treatment in two rural areas of Georgia using a volunteer-based training run by and for those affected by and/or living with HIV/AIDS.

# Topics covered in THRIVE! Weekend workshops

- understanding HIV (basic information about HIV/AIDS)
- treatment strategies and options
- disclosure
- safer sex
- advocacy
- complementary therapies and nutrition
- oral health
- legal issues (rights and legal protections against discrimination)
- substance abuse (connections to HIV infection and treatment, also harm reduction concepts)
- disability benefits and social security
- meditation



<b>Organization</b>	<b>The AIDS Survival Project</b>
Anti-Stigma Focus	Self-stigma
Target Audience	PLWHA in rural & urban Georgia
Method	Weekend workshops led by teams of PWLHA, experts, and healthcare & social service providers
Evaluation	Quantitative: Pre/post assessment of self-stigma
Results	PLWHA felt less blame & shame following weekend workshops

# Some Common Sense steps in Conducting a Stigma Reduction Intervention

- 1) Identify the manifestations you want to target
- 2) Specify how you will measure stigma reduction
- 3) Identify some effective components of past interventions
- 4) Tailor intervention components to your audience
- 5) Evaluate your intervention's outcomes and be prepared to adjust your ongoing plan

# Components of Effective Interventions

- **Education** – just the facts...“HIV 101” ...still important in 2012 (for all manifestations)
- **Counseling** – one-on-one & support groups, helping people cope with HIV as a disease and as a stigma (self-stigma & stigma-by-association)
- **Coping skills acquisition** – Master imagery and group desensitization are two techniques for acquiring coping skills (public stigma)
- **Contact with PLWHA** – one-on-one, with a public speaker, or through media (public stigma)

# Take Home Messages of Today's Talk

1. Stigma is a multi-dimensional concept. Public stigma, self-stigma, stigma-by-association, and institutional stigma represent different, but inter-related manifestations of stigma.
2. While public stigma is theorized to be pivotal to the other manifestations of stigma more research is needed that examines the inter-relationships empirically.
3. Stigma reduction interventions should identify specific manifestations of stigma for potential change and include evaluation measures that are appropriate

# Help me to understand HIV-related stigma in Texas better

- Please help me recruit Texans living with HIV/AIDS (TLAs) to participate in a web-based survey about their experiences.
- Here is a link to the survey:  
<https://survey.lilt.ilstu.edu/TakeSurvey.aspx?SurveyID=l411np90>
- How you can help:
  - Post a link to this survey on the website of your organization
  - Distribute flyers to TLAs you encounter in your work
  - Post a notice about the survey in your office
  - Include information about the survey in your newsletter

THE END

Thanks, Gracias,

Merci, Dank je wel,

Danke, Shukran, Doh je,

Dhanyawaad, Mahalo