

# It Leaves a Mark: Findings on HIV Stigma and Resilience from the Stigma Index in the United States

Andrew Spieldenner, Ph.D.

Chair, US People living with HIV Caucus

Assistant Professor, Health Communication, California  
State University - San Marcos



California State University  
SAN MARCOS

# United States People Living with HIV Caucus



- ▶ A network of national networks of PLHIV and community leaders
- ▶ Emerged 2010 with the dissolution of National Association of People with AIDS
- ▶ Host AIDSWatch and other community based PLHIV community work
- ▶ The United States People Living with HIV Caucus (the HIV Caucus) has taken on the lead coordination of the Stigma Index as of 2016



Photo credit: *Poz Magazine* (2013)

# A Changing Epidemic...

## Pre-Treatment Era



Photo Credit: Therese Frare (1990)

## Post-Treatment Era

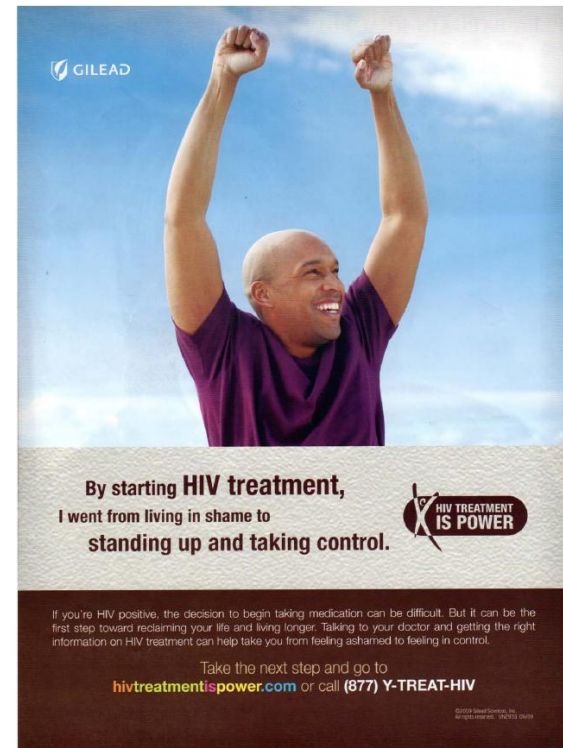


Photo Credit: Gilead

# Discrimination or Stigma?

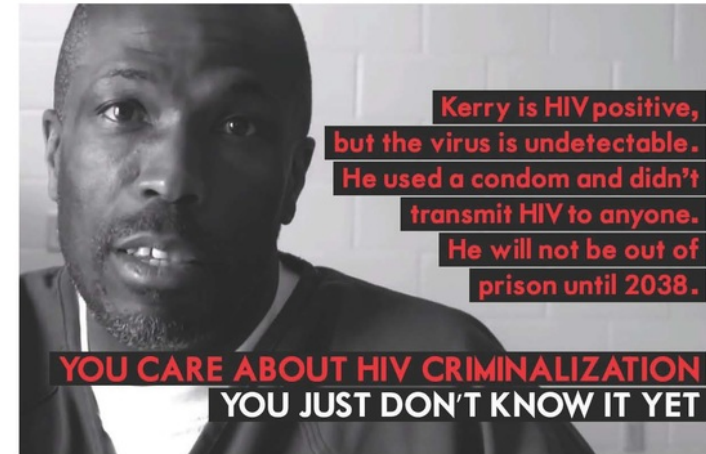
- ▶ Stigma remains a considerable barrier in healthcare access, quality of life, and personal well-being
- ▶ Some parts of the HIV community in the United States believe that HIV-related stigma is either over or that it is too complicated to address
- ▶ Discrimination refers to unfair and unjust action toward an individual or group on the basis of real or perceived status or attributes

▶ “I don't want others to know my HIV status. I pray to God that I am cleansed of HIV. People look down on me once they know I am HIV +. I feel separated from others because of HIV”

▶ -Louisiana Participant Quote

# To start...

- ▶ HIV-related stigma still exists!
- ▶ Watch:  
<https://www.youtube.com/watch?v=t4KxkzcCyBc>



**HIV**  
**IS NOT A CRIME II**  
**NATIONAL TRAINING ACADEMY**  
**MAY 17-20, 2016**  
**HUNTSVILLE, AL**

[www.HIVIsNotACrime.com](http://www.HIVIsNotACrime.com)  
**#HIVIsNotACrime**

 /HIVIsNotACrimeConference

HIV is Not a Crime II will unite and train advocates living with HIV and allies from across the country on laws criminalizing PLHIV and on strategies and best practices for repealing such laws.

Skills-building training, with an emphasis on grassroots organizing, advocacy, coalition-building and campaign planning, will leave participants with concrete tools and resources to work on state-level strategies when they return home.

*To apply for a scholarship, submit an abstract for a workshop or to register for the Training Academy, please visit our website.*

**SERO**



# The Stigma Index

- ▶ HIV stigma is a social phenomena experienced personally
- ▶ Coordinated by Global Network of People Living with HIV (GNP+) to measure HIV stigma - conducted in 50 countries
- ▶ The Stigma Index data is collected and analyzed *by* PLHIV, *with* PLHIV, and *for* PLHIV
- ▶ Stigma Index findings drive policy and community organizing efforts



For more information on global projects using the questionnaire see <http://www.stigmaindex.org/>



"THE INDEX  
PROVIDES  
THE BEST  
OPPORTUNITY  
FOR PEOPLE  
LIVING WITH HIV  
TO TELL THEIR  
SECRETS – SO WE  
NEED TO DEVELOP  
THE SKILLS TO  
ASK THEM."



**THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX**



# The Stigma Index Process

- ▶ Partnership
- ▶ Capacity-building
- ▶ Listening to the community
- ▶ Data analysis and interpretation
- ▶ Advocacy





# The Stigma Index Goals

**Document**

**Mobilize**

**Reduce stigma**

**Develop PLHIV research literacy**

**Provide an evidence base framework**

**Build and implement a shared advocacy agenda**

“Being interviewed by another person living with HIV does make a difference - you feel they really understand more about how you feel.”



# Terminology of Stigma

- ▶ Enacted stigma (discrimination)
- ▶ Anticipated stigma
- ▶ Internalized stigma
- ▶ Secondary stigma
- ▶ Intersecting/Compounded stigma
  - ▶ Gender
  - ▶ Poverty/class/race/geography
  - ▶ Sexuality or sexual orientation



# Where do people experience stigma?

- ▶ The Index asks about the last 12 month window particular to:
  - ▶ Healthcare services
  - ▶ Community support
  - ▶ Home and work
  - ▶ Family and friends
  - ▶ Intimate partners
  - ▶ Quality of life





# One Example: Estonia

- ▶ In Estonia, data indicated three primary areas that could be impacted:
  - ▶ Divided PLHIV community
  - ▶ Fear of workplace discrimination
  - ▶ Belief that healthcare services were not PLHIV-centered
- ▶ Solutions:
  - ▶ Community building activity
  - ▶ Job employment initiative
  - ▶ Healthcare clinic whose Clinic Manager is a woman living with HIV



# United States Implementation

- ▶ The Stigma Index has been conducted in three sites:
  - ▶ Detroit
  - ▶ Louisiana
  - ▶ New Jersey
- ▶ Over 750 people living with HIV participated
- ▶ Anti-stigma work is being conducted in each site
- ▶ Data highlight results:
  - ▶ Poverty
  - ▶ Intersectional stigma
  - ▶ Value of resilience



# Poverty

- ▶ PLHIV experience high rates of poverty
  - ▶ Leads to erratic housing
- ▶ Poverty is a structural condition, fed by lack of education, economic and expansive healthcare opportunities
- ▶ Poverty cannot be ameliorated by clinic-based HIV services



“I had a job cleaning house for over a year and the house owner had a friend who knew me and decided to tell the owner I had HIV not knowing my status for sure and they just fired me”



# Mechanisms for Addressing Poverty

---

**Job training** for people living with HIV, including coaching, resume reviews and assistance with understanding current job markets

---

**Employment opportunities** - work with employers on job descriptions and human resources

---

**Streamline benefits process** - being poor is a full time job. Housing, mental health, dental services are generally disconnected and difficult to obtain

---

**Resource networks** of people living with HIV in whatever shape they take - CAB, etc. - with the people living with HIV deciding how to deploy resources



# Intersectional Stigma

- ▶ PLHIV experience stigma for a range of identities and experiences, not just HIV
- ▶ Gender, sexuality, disability, poverty, homelessness, substance use, mental health, country of origin, language - all play a part in PLHIV stigmatizing experiences
- ▶ Anti-stigma work cannot be **SOLELY** about HIV, especially in interrupting stigmatizing values in a community



“In my community (community of color) there has been a lack of moral intelligence that has prevented a decrease of diagnosis because of the stigma of the virus”

# Mechanisms for Addressing Intersectional Stigma

---

Center anti-stigma work on the needs of historically marginalized people living with HIV including people of color, trans\* individuals, women, sex workers and immigrants

---

Take into account how each community has differing levels of resources and historical experiences in HIV

---

Multiple layers of stigma - personal, community and institutional levels - each will have a different solution (e.g. at the institutional level, examine clinic spaces and personnel)

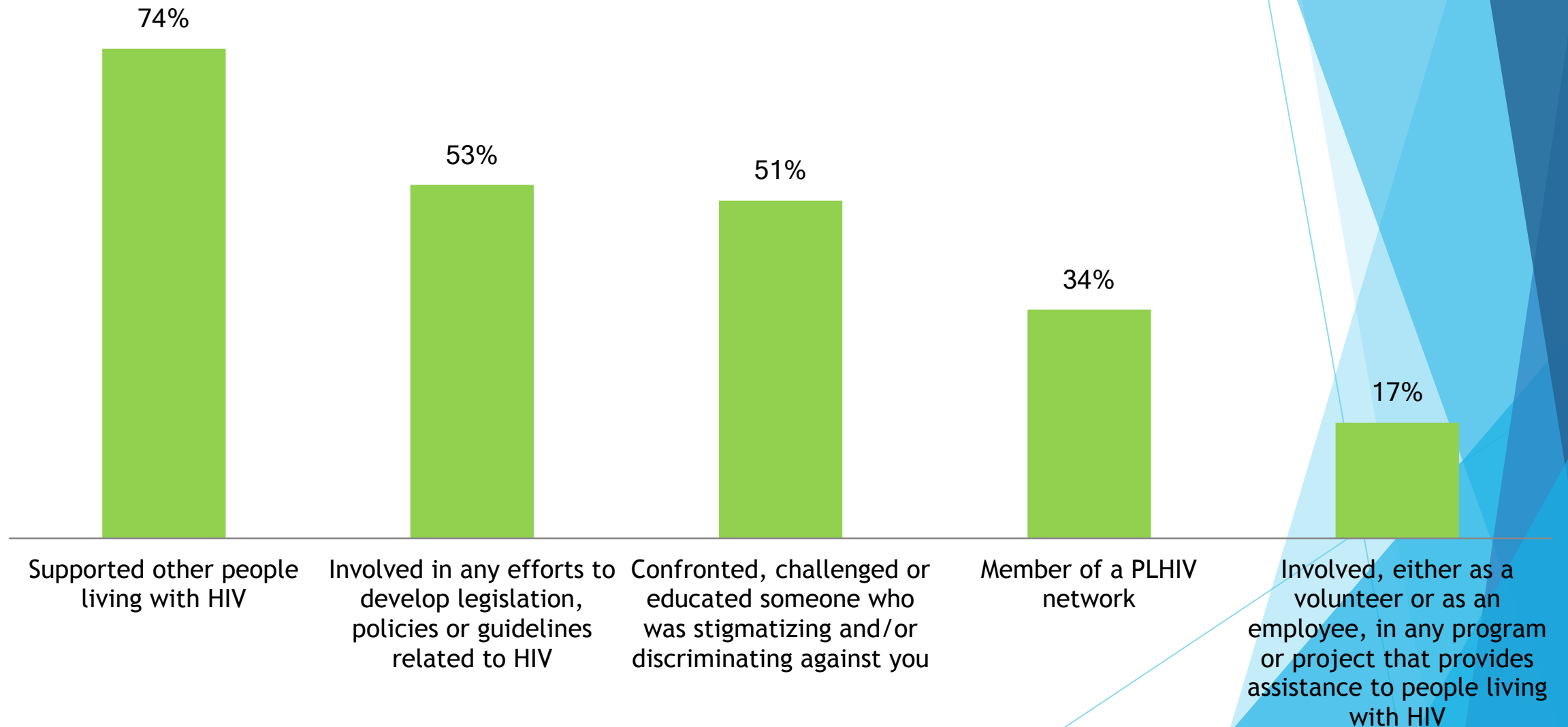
# Resilience

- ▶ People who had lived longer with HIV had more tools to manage stigmatizing events
- ▶ Resilience differs across racial lines
- ▶ Resilience can be grown through community building



“I’ve educated others who were afraid of contracting HIV from being intimate with me on their actual risk factors and how viral suppression and PrEP can both greatly reduce risk, making serodiscordant relationships possible”

# Activities of Resilience and Support\*



\*Data from Detroit



# Mechanisms for Building Resilience

---

Community building and advocacy efforts will build resistance

---

Resourcing networks of people living with HIV also builds resistance

---

Address mental health needs alongside community building

---

The Stigma Index process builds resilience amongst participants

# Questions?



Photo credit: Jacob Barrera (2017)

- ▶ Contact Info:
- ▶ Andrew Spieldenner, Ph.D.
- ▶ [aspieldenner@csusm.edu](mailto:aspieldenner@csusm.edu)
- ▶ @aspield on twitter