

Understanding & Addressing Multiple Dimensions of Stigma to Promote Engagement in Care

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Disclosures

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Presenter(s) have no financial interest to disclose.

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

- Identify the various dimensions of stigma
- Describe strategies to measure stigma
- Create strategies that can be used to address stigma at the individual, community, and systems level in order to promote linkage and engagement in HIV care



Acknowledgements:

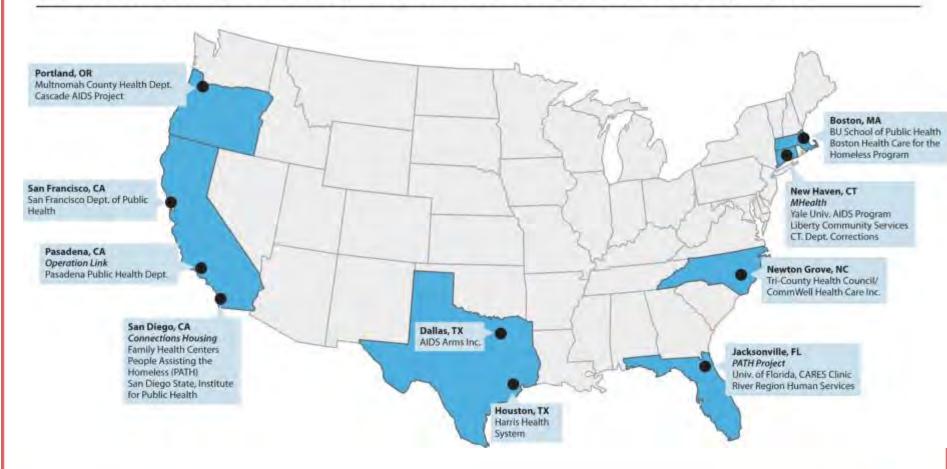
- Emily Sisson & Alex De Groot, Boston University School of Public Health
- Jessica Davila, Harris Health System, Houston, TX
- Christa Black & Jodi Davich, Multnomah County Health Department, Portland, OR
- Ruthanne Marcus, Associate Director, Clinical and Community Research AIDS Program Yale University, New Haven, CT

"This presentation was made possible by cooperative agreement number U90HA24974 from the U. S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau's Special Projects of National Significance Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the government."





HRSA/SPNS Initiative: Building a Medical Home for HIV Homeless Populations



Goal: To engage homeless/unstably housed persons living with HIV who have mental illness and/or substance use disorders in HIV and behavioral health care and obtain stable housing





Priority Population

- 1. Persons living with HIV/AIDS who are 18 years of age or older
- 2. Persons who are homeless or unstably housed
 - Literally homeless
 - Lacks a fixed, regular, and adequate nighttime residence
 - Unstably housed
 - No lease, ownership interest or occupancy agreement in permanent and stable housing in the last 60 days; or
 - Persistent housing instability as measured by two moves or more in the preceding 60 days; and
 - Expected to continue as such for an extended period of time.
 - Fleeing domestic violence
 - Fleeing or attempting to flee domestic violence, has no other residence and lacks the resources to obtain permanent housing.
- 3. Persons with one or more co-occurring mental health or substance use disorders



Stigma Defined

- "Stigma is an attribute that is deeply discrediting and results in the reduction of a person or group from a whole and usual person to a tainted, discounted one".
 Goffman 1963
- "...elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them".

 Link, BG. and Phelan, JC. Conceptualizing Stigma. Ann Rev Socio. 2001
- Stigma may be related to:
 - HIV
 - Substance use disorders
 - Mental illness
 - Housing status
 - Immigration status
 - Incarceration history
 - Gender identification
 - Race or ethnicity
 - Sexual orientation
 - Other?
- Significant intersection exists between types of stigma and the causes



Impact

- Internalized
 - Negative self-esteem
 - Depression/Anxiety
 - Fear
 - Stress
 - Social isolation
- Perceived enacted/experience (perceptions of other's opinions)
 - Discrimination
 - Delay in care-seeking
 - Poor health outcomes



Stigma & HIV Care

- Gender
- Race/Ethnicity
- Insurance status
- Co-morbidities
- Homelessness

Personal, Structural, Cultural

Stigma

- Provider
- Society
- Internal

Housing stability

Engagement & Retention in HIV care



Goals of the stigma study

- Understand and describe how stigma is manifested in individual's experience
- Develop approaches and coping skills for clients who experience stigma
- Create a medical home to reduce stigma and enhance access and quality of care



Approach

- Longitudinal study (0, 6, 12, 18 months)
- Stigma on 4 dimensions: 16 items
 - HIV (Berger scale)
 - Perceived external stigma
 - Provider-related stigma
 - Housing status/homeless (adapted from BRFSS)
 - Mental illness
 - Substance use disorders



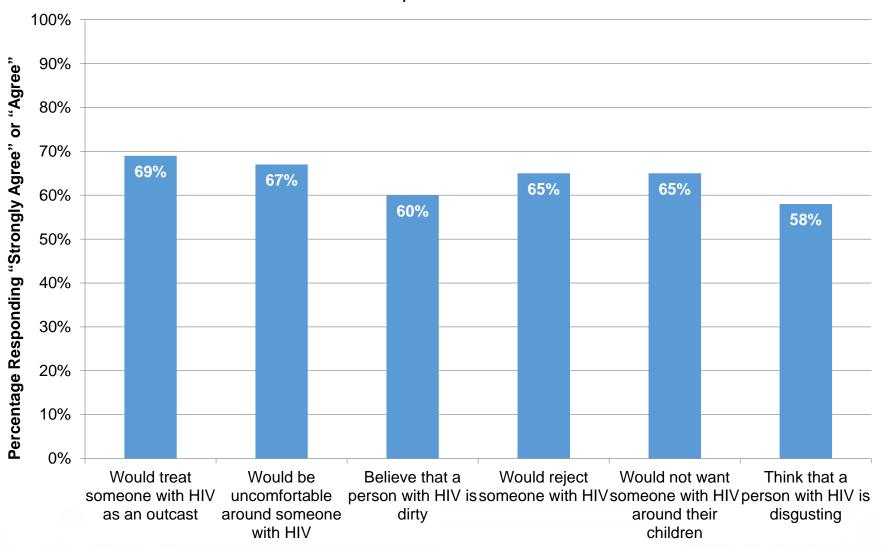
Findings from baseline survey (n=546)

Characteristic	% (n)
Age (mean, (SD) in years	42.3 (10.8)
≤30 years	20.2% (99)
31-54 years	78.1% (382)
≥55years	1.6% (8)
Gender	
Male	76% (416)
Female	21% (113)
Transgender	2% (13)
Other	1% (6)
Sexual Orientation	
Heterosexual	52% (283)
Gay/Lesbian	31% (172)
Bisexual	14% (75)
Other/unsure/refused	3% (18)
Race	
African American/Black	49% (266)
White	37% (203)
American Indian/Native American	2% (11)
Asian/Pacific Islander	.2% (1)
Multiple Races	5% (27)
Other/Refused	7.3% (40)
Ethnicity	
Hispanic	15% (81)
Length of time homeless/unstably housed, years (mean,SD)	5.7 (7.7)
Incarceration history (Jail ever)	79% (434)
Time living with HIV (mean (SD)	10.9 (9.1)
Newly HIV diagnosed (within 6 months baseline)	11% (59)
Health-related quality of life	
Physical function	42.5 (15.8)
Mental function	35.4 (10.0)
Number of unmet needs (mean)	4



General HIV Stigma Among All Participants (n = 546)

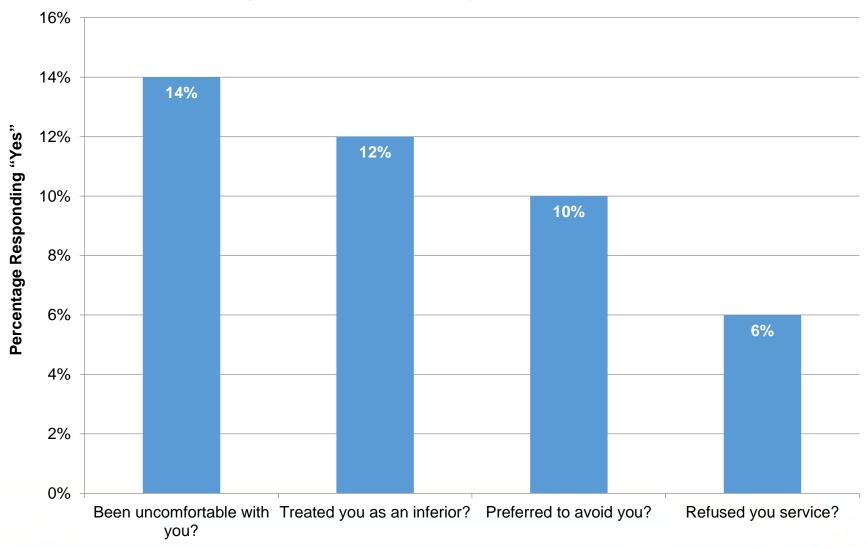
"People I know..."





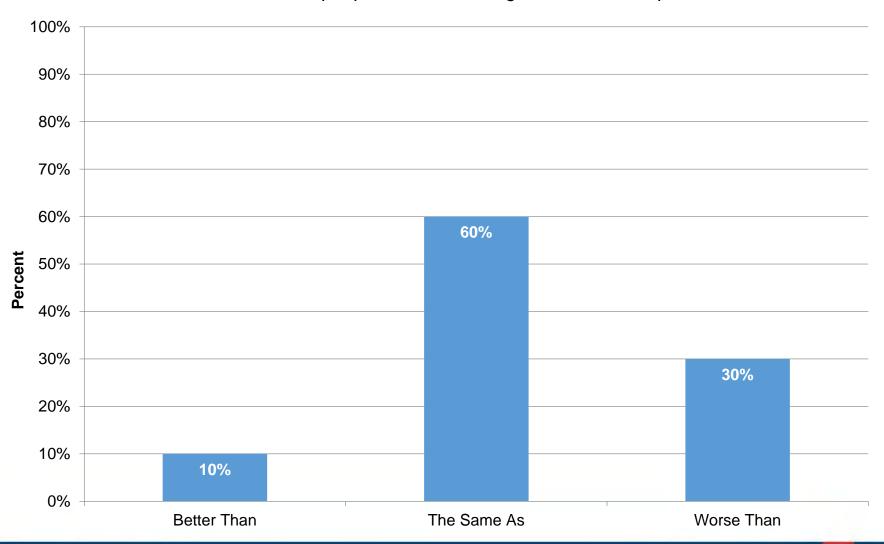
Health Care HIV Stigma Among All Participants (n=546)

"Since you have had HIV, has any health care provider ..."



Homelessness Stigma Among All Participants (n = 546)

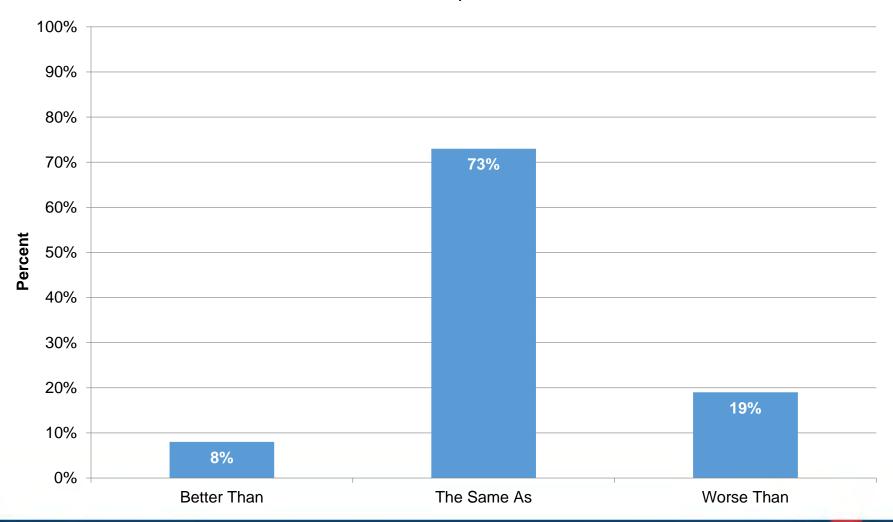
"Within the past 12 months do you feel that you were treated worse than, the same as, or better than people who have a regular and reliable place to live?"





Mental Health Stigma Among All Participants (n = 546)

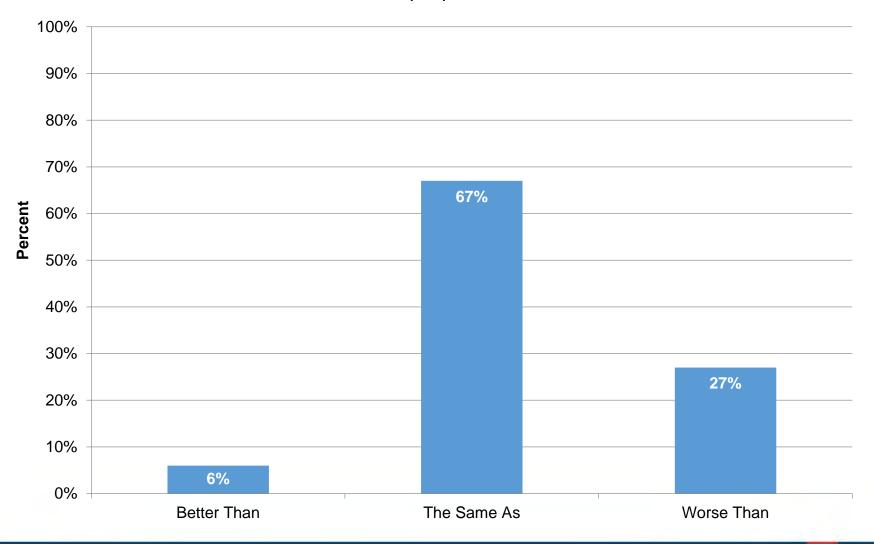
"Within the past 12 months, do you feel that you were treated worse than, the same as, or better than people who don't have a mental health condition or emotional problem?"



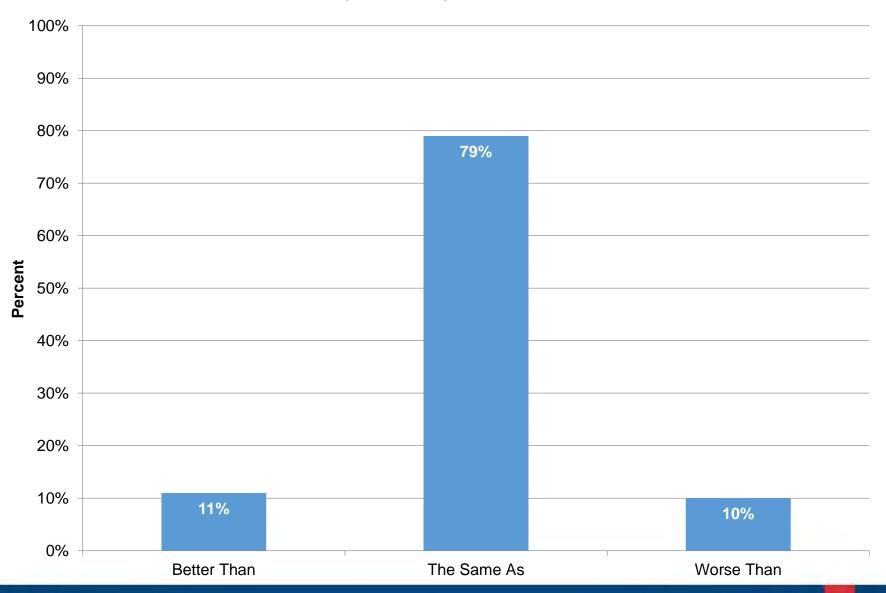


Substance Use Stigma Among All Participants (n = 546)

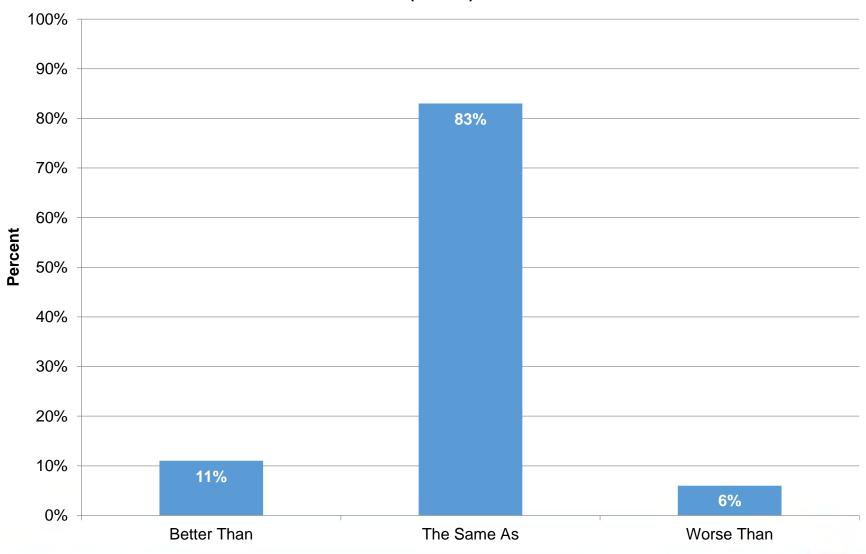
"Within the past 12 months, do you feel that you were treated worse than, the same as, or better than people who are clean and sober?"



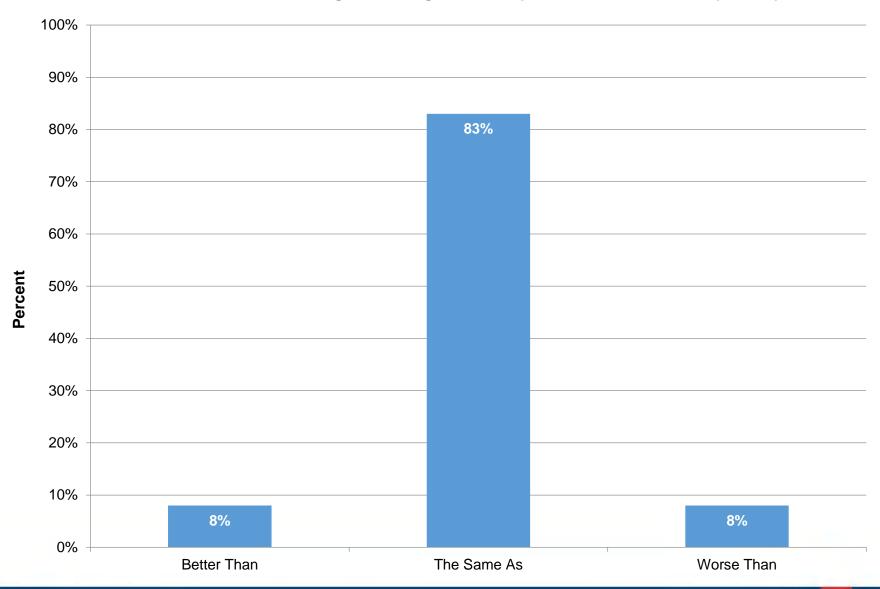
Health Care Provider Stigma Among All Participants: Homelessness (n = 546)



Health Care Provider Stigma Among All Participants: Mental Health Stigma (n = 546)



Health Care Provider Stigma Among All Participants : Substance Use (n =546)



Community approaches to addressing Stigma

Discussion





CommVell Health

Stigma

Site: CommWell Health

Presenter: Lisa McKeithan



Geographic location

Rural, southeast North Carolina





CASE EXAMPLE

Participant A

- 54 years old
- African American male
- MSM
- Unstably housed

Medical

- HIV positive with a long history of non-adherent medication use
- History of cancer
- Depression
- Cocaine dependence



Client Concerns

Stigma

1. Providers

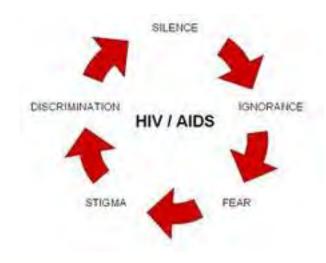
- Poor treatment by healthcare providers
- Reluctant to attend appointments
- Medication compliance

2. Family

- Shunned by family, peers
- Hiding his medication
- Disclosure

3. Community

- Handshakes
- Mistreatment





SPNS/ NC REACH

(North Carolina Rurally Engaging and Assisting Clients who are HIV positive and Homeless)

Network Navigators

- Enroll the participant in CommWell Health's inpatient substance abuse rehabilitation program for 45 days
- Advocate on participant's behalf
- Make referrals for BH, dental, SA
- Provide transportation to all medical and social services appointments
- Housing

Participant is living in an apartment and gainfully employed. He hopes to start a non profit organization to help other individuals with HIV.





SPNS/NC REACH

CommWell Health

- Waiting Rooms
 - MH Provider
 - Dental Hygienist
 - Nutritionist
- Patient Centered Medical Home
- Consumer Advisory Board

Staff

- Code of Behavior/Conduct/Ethics
- Cultural Sensitivity Trainings
- Webinars
- CAPUS C3 Trainings





Outreach in Community

- ✓ Festivals
- ✓ Health Fairs

- ✓ Faith-Based Community
- ✓ Local Business



AIDS Arms

- The AIDS Arms Health, Hope and Recovery Program addresses stigma by:
 - Assessing whether and how clients are experiencing stigma
 - Helping clients address internal and external stigma through Motivational Interviewing and Strengths-Based Counseling approaches
 - Providing advocacy on behalf of clients
 - Collaborating with and educating internal and external partners on an ongoing basis



Case Vignette – AIDS Arms

- Client with a history of AIDS-related health conditions, substance use disorder and chronic homelessness for > 20 years
- Did not believe that he would ever have permanent housing or that he deserved housing because of his substance use
- Further experience of discrimination by housing providers reaffirmed the internal stigma



Case Vignette – AIDS Arms (contd.)

- Health, Hope and Recovery Care Coordinator worked with client for 18 months
 - Utilized *Motivational Interviewing* strategies to help client reframe his experiences and follow up on appointments
 - Provided focused advocacy with housing provider on behalf of the client
 - Educated housing provider regarding *Housing First* principles
 - Enabled client to receive permanent housing
- Helping client address internal stigma and reframe his approach promoted stability and decreased acuity level



Addressing Stigma through a Socio-Ecological Approach



Socio-Ecological Framework

Societal/Public Policy

Community

Organizational

Interpersonal

Individual



Individual

- Help build protective factors
- Use a positive approach focus on strengths
- Use cognitive-behavioral approaches
- Empower
- Help build resilience, assertiveness skills
- Develop support and social network



Interpersonal

- Examine your own attitudes, beliefs
- Avoid stigmatizing labels
- Acknowledge concerns
- Strive to understand
- Use teachable moments
- Provide care and support
- Promote acceptance give more than lip service



Institutions, Community, Society

- Educate multiple levels including stakeholders, elected officials, community members, healthcare/other providers
- Leverage teachable moments
- Share stories
- Advocate
- Engage media print, internet, TV, social media; show examples of how stigma is being perpetuated or decreased
- Leverage stigma reduction resources
- Promote research
- Encourage policy development
- Utilize legal interventions



Group Think

How would you address stigma?



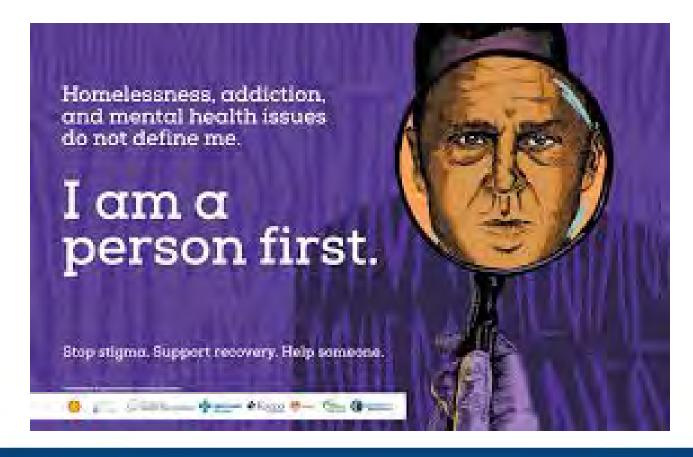
Conclusions

- •Stigma:
 - is multifaceted and complex
 - is associated with discrimination
 - comprises several domains
 - must be understood in order to be addressed effectively
 - interventions must occur at multiple levels in order to achieve elimination
- Prevention and treatment programs must help people develop strategies to help address and cope with internal and external stigma.
- Many resources are available







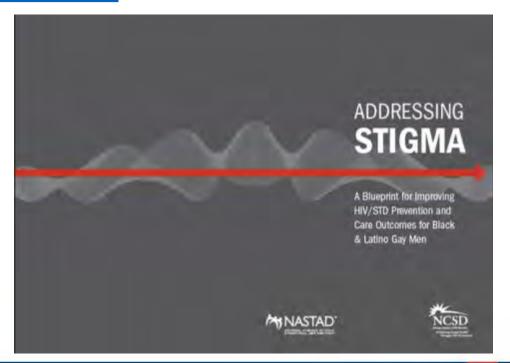








NASTAD: <u>www.nastad.org/resource/stigma-toolkit-addressing-stigma-blueprint-improving-hivstd-prevention-and-care-outcomes</u>





Selected Websites

- http://www.eachmindmatters.org/
- http://calmhsa.org/programs/stigma-discrimination-reduction-sdr/
- http://www.friendshipscount.com/
- http://promoteacceptance.samhsa.gov/archTelPDF/ADS Brouchure 508.pdf
- http://www.whocanyoutell.org/what-is-stigma
- http://www.hbo.com/addiction/stigma/52_coping_with_stigma.html
- http://www.cartercenter.org
- http://www.AIDSstigma.net
- http://www.nami.org (NAMI StigmaBuster)

Selected Videos

- Living in the Shadows Documentary; AIDS 2014, Melbourne Australia; www.youtube.com/watch?v=y10fvLpYZaA
- A New State of Mind: Ending the Stigma of Mental Illness, narrated by Glen Close; created by KVIE-TV, Sacramento, CA. Available for viewing at http://vimeo.com



Stigma Elimination

An ongoing process with many steps





Our dream of the day when stigma no longer exists, when services are available to all, and when every individual can look forward to a happy and fulfilling future, is within our reach."

-Rosalynn Carter



Questions???



Thank you!



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