

# Measuring and Addressing Stigma in Health Care Settings: Panel

Leslie Pierce Alison Kliegman

### Planning and Implementation of Staff Survey

- Survey was tailored to be Housing Works specific and questions were reformatted for Survey Monkey and reviewed by the Executive Team
- Staff survey was administered to all Housing Works employees and volunteers, including:
  - Primary Care, Psychiatric and Dental Providers
  - Clinic Support Staff
  - Case Management Departments
  - Harm Reduction Programs
  - Administrative Departments
  - Advocacy Department
  - Bookstore Café and Thrift Stores
- Email (and reminder) to all staff and volunteers was sent by Charles King, CEO



#### Planning and Implementation of Consumer Survey

- Consumer Survey was developed using selection of questions from the Employee Stigma Survey and was reviewed by the Executive Team
- Select clients piloted the survey and staff assisted with translation into Spanish
- Consumer feedback was solicited through surveys collected via paper and tablet to:
  - Patients in the waiting room
  - OASAS Community Meeting
  - AADHC Community Meeting
- Paper surveys were entered into Survey Monkey
- Included both HIV+ and HIV- Clients



## **Initial Results: Staff**

- 296 Employees and Volunteers across all disciplines completed the staff survey
  - •Health Home (19%), Bookstore and Thrifts (16%) & Clinic (10%) staff were top three departments participants
  - The number of skipped questions increased as the survey continued
  - An average of 13 minutes was spent completing the survey
  - Many staff members commented importance of assessing stigma in the workplace
- Results will be downloaded from Survey Monkey and analyzed by the Quality Improvement team



### **Initial Results: Consumer**

- 204 Consumer Surveys were collected
  - Majority of participants were HIV+ (65%)
  - Most consumers were willing to complete the survey
  - Survey took an average of 6 minutes to complete
  - In general, preliminary results are overwhelmingly positive
- Results will be downloaded from Survey Monkey and analyzed by the Quality Improvement team
- Short-term Stigma Committee will be formed to review all results and develop stigma reduction quality plan



Measuring and Addressing Stigma in Healthcare Settings:
Hudson River HealthCare
QAC, September 2017



## Organizational and Leadership Approach



- Step 1: HIV Program Leadership to review the AIDS Institute's Stigma Reduction Project guidelines.
- Step 2: Obtain medical leadership support of the Stigma Reduction Project.
  - Conduct a presentation to the Clinical Quality Committee to discuss stigma and our response by (Dr. Kerr).
  - Conduct presentations to the medical directors at each of the sites (Dr. Kerr, Dr. Khan).
- Step 3: Identify Stigma Champions at each site to act as a resource and point person for the site (Dr. Kerr, L. Reid).
- Step 4: Build support for the Stigma Reduction Project by meeting with key stakeholders (L. Reid).
  - Discuss project with the Chief of Patient Experience (L. Reid).
  - Discuss project with the Vice President of Quality (L. Reid).
  - Discuss project with the LGBTQ task force (M. Mezzatesta).

## Planning for Staff Survey



- How was the survey administered to staff members?
  - Piloted with in-person questionnaire
    - Concerns about confidentiality (handwriting, etc.)
  - Developed Survey Planet questionnaire
    - Emailed to all staff at sites
    - Team members reminded, leadership reminded
    - Response rates high congratulatory emails and pizza party sent to sites with highest response rate



The Health Policy Project's tool "Measuring HIV Stigma and Discrimination Among Health Facility Staff: Comprehensive Questionnaire" was developed and field tested in China, Dominica, Egypt, Kenya, Puerto Rico, St. Christopher & Nevis. This tool was created to be a brief, globally standardized questionnaire for measuring HIV-related stigma and discrimination in healthcare practice sites as well as a tool to be used in the creation and improvement of stigma reduction programming at the healthcare practice site-level.

The NYSDOH AIDS Institute Stigma Sub-Committee adapted the Health Policy Project "Measuring HIV Stigma and Discrimination Among Health Facility Staff: Comprehensive Questionnaire" for practice sites in NYS to administer to staff. The survey contains questions on healthcare practice site-level and personal-level HIV- related stigma with an additional section on key population-related stigma consisting of people of transgender/gender non-conforming experience, women, men who have sex with men (MSM)/men who identify as gay or bisexual, people of color, and people living with a mental health diagnosis. This survey will take 15-20 minutes to complete.

Your participation in this survey is voluntary and to ensure confidentiality, your name will not be on the survey. Please write or select the answer, as appropriate, that best represents what you think or feel. Your responses will have no adverse effect on your occupational standing.



- Consumer stigma survey compiled in SurveyPlanet adaptation of staff survey and performed during case management visits
- Elicit input from consumers regarding stigma experienced within HRHCare and how they can be involved in stigma reduction programming.
  - Regional focus groups led by Champions at each site, consumers informed and reminded by case managers, adherence nurses, and peers.
  - Conduct a focus group at the Hudson Valley Consumer Advisory Committee and the Suffolk Consumer Advisory Committee (Advisory co-chairs, L. Reid, M. Mezzatesta).
  - Recruit consumers to join the Stigma Reduction Task Force (Genesis staff).
  - Revise the Health Policy Project's tool *Measuring HIV Stigma and Discrimination Among Health Facility staff: Comprehensive Questionnaire* to administer to consumers (Genesis Leadership Team).
  - Meet individually with consumers to discuss the purpose of the stigma reduction project and have consumers complete surveys (case managers, adherence nurses, peers).

## Initial Results



- 181 Suffolk Surveys, 79 HV Surveys completed
- Feedback from teams and staff:
  - Would have been helpful to have access to survey monkey-type site on statewide basis as well as consumer questionnaire.
  - Language and questions tricky for varied literacy levels
    - "Like taking the SATs"
  - A lot of resistance to paper copies not felt to be anonymous.
  - Most confusion around questions of transgender stigma
    - "not sure what this question means," "not sure how to answer."
  - "We already know this."
  - Decent response rate from e-survey, but depends on organizational/leadership support.

## Initial Results Hudson Valley



- Hudson Valley Consumer Feedback (14 participants):
  - Preliminary results have indicated patient satisfaction with services: welcoming environment, literature, posters, etc. with sensitive staff.
  - One hearing impaired individual requested the survey include evaluation of services for the hearing impaired as he has difficulty getting interpreters from outside agency. He would like HRHCare to have an interpreter on staff rather than contracting services.
  - Consumer Advisory Committee is scheduled to review staff survey data at the September 20, 2017 meeting.
- Staff survey preliminary results:
  - Education needed regarding HIV and child bearing.
  - Staff meeting presentation provided good discussion regarding ways to enhance services and environment.
  - High accountability for survey completion; however, PlanetSurvey completed survey tabulation.

## Consumer Feedback (preliminary)

HRHCar

- Initial results presented at Suffolk Cty CAB and survey taken by 10 CAB members
- Response to survey:
  - Consumers would have preferred for the survey to be conducted face to face so that they could get valuable information from non-verbal responses
  - There was a consensus that the questions were not worded well and could have been more specific.
  - Some felt that the questions themselves do not take variables into account.

#### Responses to results:

- While all felt that the staff were kind and professional, they felt that some of the questions suggest that staff have hidden judgement.
- The consumers were impressed with the fact that the majority of the staff are both female and persons of color.
- They were uncomfortable with "Opinions about People Living with HIV" section. They struggled with the
  question "PLWHIV/AIDS have many sexual partners". One participant contracted HIV through a sexual
  assault and two from unfaithful partners.
- Some felt that the staff would have answered the questions differently if they themselves were HIV +.
- The consumers unanimously felt that question "HIV is punishment for bad behavior" should have been answered with "strongly disagree". They were uncomfortable with the staff who just "disagreed".

#### Suggestions for improvement:

- The consumers struggled with the term "gender non-conforming". They requested more training on transgender issues and language.
- One staff member had mentioned the need for babysitting services and this was wildly supported by the consumers.

## Consumer Feedback (preliminary)



- Overall the consumers were pleased with the results of the survey.
   They felt that the survey reinforced their experience at HRHCare; of being a welcoming, safe and supporting environment.
- But, due to survey responses, they felt that some staff had inner judgements about people with HIV/AIDS and they felt that trainings and deeper conversations with consumers to "hear their story" would help to create change.
- Five of the ten consumers would be willing to speak with staff in some type of follow-up session and share their HIV story.

# Measuring and Addressing Stigma in Healthcare Settings: Panel

Open Door Family Medical Centers

Karen Mandel, LMSW
Director of Care Coordination Programs



## Planning for Staff Survey

- How will the survey be administered to staff members?
  - Staff at the facilities where HIV medical care is provided
  - All of the staff who work on the medical units where the HIV medical specialists work
  - Staff members of the medical units with whom patients living with HIV may interact (e.g. lab, call center)
  - Digital administration using iPads and online (sent via email)



## Planning for Staff Survey

- How will the results be aggregated/ analyzed?
  - By site
  - By job function



- How will consumer feedback be solicited?
  - Survey is being created based on select questions from the provider survey
    - For staff:

2. In the past 12 months, how often have you observed the following in your healthcare practice site?					
	Never	Once or Twice	Several Times	Most of the time	
a. Other healthcare workers providing poorer quality of care to a MSM/men who identify as gay or bisexual than to other patients.					
b. Other healthcare workers talking badly about MSM/men who identify as gay or bisexual (ex. making negative comments, speaking harshly to or about, using derogatory language).					

• For consumers:

In the past 12 months, how often have you experienced the following at Open Door?						
Never	Once	Several	Most of			
	or	Times	the			
	Twice		Time			
		Never Once or	Never Once Several or Times			



- How will consumer feedback be solicited?
  - Spanish translation with the survey being administered in a bilingual (English/Spanish) format
  - Digital administration using iPads in medical exam rooms or private offices
  - Follow-up conversation with support group participants for additional clarity/details



- How will the results be aggregated?
  - By site
  - By gender identity
  - By sexual orientation



## Organizational and Leadership Approach

- How was the organization and leadership involved in this process?
  - The Senior Director of Care Coordination and Wellness and the Director of Coordination Programs were involved in the planning process alongside Open Door's HIV QI Team



### **Current Status**

- The most significant challenge to-date is choosing the digital survey platform to use for the survey administration (cost vs. features)
- Immediate next steps:
  - Complete consumer survey modification and Spanish translation
  - Final selection of digital survey platform followed by upload of both provider and consumer survey versions
  - Simultaneous survey administration to providers and consumers



## **Contact Information**

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# Measuring and Addressing Stigma in Healthcare Settings: Panel

Institute for Advanced Medicine
Amy Newton, MPH
HIV Quality Improvement Manager



#### **Planning for Staff Survey**

- Survey was administered across all five of IAM's HIV practices
  - Distributed to all IAM staff (300 in total) including medical providers, nursing, behavioral health providers, social work, administration, grant programs, and front desk staff
  - Administered via email through the online survey platform, SurveyMonkey
- Survey results were collected and aggregated in SurveyMonkey
  - Aggregate survey results were extracted to Excel/R for analysis
  - Cross-tabulations between types of healthcare workers and practice sites

- Solicited consumer feedback through all four Consumer Advisory Boards (CABs)
  - Educated CABs on HIV-related stigma, types of stigma, and impact on health
  - Open discussion about stigma experienced or observed and ways to reduce stigma at IAM clinics
  - Administered consumer survey to CAB members (adapted from the NYSDOH AIDS Institute questionnaire as well as the FRESH Study)
- Survey responses were inputted into SurveyMonkey for analysis

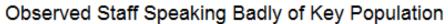
#### **Organizational and Leadership Approach**

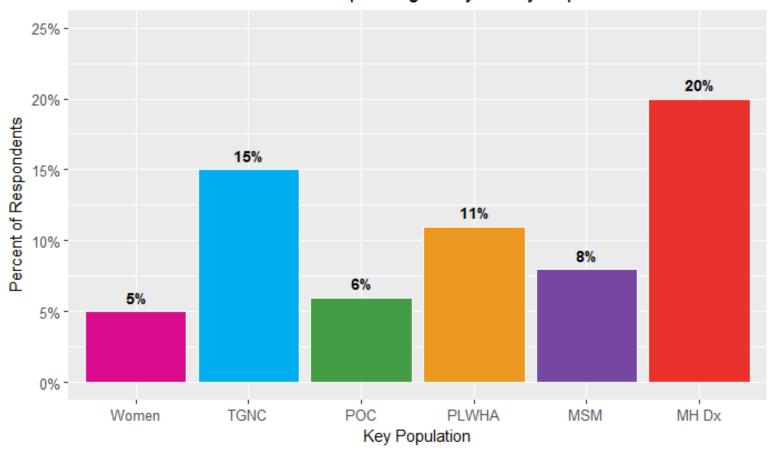
- Stigma initiative was announced at the IAM CQI Committee in July
  - Attended by multidisciplinary leadership staff across IAM
- Coordination with leaders of CABs
- Results and action plan will be reviewed by senior leadership and shared with all staff in October

#### **Initial Results & Major Findings**

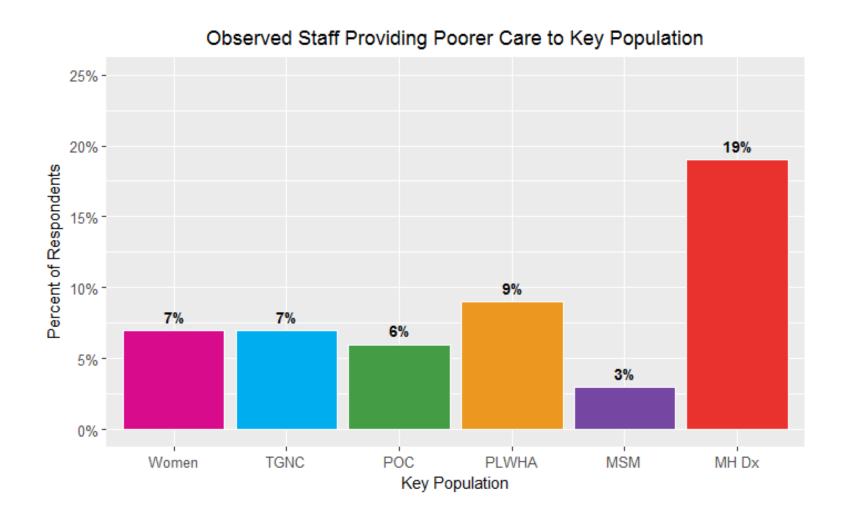
- Collected 200 healthcare worker surveys (66% response rate)
- Met with 3 CABs so far and collected 19 consumer surveys
- Gaps in stigma training for healthcare workers
  - 32% have not received training on HIV stigma and discrimination
  - 30% have not received training on key population stigma and discrimination
- Need for written guidelines & policies against discrimination
  - 19% reported not having written guidelines to protect PLWH from discrimination
- Negative opinions about PLWH
  - 20% agreed that most people living with HIV had many sexual partners
  - 24% agreed that people get infected with HIV because they engage in irresponsible behavior

#### **Observed Stigma for PLWHA & Key Populations**



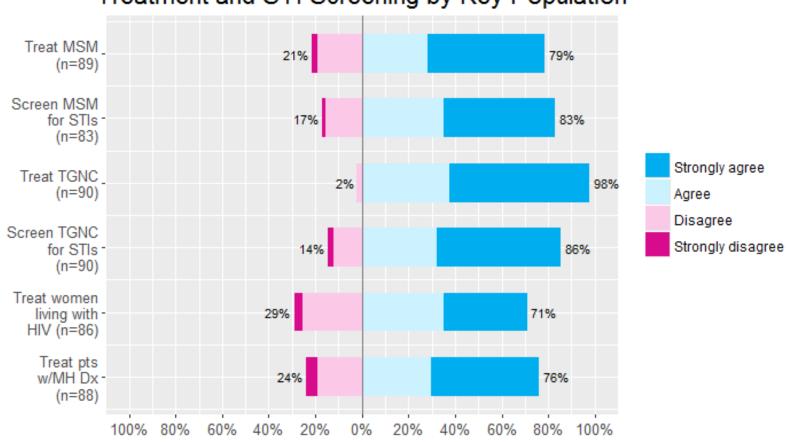


#### **Observed Stigma for PLWHA & Key Populations**



#### **Trainings for Treatment & STI Screening**

#### Trainings Received by Providers in Past 12 Mo. for Treatment and STI Screening by Key Population



### Acknowledgements

- Shruti Ramachandran, Director of Quality Management and Evaluation
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- Consumer Advisory Board Members & Leaders