

# From Rhetoric to Implementation: Stigma Reduction in New York City Utilizing Implementation Science and Structural Approaches

Prevention Science and Methodology Group  
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*Envisioning a New York City without transmission or illness related to viral hepatitis, HIV, and sexually transmitted infections.*

# Outline

- NYC HIV epidemic inequities drive an explicit focus on stigma
- HIV and intersectional stigma
- HIV and intersectional stigma monitoring in NYC
- 3 examples of innovative stigma monitoring-related activities in NY
- Stigma and Resilience (STAR) Project

An aerial view of the New York City skyline, including the Freedom Tower, with a blue-to-purple gradient overlay.

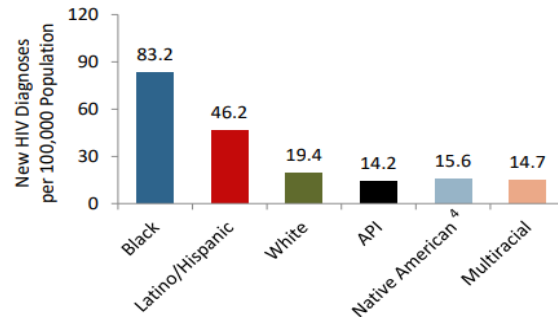
# **NYC HIV EPIDEMIC INEQUITIES DRIVE AN EXPLICIT FOCUS ON STIGMA**

# Large HIV Epidemic, Large Disparities

- NYC has made great strides in reducing new HIV diagnoses, but it remains the largest epidemic in the US
  - Approximately 84,700, ~13% of US population with HIV
- Inequities drive large disparities for certain subpopulations
  - E.g., Racial/ethnic disparities in new HIV diagnoses\*

## HIV Among Men

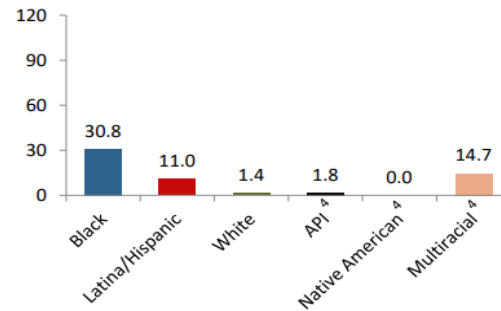
Figure 5.1: HIV<sup>1</sup> diagnosis rates<sup>2</sup> among 13- to 59-year-old men<sup>3</sup> by race/ethnicity, NYC 2020



In 2020, the HIV diagnosis rate among Black men was 1.8 times higher than the rate among Latino/Hispanic men, more than four times higher than the rate among White men, and more than five times higher than the rates among API, Native American and multiracial men.

## HIV Among Women

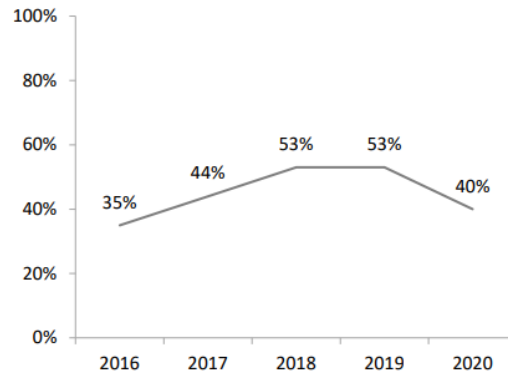
Figure 6.1: HIV<sup>1</sup> diagnosis rates<sup>2</sup> among 13- to 59-year-old women<sup>3</sup> by race/ethnicity, NYC 2020



In 2020, the HIV diagnosis rate among Black women was more than two times higher than the rates among Latina/Hispanic and multiracial women, 22 times higher than the rate among White women, and more than 17 times higher than the rates among API women.

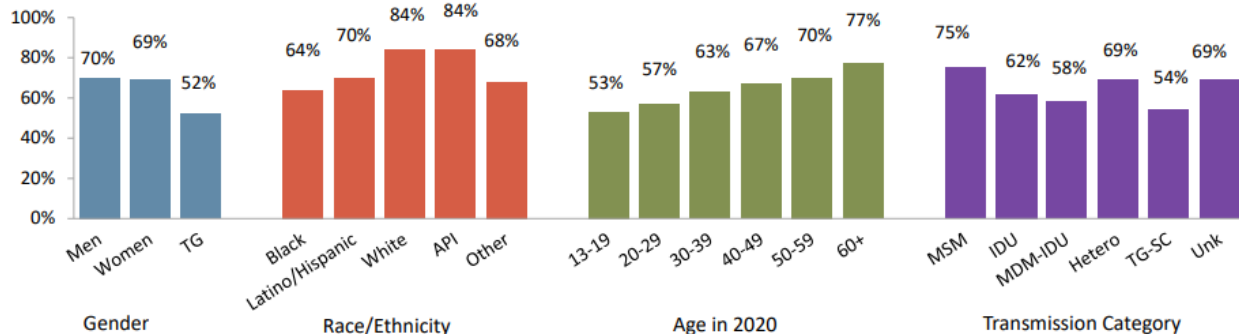


Figure 14.2: Viral suppression<sup>3</sup> within three months among newly diagnosed people, NYC 2016-2020<sup>2</sup>



- **COVID-19 resulted in some lost progress**
  - E.g., Timely viral suppression went from 53% in 2019 to 40% in 2020\*

Figure 15.4: Sustained viral suppression<sup>3</sup> among people established in HIV medical care<sup>4</sup>, NYC 2020



- **Disparities are high for clinical outcomes**
  - E.g., Sustained viral suppression

API=Asian/Pacific Islander; MSM=Men who have sex with men; IDU=Injection drug use history; TG-SC=Transgender people with sexual contact; Unk=Unknown.

<sup>1</sup>Last HIV viral load (VL) value in 2020 was <200 copies/mL.

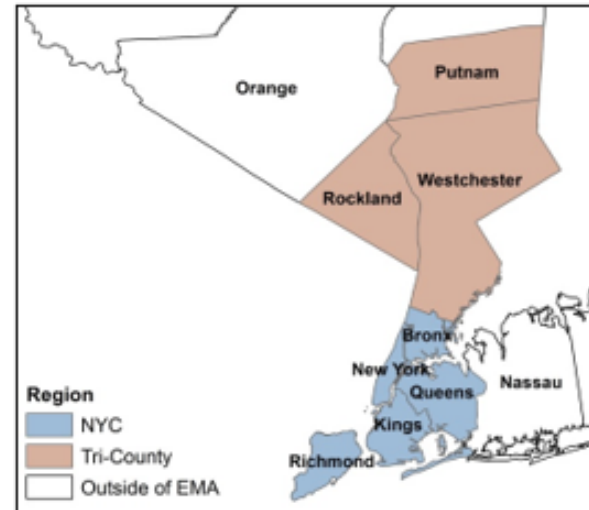
<sup>2</sup>At least one HIV VL/CD4 in 2020; includes those ages 13 and older.

<sup>3</sup>At least two VL tests ≥14 months apart and all VLs <200 copies/mL in 2019 and 2020.

<sup>4</sup>At least two VL tests in 2019 and 2020; includes those ages 13 and older.

# Ryan White Part A Funding at NYC Health Department (HD)

- Ryan White legislation enables payor of last resort funding for HIV services
  - E.g., food and nutrition, housing, mental health, legal, etc.
- NY Eligible Metropolitan Area (EMA) is funded at ~93 million
  - Covers NYC and Tri-County (Rockland, Putnam, Westchester)
  - 88 funded agencies; 12,462 clients; 461,835 services in 2021
  - PWH in NY Ryan White EMA:
    - 72% men, 76% Black or Latino, 69% >45 years
    - 63% on Medicaid vs 33% general population
- Legislation mandates community planning to direct how to spend money (Planning Council)



# Integrating Stigma Within NYC Ending the HIV Epidemic (EHE) Plan

- 4 main EHE strategies: Prevent, Treat, Respond, Diagnose
- In response to persistent inequities, 2021 NYC EHE Plan:
  - Added a 5<sup>th</sup> strategy focused on stigma
  - Included key activities for stigma and priority populations

Strategy 5: In all NYC EHE strategies, utilize an intersectional, strengths-based, anti-stigma, and community-driven approach to mitigate racism, sexism, homophobia, transphobia, and other systems of oppression that create and exacerbate HIV-related health inequities



# HIV AND INTERSECTIONAL STIGMA



# What is Stigma?

## It's a Dynamic Social Process



Stigma is 4 components within the context of a **power imbalance**:

1. People distinguish and label human differences

**“That person has HIV”**

2. Dominant cultural beliefs link labeled individuals to undesirable characteristics creating negative stereotypes

**“People with HIV are promiscuous, irresponsible, dangerous”**

3. Labeled individuals are placed in categories in order to separate “us” from “them”

**“I stay away from people with HIV; They should be separate from the rest of us”**

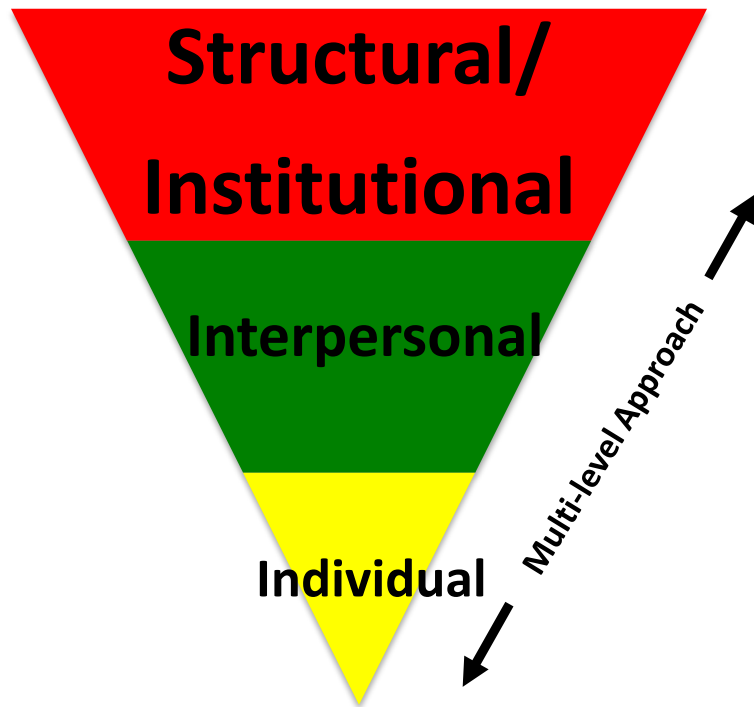
4. Labeled individuals experience status loss and discrimination that lead to unequal outcomes.

**Harassment, denial of services/employment, poorer health outcomes**

For additional information read [Link and Phelan's manuscript](#).

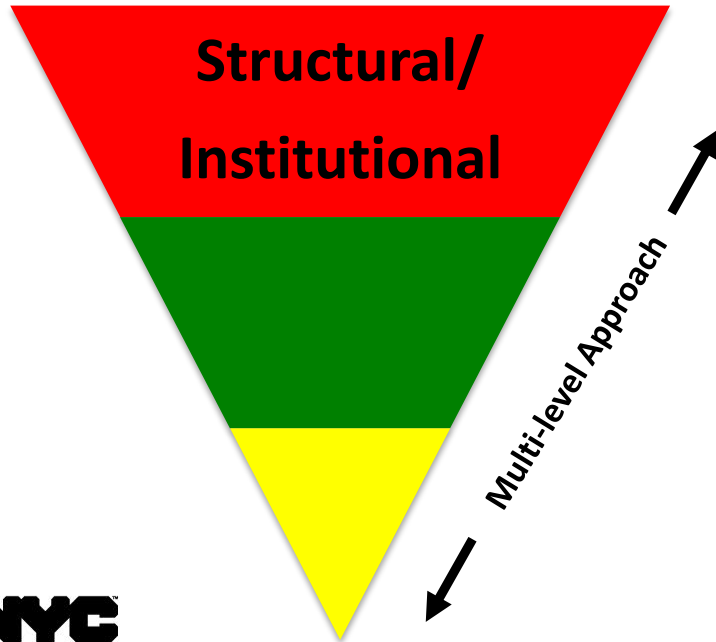
# Stigma is a Multi-level Problem

It's important to recognize each level where stigma occurs in order to intervene at each level where we see it happening



# Structural Level

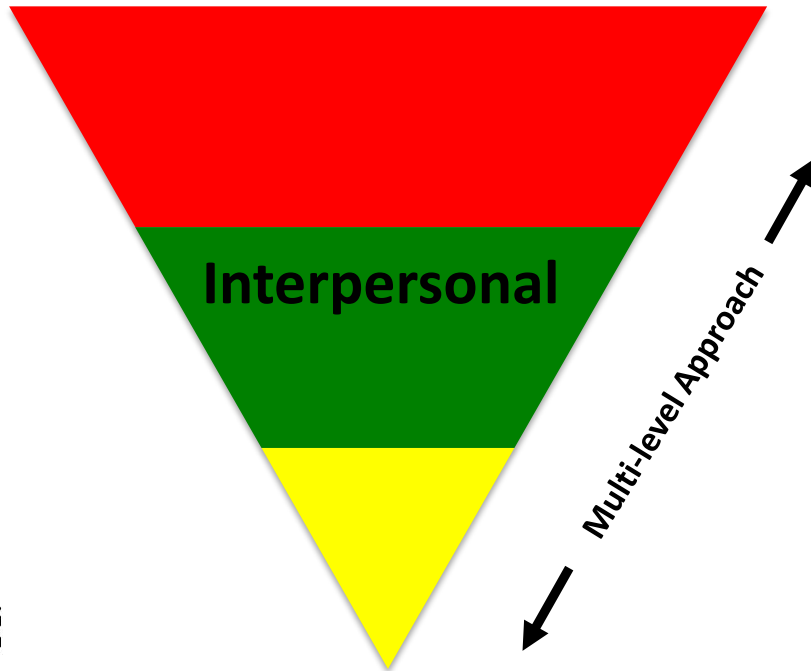
**Structural Stigma:** Societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized



Examples:

- **Criminalization of HIV, sex work, same-sex behavior**
- **Widespread negative public attitudes**
- **Lack of anti-stigma policies or enforced grievance policy**
- **Lack of staff training on stigma**
- **Unwelcoming waiting areas**
- **HIV-specific areas**

**Enacted Stigma:** Overt behavioral expressions of stigma



Examples:

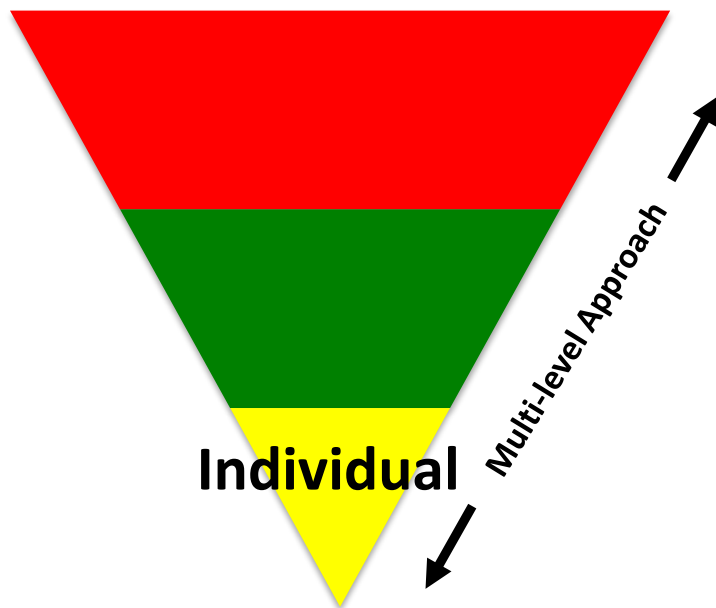
- **Differential treatment (e.g. double gloving)**
- **Disclosing HIV status without consent**
- **Denial of care**
- **Verbal harassment/gossip**



# Individual Level

**Anticipated Stigma:** Fear that enacted stigma may occur

**Internalized Stigma:** Personal acceptance of stigma as part of self-concept



Examples of Anticipated Stigma:

- **Fear of stigma at a health facility**
- **Not feeling safe in public**
- **Fear of disclosure**

Examples of Internalized Stigma:

- **Shame about diagnosis**
- **Feeling dirty, worthless, guilty**

# HIV Stigma is Common in New York

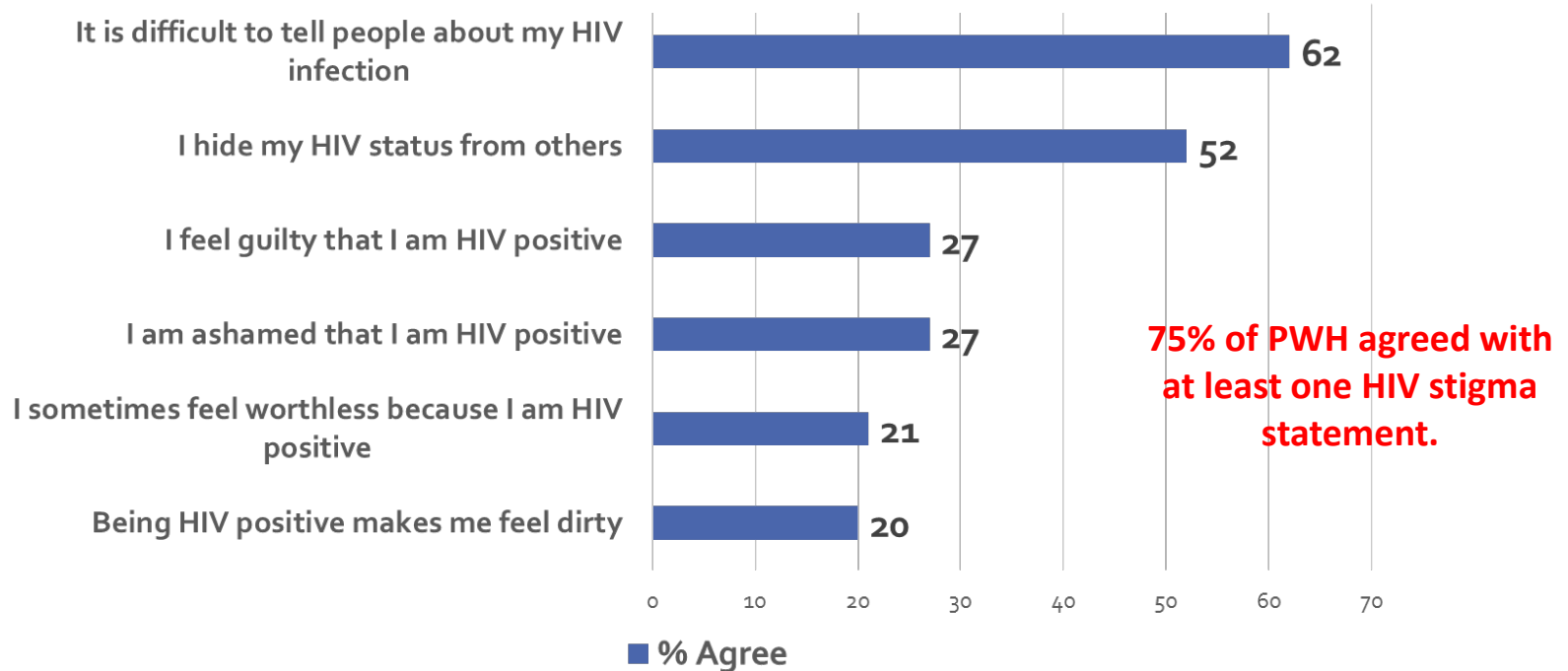
Stigma found to be common among HIV organizations surveyed by the NYS HD. Stigma was highest towards people with a mental health diagnosis, transgender people, and PWH.

From Ahmed et al. poster at 2018 National Ryan White Conference on HIV Care & Treatment

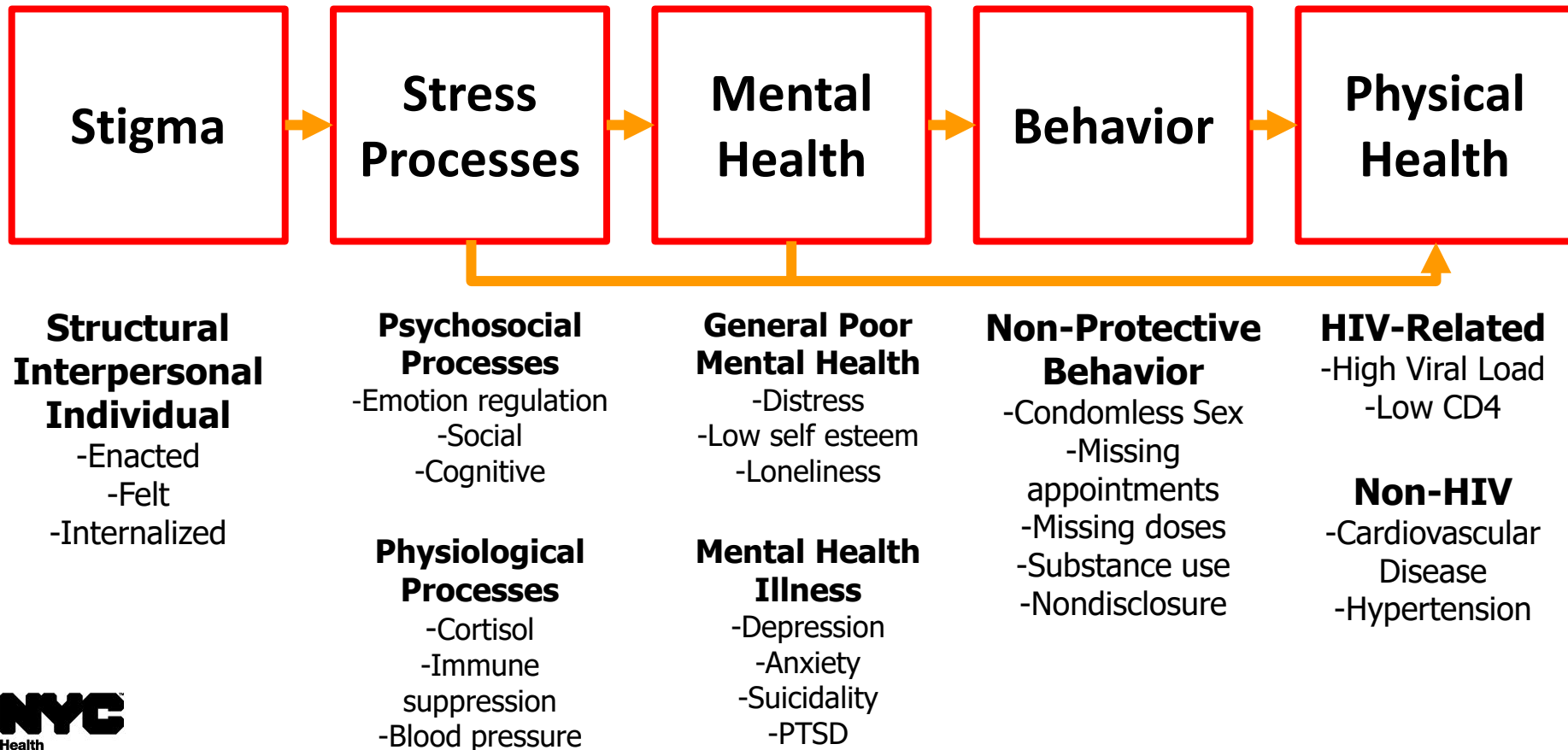
Healthcare staff agreed...	%
Have not received training on HIV-related stigma and discrimination and key populations	<b>36%</b>
Did not have knowledge of a policy against discrimination of key populations	<b>17%</b>
Agreed that infection occurs due to irresponsible behavior	<b>26%</b>
Agreed that PWH have had many sexual partners	<b>16%</b>
Expressed lack of comfort working with patients with a mental health diagnosis	<b>18%</b>

# HIV Stigma is Common in NYC

## Stigma among PWH in NYC Medical Monitoring Project, 2011-2014 (N=1,321)



# Stigma is Part of Causal Pathway to Physical Health







# Intersectionality as a Guiding Theoretical Framework for Stigma Field

- Was first coined in 1989 by Kimberlé Crenshaw regarding the unique experiences of Black women at the intersection of racism and sexism
- Intersectionality is a framework focused on the interdependent systems of power and oppression that impact people in ways that lead to unique experiences, vulnerabilities, and strengths
- These avenues can be overlooked because we often do not consider people as a whole, but try to break them down into parts by looking at one identity or need at a time
- An intersectional approach is needed from design through to intervention
  - E.g. NYC EHE Plan key activity: Conduct analyses of NYC Health Department HIV-related data in an intersectional manner



# Monitoring With An Intersectional Lens 2022 AJPH Opinion Piece

## **“Monitoring Intersectional Stigma: A Key Strategy to Ending the HIV Epidemic in the United States” Rodriguez-Hart et al.\***

- Combines perspectives grounded in practice and research
- Uses this monitoring definition: ongoing, systematic processes to collect, analyze, disseminate, and utilize information regarding precursors, mechanisms, and outcomes of intersectional stigma within multiple spheres of influence
- Recommends monitoring intersectionally from conception to dissemination
- Includes supplementary table of data sources and current opportunities for intersectional monitoring



# Intersectional Stigma Research Gaps

- Types of gaps: Conceptual, methodological, policy and procedural
  - Focusing solely on demographic differences in outcomes without their structural, social, cultural, and historical origins
  - Not using more meaningful variables (e.g., race instead of racism)
  - Focusing on HIV stigma without including other types of stigma
  - Inappropriate measurement
    - Intersectional stigma measures still an area in development. Use mixed methods approaches and partner with impacted communities
  - Focusing on individual-level factors and excluding strengths-based measurement
  - Lacking national strategy, policies and procedures, regulatory and scientific guidelines
  - Collecting data via inadequate systems that overburden providers

# Intersectional Stigma Key Strategies

 **AJPH** OPINIONS, IDEAS, & PRACTICE

## Monitoring Intersectional Stigma: A Key Strategy to Ending the HIV Epidemic in the United States

*Cristina Rodriguez-Hart, PhD, MPH, Cheriko A. Boone, MSW, MPH, MA, Ana María del Río-González, PhD, Bryan A. Kutner, PhD, MPH, Stefan Baral, MD, Paul A. Burns, PhD, Danielle German, PhD, MPH, Lisa Eaton, PhD, Lisa Lucas, MSc, Robert H. Remien, PhD, Marcia Ellis, MA, and Sannisha K. Dale, PhD*

- Key implementation strategies:  
Access, motivation, and partnerships
  - Free access to toolkit of valid measures and capacity building to use them
  - Motivate routine monitoring and rapid feedback loops
  - Ethical, power-sharing partnerships that rebuild trust and empower community partners





# HIV AND INTERSECTIONAL STIGMA MONITORING IN NYC

# Two Commonly Used and Adapted Stigma Measures

## Berger HIV Stigma Scale

- Developed in 2001 and one of the most widely used and adapted HIV stigma scales
- 40 items within four subscales: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes
- Good validity, reliability, and holds up in use across different time periods and cultural contexts\*

## Everyday Discrimination Scale

- Developed in the 1990s to measure experiences of racial discrimination
- Has since been re-tested and showed good reliability and validity as a multidimensional construct, although single-item questions did not score as well\*\*

# Community Health Advisory & Information Network (CHAIN) Study

Mailman School of Public Health – Columbia University

**C. H. A. I. N.**

Community Health Advisory &  
Information Network

CHAIN is a longitudinal study of PWH in NYC and Tri-County

- Utilizes shortened Berger Scale and Everyday Discrimination Scale

## 2020 Stigma Report

### • Key Findings

- Disclosure concerns were higher than enacted and internalized stigma
- All HIV stigma associated with lower perceived quality of HIV care
- Enacted HIV stigma associated with more inpatient hospitalizations
- Internalized HIV stigma associated with lower adherence to HIV medications

# Other Anti-Stigma Data and Communications Approaches

- **Sexual Health Survey:**
    - Study of women of color and MSM
    - Collects data on HIV status and viral load disclosure, avoiding healthcare due to fears of discrimination
      - Prior versions also collected data on PrEP stigma
  - **National HIV Behavioral Surveillance Study:**
    - Cyclical study of several groups inequitably impacted by HIV
    - Collects community HIV-related stigma scale, and other types of stigma data (e.g., stigma towards sexual minorities)
  - **Other communications:**
    - Ad-hoc townhalls, listening sessions, and studies among priority populations and on special topics
- HIV Planning Group and Ryan White Planning Council



# Medical Monitoring Project (MMP)



- Annual study of PWH conducted in 23 localities in the US
  - Includes shortened Berger Scale and Everyday Discrimination Scale (past 12 months)
- National HIV/AIDS Strategy (NHAS) stigma metric\* uses MMP data as a score:

## **Personalized stigma** (asked in regards to last 12 months since 2018)

I have been hurt by how people reacted to learning I have HIV

I have stopped socializing with some people because of their reactions of my having HIV

I have lost friends by telling them I have HIV

## **Disclosure**

I am very careful who I tell that I have HIV

I worry that people who know I have HIV will tell others

## **Negative self-image**

I feel that I am not as good a person as others because I have HIV

Having HIV makes me feel unclean

Having HIV makes me feel that I'm a bad person

## **Public attitudes**

Most people think that a person with HIV is disgusting

Most people with HIV are rejected when others find out

\*<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2001277/>

# Stigma Metrics, Necessary but not Sufficient

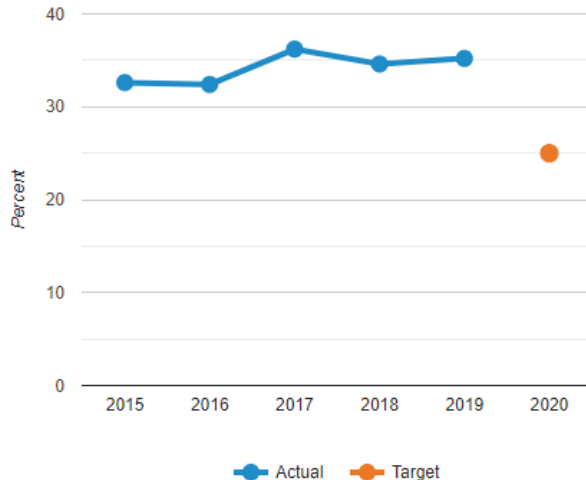
- NYC EHE goal: 50% reduction in HIV stigma, same as NHAS goal

## NYC Stigma Metric 2015-2020

From NY EtE Dashboard

2020 Target 25%

2019 Actual 35% (NYC)



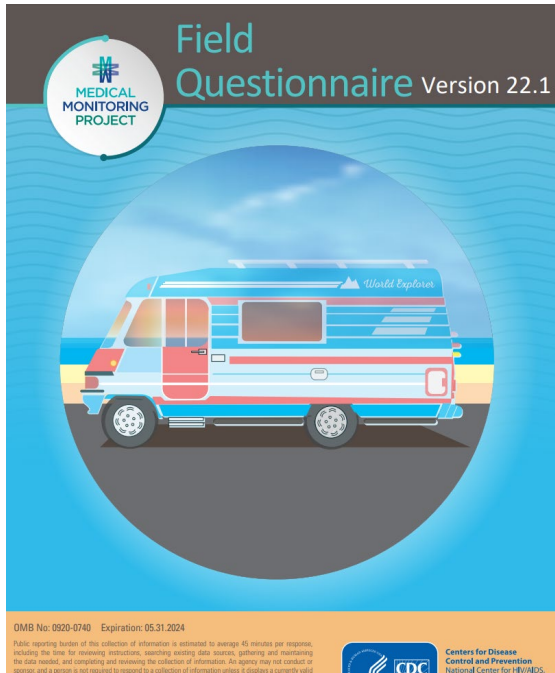
This finding leads to additional questions:

- Is this a good way to measure stigma?
- What is the trend among subpopulations?
- Should we triangulate with other data?
- How do we turn our monitoring into action?
- How do we monitor in a rapid way that is fed back to implementers and policymakers for timely change?
- How do we compare how we're doing with that of other US jurisdictions and countries?



# Comparison of MMP vs Global AIDS Monitoring (GAM) Stigma Indicators

**MMP and GAM collect stigma data across similar levels of stigma but using different questions  
Neither collects stigma data from providers or healthcare organizations**



UNAIDS 2021  
GUIDANCE

## Global AIDS Monitoring 2022

Indicators and questions for monitoring progress on the  
2021 Political Declaration on HIV and AIDS



# Ways to Improve US HIV Stigma Metric

- Items cover stigma that may have occurred anywhere →
- Time periods that vary by question →
- Lack of intersectional measures →
- A single score that may obscure which items are more prevalent →
- No provider reported stigma →
- Doesn't align with UNAIDS stigma monitoring indicators →
- Use 7 “when you got HIV care” stigma items that exist in MMP
- Use only “during the past 12 months” items that exist in MMP
- Use items in MMP that ask to what they attribute the stigma experienced
- Stratify by subpopulations
- Show per item score in addition to overall score
- Collect provider-reported data
- Include some GAM items in MMP to enable comparisons

An aerial view of the New York City skyline, including the Freedom Tower, with a blue and purple color overlay. The text is centered in a dark blue rectangular box.

# **3 EXAMPLES OF INNOVATIVE STIGMA MONITORING-RELATED ACTIVITIES IN NY**

# Innovative Stigma Reduction Data-Related Efforts in NY

## Assess provider/organizational-level stigma during quality improvement

- 2016 NYSDOH stigma provider survey



## Implement stigma-reducing strategies through service planning models

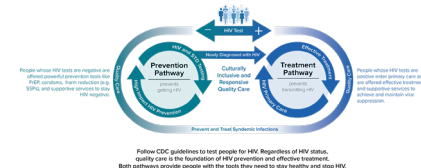
- 2020 Framing Directive to address stigma throughout Ryan White Part A



## Tie funding to stigma-related quality measures

- 2022 Quality-Based Financing for Playsure 2.0 contracts

### Status Neutral HIV Prevention and Care





# NYSDOH Provider Stigma Survey

- In 2016 NYSDOH utilized the Health Policy Project (HPP) “Measuring HIV Stigma and Discrimination Among Health Facility Staff: A Comprehensive Questionnaire”\*
- HPP survey is one of most widely used provider stigma surveys
- Survey includes questions on:
  - Stigma-related training
  - Infection control
  - Enacted stigma within health facility environment
  - Stigma-related health facility policies
  - Attitudes towards PWH and other key populations (people who inject drugs, men who have sex with men, sex workers)
  - Stigma towards pregnant PWH
- NYSDOH adapted HPP survey for NY context



# NYSDOH Provider Stigma Survey Findings

- Over 80 healthcare sites in NY were asked to distribute it to their staff and create stigma reduction plans as part of annual Quality of Care Program Review
  - 50 agencies participated
- Notable findings:
  - Lack of training on stigma and key populations
  - Lack of knowledge of agency policies against discrimination towards key populations
  - Stigmatizing attitudes (e.g., HIV due to irresponsible behavior, many sex partners, etc.)
  - Enacted stigma highest towards people with a mental health diagnosis, followed by PWH and trans people



# NYSDOH Provider Stigma Survey Barriers and Facilitators

- Barriers:
  - Data collection not planned in advance
  - Consumer participation uneven
  - Stigma not well understood across agencies
  - Not having models for this work
  - HPP survey the only one they knew of to use at the provider level
- Facilitators:
  - Established relationships with providers
  - Consumer advocacy to address stigma
  - Structured integration into quality improvement activities
- Most agencies have not repeated the survey
  - During 2020 interviews, staff reported not repeating the survey
  - Some agencies continued with their stigma reduction plans but they were not evaluated -> need a more structured, formalized process for this



# Ryan White Planning Council Framing Directive

- Ryan White part A service directives developed by Planning Council for each category
- The directive that applies across all service categories-> Framing Directive\*
- Planning Council revised this to explicitly focus on stigma and equity using implementation research logic model
- Multilevel determinants were included
- Implementation strategies were introduced to tackle stigma
  - E.g., Stigma organizational assessment, staff pay equity, decarceral crisis plans
- Implementation outcomes + client outcomes are used to measure success
  - E.g., % of agencies with a plan for establishing pay and racial equity
  - E.g., % of clients that report anticipated stigma





# Playsure 2.0 Quality-Based Financing (QBF) Rollout

- Rebidding of status neutral HIV prevention contracts utilized to explicitly tie stigma-related quality improvement to funding
- Playsure 2.0 goal: “Provision of equity-focused, one-stop shop, client-centered model that is affirming and non-stigmatizing, and which decreases inequities in HIV prevention for priority populations (PPs)”
- New QBF model to shift away from paying for *quantity* of services to *quality* of services
- 3 types of multi-level quality indicators to be reported:
  - Process: Training (10), infrastructure (16), leadership/staff diversity (2)
  - Experience: Staff experience (9), client experience (13)
  - Outcomes: Universal screening (42), service access (5), service utilization (44)



# QBF Indicator Examples By Type

## Process

- Training: % of staff who have been trained on trans-affirming healthcare
- Infrastructure: Gender-neutral restrooms are available for staff and clients

## Experience

- Leadership/staff diversity: % of staff and leadership representative of PPs
- Staff experience: % of staff who observe stigma towards clients at agency
- Client experience: % of PP clients reporting positive patient-provider relationship

## Outcomes

- Universal screening: % of clients screened for mental health at least annually
- Service access: % of clients who receive a follow-up navigation check-in after their initial assessment within a year
- Service Utilization: % of visits where PP clients are provided/linked to additional supportive services (e.g., legal, employment, food) within a week



# QBF Funding Model

- Year 1: Funding will not be tied to QBF indicators
  - Reporting on QBF indicators in Year 1 serve as baseline values
- Years 2-5: Agencies are expected to improve from baseline values (5% increase each year).
  - Up to 30% of total award amount can be withheld if QBF metrics are not met
- Penalty and incentive system:
  - 15% of award amount can be deducted for not meeting QBF metrics
  - Up to 15% additional funding if they meet all benchmark metrics
- 3 types of QBF indicators weighted equally



# STIGMA AND RESILIENCE (STAR) PROJECT

# STigma And Resilience (STAR) Ending the HIV Epidemic Project

## Goals

- Gain a comprehensive view of best practices to eliminate HIV-related stigma and promote resilience
- Identify gaps in anti-stigma efforts that remain to be addressed
- Form a STAR Coalition bringing together HIV organizations, government, and researchers to address stigma
- Funded by NIH as an implementation science supplement to the HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute and Columbia University





# Mapping Stigma Reduction at NYC HIV Organizations

- We asked about existing practices and determinants (barriers and facilitators) of stigma reduction
- 51 staff across 27 organizations participated in 2020

## Key Organizational Barriers:

- Leadership support, shared decision-making with consumers, and staff expertise to reduce stigma were rated the lowest by surveyed staff
- Only 32% reported that funders fund them to do stigma reduction activities specifically

## Key Gaps:

- Economic empowerment services and sustainment were both lacking

# Top Facilitators Of Stigma Reduction

- **Integration of HIV services**

- Combats stigma by treating HIV as a normal part of primary care
- May help address intersectionality through team-based care
- Is part of holistically serving clients

“We don’t treat HIV testing like it’s apart from anything else in someone’s healthcare. We try to deal with patients holistically. We treat HIV as *one* of the problems”

- **Representative staff**

- Mentioned as a “most effective” strategy to reduce stigma

“The way that we have used peers in this agency is probably one of the best tools that we have. It really shows clients that are coming in that we are from the community for the community”

- **Ongoing training for staff that is relevant to stigma**

- Creates a safe space for clients because staff are culturally competent
- Establishes learning as a part of their culture

“Training is useful because it reminds people of what they’ve previously heard and reinforces the organization’s mission. Our staff meetings are not just about programming but serve as reminders of who we are and how we should deliver our services.”





# Barriers & Gaps for Stigma Reduction

## Internal Context

- Lack of formal evaluations of stigma reduction strategies
- Lack of intersectional approaches
- Organizational structure & capacity issues
  - Large client volumes
  - Staff burnout/turnover
  - Leadership disconnected from day-to-day experiences, communication difficult between levels of the organization
  - Influence of capitalism on quality of care

## External Context

- Insufficient funding
- Lack of control over provider sites for outside referrals
- Less stigma awareness in the broader community

**Most common barriers were related to organizational structure and capacity**



# Recommendations from Organizations for Addressing Barriers

- Improve feedback and communication mechanisms between leadership and direct service staff and increase leadership support for stigma reduction
- Minimize staff turnover, burnout, and trauma
- Address why some clients are not attending HIV services: transgender people, immigrants, and people afraid to be associated with an HIV organization
- Improve understanding of intersectionality and how to address it



# Locally Relevant Stigma Interventions In Need of Testing

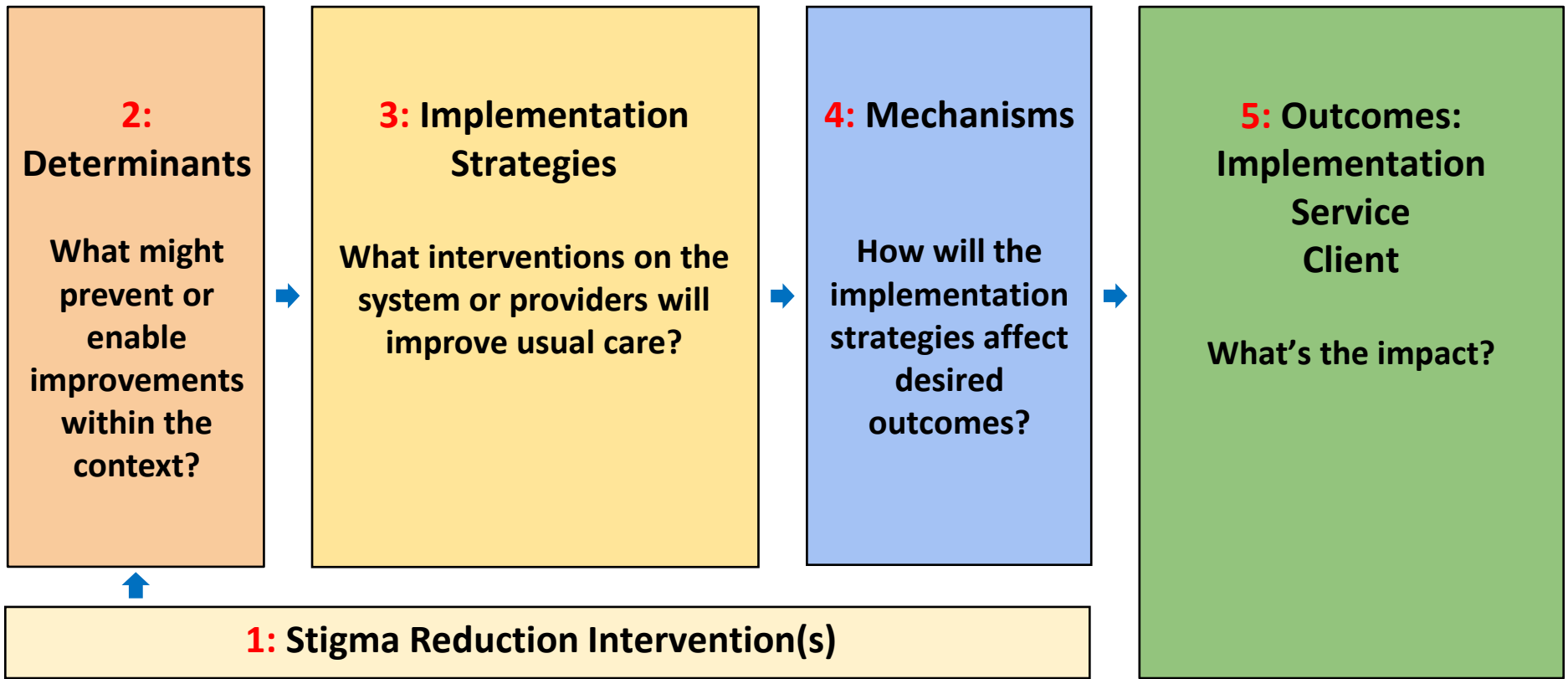
- Two key findings from STAR Mapping:
  - there are **emerging strategies** for stigma reduction within organizations that do not appear in the stigma research literature
  - there is a **lack of evaluation** of stigma reduction practices
- HRSA has identified implementation science as key to identifying, evaluating, and disseminating emerging and effective interventions\*
- So how do we help organizations who are doing the work on stigma reduction, to utilize implementation science in a structured fashion?

# The Implementation Research Logic Model (IRLM)

- Following STAR mapping, we reviewed implementation science models and frameworks to help with its translation for HIV providers
- Decided to use the IRLM and adapt it for stigma reduction
- IRLM\* integrates different frameworks into 1 organizational tool
  - Similar to the traditional pipeline logic model
- Can be used with different stakeholders to agree on the “what” and “how” of a project
- Shows the consecutive relationships between implementation steps, serving as a roadmap

# Stigma Reduction Logic Model (SRLM)\*

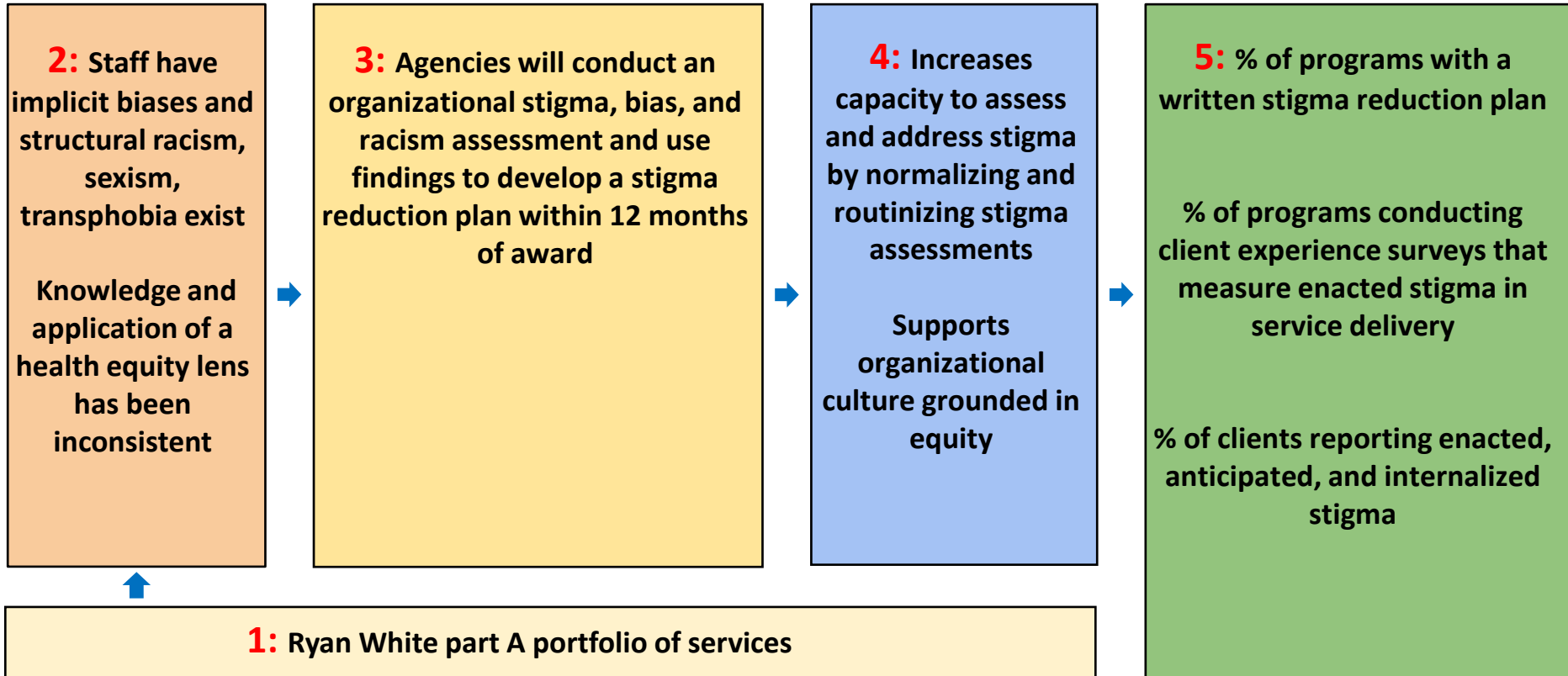
SRLM components each include guiding questions, tips, tools, and suggested frameworks to use



\*[https://journals.lww.com/jaids/Fulltext/2022/06001/Reducing\\_Intersecting\\_Stigmas\\_in\\_HIV\\_Service.26.aspx](https://journals.lww.com/jaids/Fulltext/2022/06001/Reducing_Intersecting_Stigmas_in_HIV_Service.26.aspx)

# Example of Stigma Reduction in Ryan White Part A Planning

Using an implementation science model, stigma is explicitly integrated into service models





# Tools Available Within SRLM Package

- SRLM manuscript includes a number of tools to assist implementors\*
  - Implementation science terminology guide for stigma reduction
  - Stigma Reduction Organizational Readiness Tool
  - Guiding Model
  - Menus of options for interventions and determinants
  - Figure to illustrate mechanisms
  - Example of a completed model
- SRLM needs to be piloted to assess its utility
  - R34 proposal being prepared for January 2023 submission





# Assistance For Successful Implementation of the SRLM Pilot

- Four steps for each organization
  1. Stigma surveys-> normalize stigma data collection and tailor
  2. Readiness checklist-> assess organizational capacity and infrastructure
  3. A 5-step stigma reduction logic model-> develop plan and set goals
  4. Implement stigma reduction intervention-> develop evidence base
- Facilitation
  - Implementation teams, including PWH, to champion
  - Training, implementation coaching, peer learning
- Outcomes
  - Acceptability, appropriateness, feasibility, adoption, organizational capacity

# Published Results of STAR Mapping Project

AIDS and Behavior  
https://doi.org/10.1007/s10461-021-03498-0

ORIGINAL PAPER



## HIV and Intersectional Stigma Reduction Among Organizations Providing HIV Services in New York City: A Mixed-Methods Implementation Science Project

Cristina Rodríguez-Hart<sup>1</sup> · Grace Mackson<sup>1</sup> · Dan Belanger<sup>2</sup> · Nova West<sup>2</sup> · Victoria Brock<sup>2</sup> · Jhané Phanor<sup>2</sup> · Susan Weigl<sup>2</sup> · Courtney Ahmed<sup>2</sup> · Jorge Soler<sup>3</sup> · Alana Rule<sup>4</sup> · Francine Cournos<sup>4,5</sup> · Karen McKinnon<sup>4,5</sup> · Theo G. M. Sandfort<sup>4</sup>

Accepted: 9 October 2021

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### Abstract

Stigma remains a pervasive barrier to Ending the HIV Epidemic (EHE) in New York City (NYC). As part of an EHE implementation science planning process, we mapped multi-level HIV-related stigma-reduction activities, assessed their evidence base, and characterized barriers and facilitators. We interviewed and surveyed a convenience sample of 27 HIV prevention and/or treatment services organizations in NYC, March–August, 2020, using an embedded mixed-methods design. The greatest facilitators of stigma reduction included integration of health services, hiring staff who represent the community, and trainings. Intersectional stigmas were primarily addressed through the integration of HIV with mental health and substance use services. Barriers were multilevel, with organizational structure and capacity most challenging. A strong base of stigma-reduction activities was utilized by organizations, but intersectional frameworks and formal evaluation of activities' impact on stigma were lacking. Effectiveness-implementation hybrid research designs are needed to evaluate and increase the uptake of effective stigma-reduction approaches in NYC.

**Keywords** Stigma · HIV · Intersectional stigma · Mixed methods · Implementation science

### Introduction

Much has been done to end the HIV epidemic in New York City (NYC). In 2018, new diagnoses fell under 2000 for the

41% from 2014 to 2018. However, it continues to be one of the epicenters of the epidemic, containing 13% of all people with HIV (PWH) in the US and 5% of new diagnoses nationwide [1]. Inequities in new diagnoses persist by race,

SUPPLEMENT ARTICLE

## Reducing Intersecting Stigmas in HIV Service Organizations: An Implementation Science Model

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**Background:** HIV-related and intersectional stigmas are key barriers for service delivery, but best practices are nascent for addressing them in high-resource and high-burden contexts such as New York City (NYC). The Stigma Reduction and Resilience (STAR) implementation science (IS) Mapping Project in 2020 identified unmet stigma reduction efforts in HIV organizations, highlighting the need for an IS framework.

**Setting:** Organizations providing HIV prevention and/or care in NYC.

**Methods:** An interagency team determined that IS provides a structured approach for addressing identified gaps in stigma reduction efforts, but defining existing IS concepts and adapting IS frameworks were necessary to facilitate its use. The Implementation Research Logic Model was adapted to empower HIV organizations to use IS to implement stigma reduction.

**Results:** Questions, definitions, and tips were developed to guide, strengthen, and simplify the application of IS within HIV organizations to improve the reduction of HIV and intersecting stigmas. The resulting Stigma Reduction Logic Model incorporates tools for implementers who synthesize each component of the logic model (intervention, determinants, implementation strategies, mechanisms, and outcomes), including a menu of options for selecting stigma reduction interventions and implementation determinants, a checklist to assess organizational readiness for stigma reduction, and an IS terminology guide applied for stigma reduction.

**Conclusions:** Stigma reduction initiatives and research can use this model to enable implementers, researchers, and HIV organization stakeholders to use the methodology of IS to build consensus for, systematically plan, implement, and evaluate stigma reduction activities relevant to the HIV epidemic. The next step is testing the model's utility.

**Key Words:** implementation science, stigma interventions, HIV stigma, intersectional stigma

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- **Evidence-based innovation:** An adaptation of the Implementation Research Logic Model to guide stigma reduction initiatives.
- **Innovation recipients:** Staff delivering HIV-related services who wish to address HIV and intersectional stigmas. Secondly, collaborators of such individuals (eg, researchers and health department staff).
- **Setting:** Clinical and community-based organizations delivering HIV-related prevention and/or care services.
- **Implementation gap:** HIV-related organizations are unfamiliar with implementation science and may have limited capacity for research and systematic implementation of stigma reduction initiatives.
- **Primary research goals:** Identify determinants of implementation, select/pilot implementation strategies, and evaluate implementation strategies for stigma reduction.
- **Implementation strategies:** Our model offers organizations a package of tools to systematically plan and evaluate stigma reduction innovations in their local contexts, including a menu of emerging interventions and a stigma

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# Theory-Based Compendium of Stigma Interventions in US

**“A systematic review of intervention studies that address HIV-related stigmas among US healthcare workers and health systems: Linking theory-based intervention types, techniques, and mechanisms of action to potential effectiveness” Kutner et al. (under review)**

- If we understand the theory behind strategies, we can better evaluate why some work and others do not
- 28 studies identified
- Review aimed to describe intervention components using transtheoretical taxonomies from the Behavioral Change Wheel
- Can be utilized to identify promising ingredients for stigma interventions
- Suggests future directions e.g., teasing apart individual effects



# Findings of Theory-Based Compendium of Stigma Interventions in US

## Good

- Most promising: function- persuasion; techniques- credible sources delivering content, time for skills practice, cognitive reframing, addressing emotions, informing workers of the consequences of stigma for their patients; mechanism- increasing knowledge and beliefs about one's capability to change stigmatizing behavior.

## Bad

- Theory was explicitly referenced in less than half of studies
- Lack of intersectional and structural approaches

## Ugly

- Mismatch between conceptualization and operationalization of outcomes
- Few studies focused on racism or poverty-related stigma



# Challenges for Stigma Reduction Locally


- Stigma research not well known among providers and community
  - Unclear which stigma measurement tools we should use
- Lack of structural stigma measures to disseminate to providers
- Provider pushback to measuring and addressing stigma
- Difficulty of gaining attention for stigma vs. HIV clinical outcomes
- Research-practice gaps leaving us siloed from research expertise
- Steep learning curve for implementation science
  - Over-reliance on peer-reviewed publications vs. translational tools
- Dynamic context, resulting in less time to study our process and outcomes
  - High volume of data to collect, process, analyze
- Equitable partnerships to conduct research can require more time



# Recommendations

- When selecting stigma measures: consider their purpose, the levels and who is being asked, time period, and intersectionality
- Make action plans after collecting stigma data
- Use quality improvement and implementation science to integrate stigma activities into healthcare settings
- Create structural requirements for stigma monitoring e.g., funding
- Include stigma and other structural determinants of health in your goals
- Consider broader context of anti-stigma work: language, criminalization
- Invest in low-threshold funding mechanisms for emerging practices and government-community stigma reduction collaborations
- Adopt a researcher role of a translator, an ambassador to communities





# Thank you!

## Contact Information

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