STIGMA TASK FORCE

January 18, 2018

Agenda

- Recap last focus group and Patient Care and Prevention Planning Group Meeting

- Ongoing SHARC/SWG research

- Future research and contract renewal

- Recommendations to be made for the Florida Department of Health

Recap of Stigma Task Force Focus Group 1

- Education (but who? How?)
- People-first language
- Videos or visual messages
- Changing laws that criminalize HIV
- Self-testing for HIV

Exploring HIV-Related Stigma in the Southern United States: A Qualitative Study

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INTRODUCTION

The Southern United States (U.S.) has the highest transmission rates of HIV with a rate of 16.1 per 100,000 people, as compared to 10.6 (Northeast), 9.4 (West), and 7.4 in the Midwest, respectively. While the U.S. is seeing an overall reduction in HIV cases, Florida and other Southern states (i.e., Georgia, Alabama, etc.) continue to see an increase. One possible explanation for this disparity may be due to HIV-related stigma. Studies suggest HIV-related stigma may significantly affect an individual's ability to achieve viral suppression, medication adherence, psychological and social support, mental health, and decreased quality of life. Florida is a complex state in terms of geography and population, thus our understanding of HIV-related stigma is not well understood across populations living with HIV in the state.

OBJECTIVES

1) Examine the perceptions of HIV-related stigma in the Southern U.S.
2) Identify approaches for reducing HIV-related stigma

METHODS

- An anonymous open-ended survey was developed and distributed to community members, community partners, and stakeholders in Florida and Georgia
- Participants were asked to define HIV-related stigma and to provide examples of:
  i. HIV-related stigma that they have seen or heard about
  ii. Methods they have seen or heard about to reduce HIV-related stigma
  iii. Recommendations based on what they perceive as the most important strategy to reduce HIV-related stigma
- Participants were also asked a series of multiple-choice questions to obtain demographic information
- Consistent with thematic analysis, data were coded and grouped into categories guided by the Social Ecological Model (SEM)
- Word clouds of responses were created using stemmed words on Nvivo 12

RESULTS

Figure 1a: Word cloud of the definition of HIV-related stigma

Figure 1b: Word cloud of the recommendations to reduce stigma

Figure 2a: Categories of HIV-related stigma examples grouped into levels of the SEM

| Individual	Interpersonal	Community	Institutional	Structural
• Fear • Lack of knowledge • Being perceived negatively	• Being treated differently by family or friends • Refusal of sharing food or utensils	• Social norms • Community enacted stigma • Discrimination	• Health-care related issues	• Criminalization • Healthcare barriers

Figure 2b: Categories of HIV-related stigma reduction methods grouped into levels of the SEM

Individual	Interpersonal	Community	Institutional	Structural
• Increasing knowledge	• Communication between family and friends	• Changing social norms • Peer-led groups and campaigns • Media	• Health services • providers	• Education curriculums • Updating policy • Using first-person language

RESULTS

DEMOGRAPHICS

Figure 3: Participant Demographics (n=66)

*Other indicates Asian (n=2), American Indian or Alaska Native (n=1), or multi-racial (n=5)
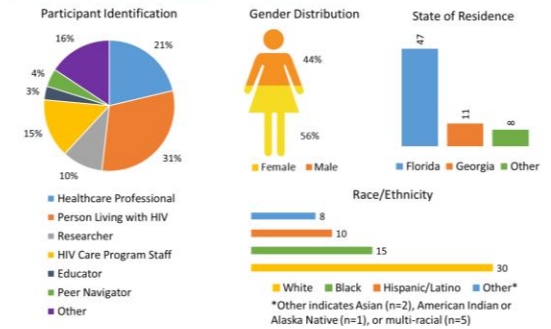
DISCUSSION

CONCLUSIONS

- To combat HIV-related stigma, we need stigma-reduction approaches that are informed by the communities in which stigma exists

- Stigma interventions may be needed to address all of the SEM levels

LIMITATIONS

- This study used a convenience sample and may not reflect the full diversity of the population in the Southern US

FUTURE DIRECTIONS

- We will be obtaining additional surveys and conducting additional analyses in the future
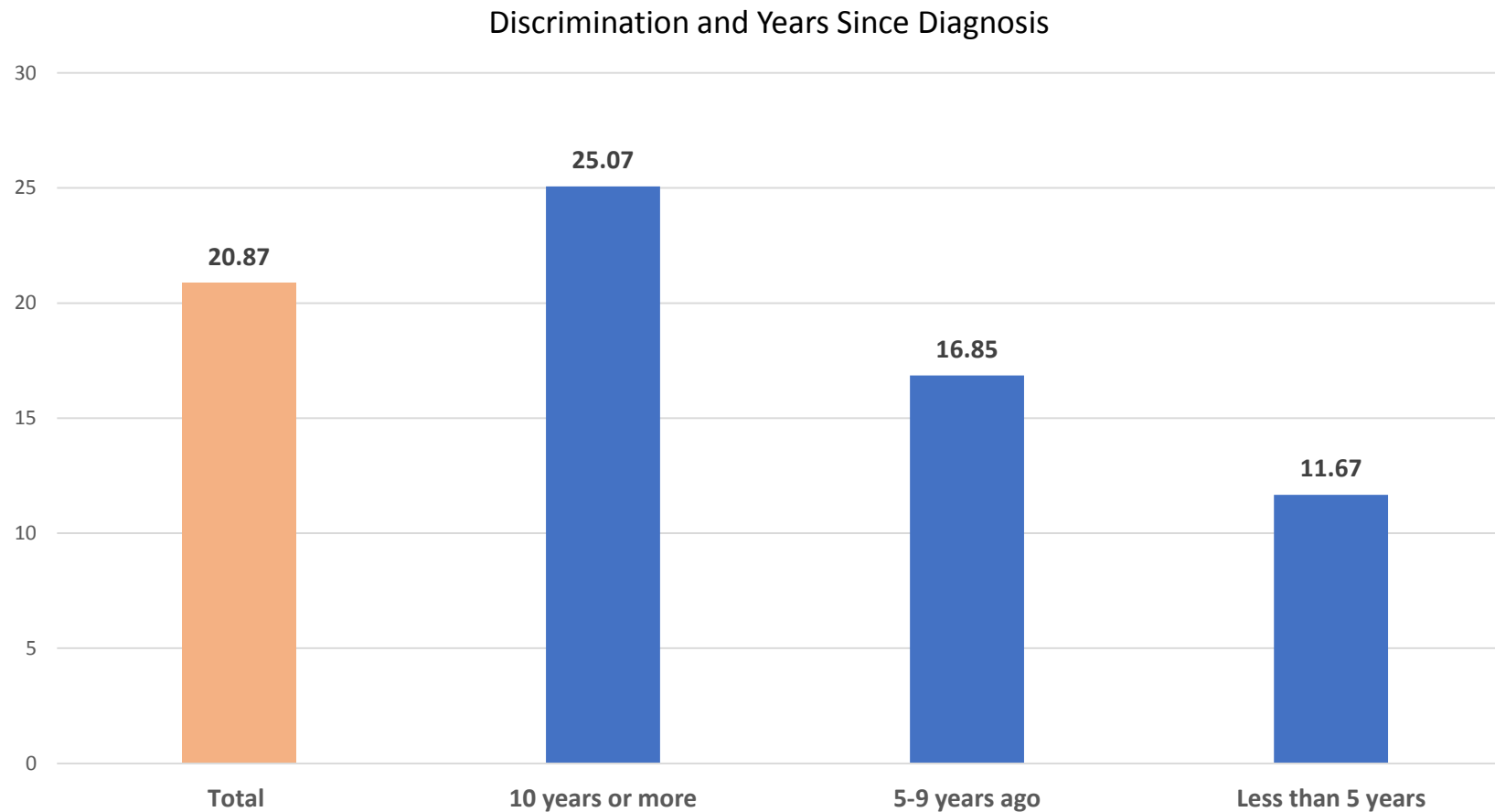
Contact

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Experiences of Provider Discrimination and Years Since Diagnosis

Discrimination and Years Since Diagnosis

Patient Care and Prevention Planning Group Meeting Tampa Fall 2018 Audience Participation

- What can we do to reduce HIV stigma?
  - Listen, educate, support, normalize
- Suggestions from audience
  - Public presentations by HIV +
  - Intersectional stigma
  - Mr. Friendly
  - Surveys at consortia meetings
  - Urban vs. Rural
  - Provider types
  - Change language (people first language)
  - Educate youth
  - Education and cultural competence training for providers

HIV Stigma Scale*: Background

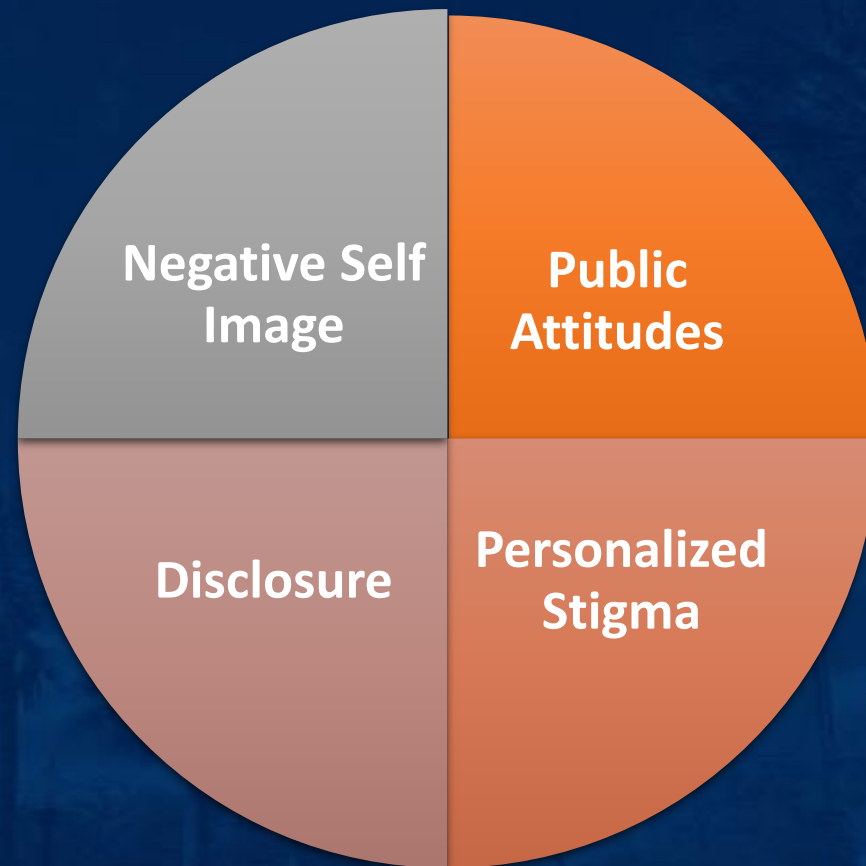**Measures perceived stigma in people living with HIV**

Shortened version of the 40-item HIV Stigma Scale was used in the MMP

Measures underlying dimensions of stigma (public attitudes, negative self image, disclosure, personalized stigma)

*Berger B, Ferrans C, et al. Measuring Stigma in people with HIV. Psychometric assessment of the HIV stigma scale Research in Nursing and Health 2001;24:518–529.

HIV Stigma Scale* Measures

- Personalized Stigma: consequences of other people knowing their status.
- Disclosure Concerns: keeping HIV status a secret or controlling who knows
- Negative Self Image: Feeling badly about oneself because of HIV status
- Public Attitudes: what people think about HIV status and fear of discrimination

*Berger B, Ferrans C, et al. Measuring Stigma in people with HIV. Psychometric assessment of the HIV stigma scale Research in Nursing and Health 2001;24:518–529.

| Stigma Questions	Subscale
1. I Am Very Careful Who I Tell That I Have HIV	Disclosure
2. I Worry That People Who Know I Have HIV Will Tell Others	
3. I Worry That People Who Know I Have HIV Will Tell Others Most People With HIV Are Rejected When Others Find Out	Public Attitudes
4. Most People Think That a Person w/ HIV is Disgusting	
5. I Have Been Hurt by How People Reacted to Learning I Have HIV	Personalized Stigma
6. I Have Stopped Socializing With Some People Because of Reactions to HIV Status	
7. I Have Lost Friends By Telling Them I Have HIV	
8. Having HIV Makes Me Feel Unclean	Negative Self-Image
9. I Feel That I'm Not as Good a Person as Others Because I Have HIV	
10. Having HIV Makes Me Feel That I'm a Bad Person	

Average Stigma Scores

- HIV Stigma Scale:
  - Scores ranged from (low stigma) 0 -100 (high stigma)
- Sample:
  - 603 Participants
  - Maximum Score: 100
  - Minimum Score: 0
  - Average Score: 42.0
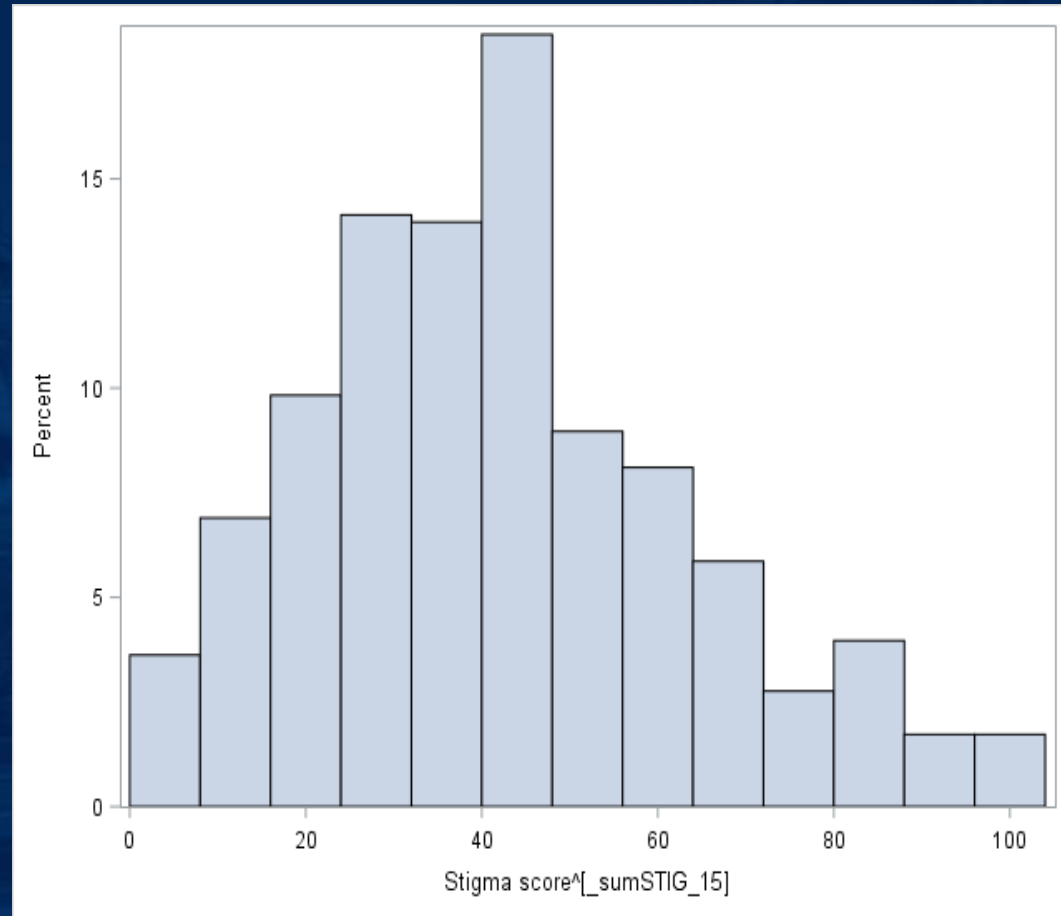
Average Stigma Scores by Top 9 Priority Populations
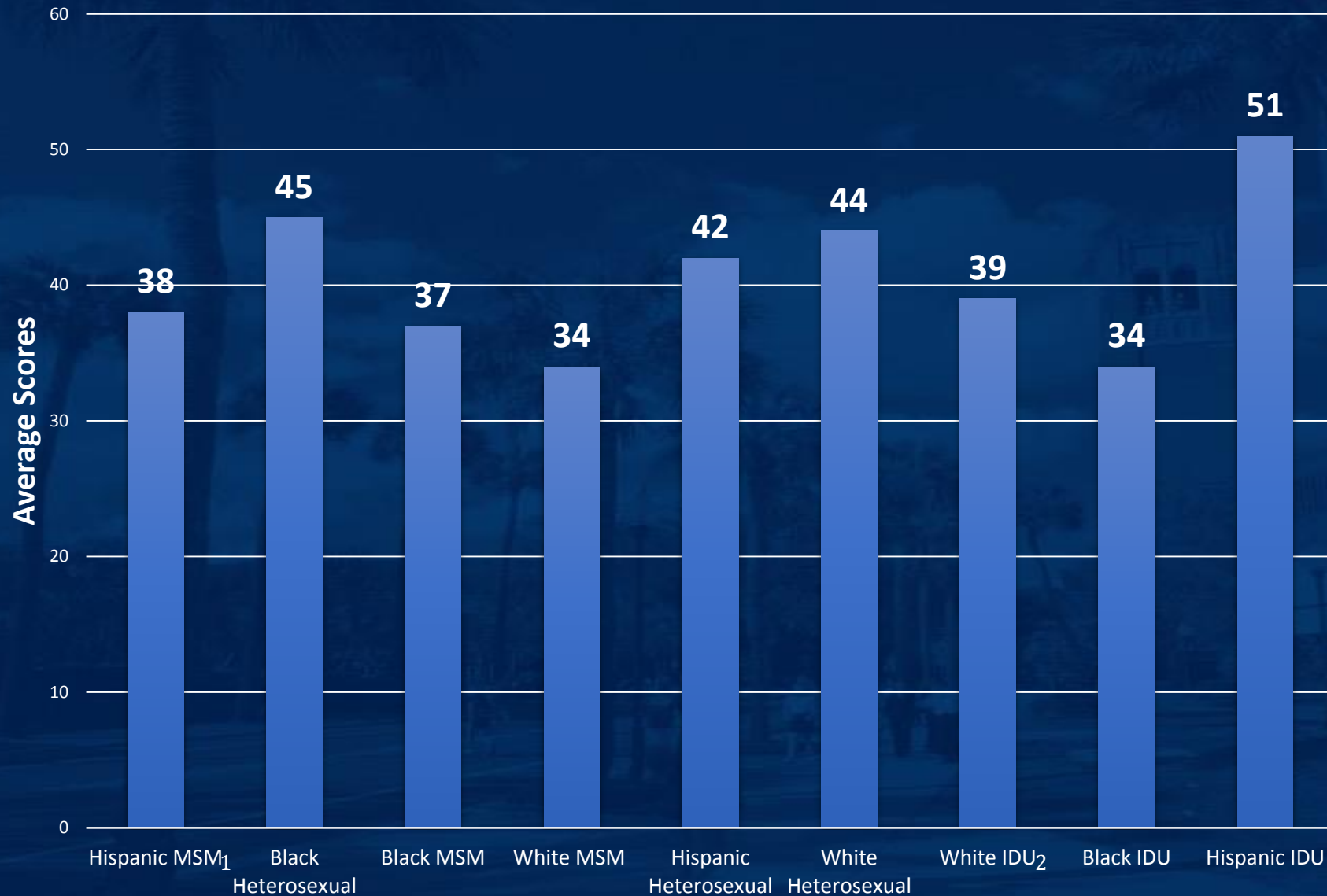
Men who have sex with men[1]

Injection drug user[2]

Proportion of Respondents who selected "Neutral", "Somewhat agree", or "Strongly agree" to each item (N= 603)

Item	Percentage
I Am Very Careful Who I Tell That I Have HIV (n= 535)	90
Most People With HIV Are Rejected When Others Find Out (n= 428)	73
I Worry That People Who Know I Have HIV Will Tell Others (n= 403)	67
Most People Think That a Person w/ HIV is Disgusting (n= 319)	55
I Have Been Hurt by How People Reacted to Learning I Have HIV (n= 316)	52
I Have Stopped Socializing With Some People Because of Reactions to HIV Status (n= 228)	36
I Have Lost Friends By Telling Them I Have HIV (n= 197)	31
Having HIV Makes Me Feel Unclean (n= 131)	22
I Feel That I'm Not as Good a Person as Others Because I Have HIV (n= 127)	21
Having HIV Makes Me Feel That I'm a Bad Person (n= 59)	10

Percentage