HIV Stigma Reduction in Florida
Update from the SHARC Stigma Working Group
HIV Care and Prevention Planning Meeting
Tampa, May 2019
Christa Cook, PhD, MSN, RN
Robert L. Cook, MD, MPH
AGENDA

- Overview of Stigma Working Group
- Early analyses from MMP 2015/2016
  - Proportion of persons with different types of stigma
  - Proportion of persons with experiences of discrimination
- Year 1 final recommendations to FDOH
- Audience participation - Menti.com
State of Florida Stigma Reduction

**State Stigma Reduction Planning Committee**

- Members of State Stigma Task Force, SHARC, and the Florida Department of Health HIV/AIDS Section

**State Stigma Task Force**

- People living with HIV, community members, researchers, public health, organizations
Mission of Stigma Working Group

- Engage community members, researchers, and Department of Health representatives to identify sources of HIV related stigma and create strategies to decrease stigma in Florida.
Stigma Reduction Framework

Assessment
- Stigma Taskforce
- Survey
- MMP Analysis

Prioritization
- Populations
- Level of intervention (Individual, Community, Policy)
- Types of Stigma

Specific interventions to reduce stigma in Florida

2018

2019

Future
Renessa Williams, BSN, PhD Student, College of Nursing

- **Aim 1**: Determine the prevalence of stigma among adults living with HIV in Florida
- **Aim 2**: Compare the prevalence of community, anticipated, enacted, and negative self-image stigma among PLWH in Florida
- **Aim 3**: Describe which socio-demographic groups have the greatest burden of stigma
MMP 2015

- Included 10-item HIV stigma scale
- 4 types of stigma
- Asked about experiences of discrimination
## Disclosure Related Stigma (anticipated)

| Concerns or fear about telling others about HIV status | • I worry that people who know I have HIV will tell others  
• I am very careful who I tell that I have HIV |

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Public Attitudes Stigma (community)

| What the general public thinks about HIV and people living with HIV | • Most people think that a person with HIV is disgusting  
• Most people with HIV are rejected when others find out |

- Most people think that a person with HIV is disgusting
- Most people with HIV are rejected when others find out
## Personalized Stigma (enacted)

| Consequences of others knowing HIV status | • I have lost friends by telling them I have HIV  
• I have stopped socializing with some people because of reactions to my HIV  
• I have been hurt by reactions to learning I have HIV |

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**Personalized Stigma**

- I have lost friends by telling them I have HIV
- I have stopped socializing with some people because of reactions to my HIV
- I have been hurt by reactions to learning I have HIV
## Negative Self-Image (personalized)

| Feelings of being bad, dirty, shame, guilt related to HIV status | • Having HIV makes me feel that I am unclean  
• Having HIV makes me feel that I am a bad person  
• I feel that I am not as good a person as others because I have HIV |

Proportion of People with Stigma and Stigma Subtypes
Florida MMP 2015/2016

Agree to Stigma (weighted%) *

- Negative Self-Image: 24%
- Personalized Stigma: 49%
- Public Attitudes: 69%
- Disclosure Concerns: 87%
- Overall Stigma: 94%

*Respondents who agreed to any stigma statement within each subscale.
Agree responses include proportion of respondents who selected “strongly agree,” or “somewhat agree”
HIV Stigma Subscale Weighted Proportions by Race

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Multiracial (n=16)</th>
<th>Hispanic (n=130)</th>
<th>Black (n=299)</th>
<th>White (n=155)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative Self-Image</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Personalized Stigma</td>
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<tr>
<td>Disclosure Concerns</td>
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<tr>
<td>Public Attitudes</td>
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</tbody>
</table>
HIV Stigma Subscales Weighted Proportions by Age

**Negative Self-Image**
- 50+ (n=321)
- 30-50 (n=244)
- 18-30 (n=38)

**Personalized Stigma**
- 50+ (n=321)
- 30-50 (n=244)
- 18-30 (n=38)

**Disclosure Concerns**
- 50+ (n=321)
- 30-50 (n=244)
- 18-30 (n=38)

**Public Attitudes**
- 50+ (n=321)
- 30-50 (n=244)
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HIV Stigma Subscales Weighted Proportions by Gender

- Negative Self-Image
- Personalized Stigma
- Disclosure Concerns
- Public Attitudes

Female (n=216)  Male (n=387)
Experiences of Discrimination among PLWHA

- Describe experiences of health care provider discrimination from people living with HIV
- Determine how experiences of provider discrimination and types of stigma have varied by years since HIV diagnosis.
- Florida MMP Data 2015-2016
Percentage of PLWH with Discrimination Experiences:  MMP 2011-2014 (n=1720)

- Any type of discrimination: 20.60%
- Refused service: 6.00%
- Gave you less attention: 13.40%
- Exhibited Hostility/Lack of Respect: 18.20%
Percentage Reporting Discrimination and Stigma Subtype by Years Since Diagnosis MMP 2015/2016

- Disclosure related stigma
- Public attitude stigma
- Personalized stigma
- Negative self-image related stigma
- Discrimination from providers

<table>
<thead>
<tr>
<th>Years Since Diagnosis</th>
<th>Disclosure related stigma</th>
<th>Public attitude stigma</th>
<th>Personalized stigma</th>
<th>Negative self-image related stigma</th>
<th>Discrimination from providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥10 years</td>
<td>88</td>
<td>69.3</td>
<td>42.9</td>
<td>29</td>
<td>23.4</td>
</tr>
<tr>
<td>6-10 years</td>
<td>86.9</td>
<td>68</td>
<td>49.7</td>
<td>24.3</td>
<td>16.9</td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>91</td>
<td>83.2</td>
<td>42.9</td>
<td>27.4</td>
<td>9.8</td>
</tr>
</tbody>
</table>
Audience Question

Why do you think there is an increase in public attitudes related stigma among those diagnosed in past five years?

Go to Menti.com and use the code 96 25 37
What should Florida DOH do to help reduce HIV in Florida?
To create final recommendations,

- Incorporated ideas and suggestions from:
  - Stigma Task Force (phone discussions)
  - meetings with FDOH team
  - MMP data analyses
  - expert consultation (individuals and other states)
  - open-ended surveys
  - scientific literature.
Final Report Recommendations

1. Expand target audiences and potential reach of DOH messaging to address HIV-related stigma and misconceptions about HIV.
Final Report Recommendations

1. Expand target audiences and potential reach of DOH messaging to address HIV-related stigma and misconceptions about HIV.
   - Ensure that social media is extended to general population as well as high-risk groups
   - Use PLWH within messaging to present a positive image and success stories
   - Ensure people-first language in all communications
Final Report Recommendations

2. Expand HIV-related stigma surveillance to under-represented populations.
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   - Identify optimal “measures” of stigma to monitor changes over time
   - Conduct supplemental data collection among priority populations who are under-represented by the MMP survey
3. Create a publicly-available repository of existing information from DOH and local agencies related to stigma
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- Create a website that includes DOH information related to stigma, as well as other documents from local communities or agencies (e.g. Ryan White needs assessments, community assessments or focus groups).
Final Report Recommendations

4. Implement structural changes to reduce the risk or perceived risk of accidental disclosure in settings providing HIV-related healthcare or services.
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- Ensure availability of more discrete locations for receiving HIV services (e.g. not an obvious “HIV clinic”)
- Continue to expand access to HIV care and prevention services that are more anonymous, e.g. telemedicine, mail-order pharmacy, home HIV testing
5. Develop new trainings related to HIV-related stigma (including stigma related to PrEP and HIV testing) for all healthcare workers and staff who encounter PLWH.
Final Report Recommendations

5. Develop new trainings related to HIV-related stigma (including stigma related to PrEP and HIV testing) for all healthcare workers and staff who encounter PLWH.

- Training could address stigmatizing language and examples of stigmatizing behavior
- Training could be incorporated into other required HIV training for healthcare providers
Final Report Recommendations

6. Continue to explore the role of religion and religious organizations in contributing to HIV-related stigma, and also that help to reduce HIV-related stigma.
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- Develop messages appropriate to be distributed in church settings, and provide examples of positive messages provided by churches and religious organizations as examples.

- Consider how to address religious leaders more broadly, especially those who serve higher-risk populations, and identify religious leaders willing to help work towards HIV stigma reduction in Florida.
Go to Menti.com and use the code 96 25 37

Rank the interventions we just discussed. Let us know what you think is most important to begin with to address stigma in Florida.

1. Evaluate and expand HIV messaging
2. More stigma assessment in under-represented populations
3. Create more access to existing stigma information
4. Structural changes to reduce perceived risk of disclosure
5. New trainings related to stigma for healthcare workers
6. Explore how religious organizations can help address stigma
AUDIENCE QUESTION?
Prioritization of Recommendations

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Next Steps – 2019-2020

- Collect new data
  - Stigma examples survey (ongoing)
  - Ryan White Needs Assessment – question added
- Prioritization of populations and interventions
  - Stigma task force calls
  - Continued input from community stakeholders
- Complete several new analyses and manuscripts
  - Stigma and HIV viral suppression
  - Stigma and disability
  - Improving measurement
  - PrEP-related stigma
Thank you

- Southern HIV Alcohol Research Consortium (Dr. Robert Cook)
- Florida Department of Health HIV/AIDS section
- State Stigma Planning Committee
- State Stigma Taskforce
- Community
Got Ideas?

Meet us at happy hour after the conference today in the bar area.
What is important for us to know moving forward?

Go to Menti.com and use the code 96 25 37.