Achieving Health Equity for Lesbian, Gay, Bisexual, and Transgender People

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The National LGBT Health Education Center, The Fenway Institute
Professor of Medicine, Harvard Medical School
WA PCA Training Series

- Session 2: 12/01-UDS data collection on sexual orientation and gender identity
  - Chris Grasso, MPH, Associate Director of Data and Informatics, The Fenway Institute

- Session 3: 1/04-LGBT health training for front-line staff
  - Chris Grasso, MPH, Associate Director of Training and Informatics, The Fenway Institute and Amika Brewster, Director, Patient Services and Financial Assistance, The Fenway Health

- Session 4: 2/01-Gender-affirming hormone management
  - Tim Cavanaugh, MD, Medical Director of Trans Health/Physician, The Fenway Health
The Fenway Institute

Fenway Health
- Independent 501(c)(3) FQHC
- Founded 1971
- Mission: To enhance the wellbeing of the LGBT community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research and advocacy
- Integrated primary care model, including HIV services and transgender health

The Fenway Institute
- Research, Education, Policy
LGBT Education and Training

The National LGBT Health Education Center offers educational programs, resources, and consultation to health care organizations with the goal of providing affirmative, high quality, cost-effective health care for lesbian, gay, bisexual, and transgender (LGBT) people.

- Training and Technical Assistance
- Grand Rounds
- On Line Learning
  - Webinars and Learning Modules
  - CE, and HEI Credit
- Resources and Publications
Why Programs for LGBT People
Stigma, Discrimination and Health

<table>
<thead>
<tr>
<th>Stigma</th>
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<tbody>
<tr>
<td>Interpersonal</td>
<td>Structural</td>
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Intrapersonal Stigma

Stress/Anxiety/Depression

Health Disparities/Inequities

Interpersonal Stigma
Structural Stigma

- Structural, or institutional, discrimination includes the policies of private and governmental institutions that intentionally restrict the opportunities of certain people, as well as policies that unintentionally restrict these opportunities.
Intrapersonal Stigma:

- “...And to the degree that the individual maintains a show before others that he himself does not believe, he can come to experience a special kind of alienation from self and a special kind of wariness of others.”

Goffman, The Presentation of Self in Everyday Life, 1959 (25)
Effects of Stigma on Health

- Internalized homophobia, experiencing discrimination, and expectations of rejection, were associated with HIV risk behavior (Hatzenbuehler, Nolen-Hoeksema, & Erickson, 2008)

- Enacted and anticipated stigma resulted in approximately a 40% increase in delaying needed urgent and preventive care in a sample of 2,578 FTM trans masculine people. Reisner et. al. 2015
Health Issues Throughout the Life Course

Childhood & Adolescence

Early & Middle Adulthood

Later Adulthood

www.lgbthealtheducation.org
LGBT Disparities: Healthy People 2020

- LGBT youth
  - 2 to 3 times more likely to attempt suicide.
  - More likely to be homeless (20-40% are LGBT)
  - Risk of HIV, STD’s

- MSM are at higher risk of HIV/STDs, especially among communities of color

- LGBT populations have the highest rates of tobacco, alcohol, and other drug use

- Lesbians and bisexual women are less likely to get preventive services for cancer
LGBT Disparities: Healthy People 2020

- Transgender individuals experience a high prevalence of HIV/STDs, victimization, mental health issues, and suicide
  - They are also less likely to have health insurance than heterosexual or LGB individuals
- Elderly LGBT individuals face additional barriers to health because of isolation, fewer family supports, and a lack of social and support services
L,G,B,T Concepts
Gender Identity and Sexual Orientation: The basics

- Gender Identity
- Sexual Orientation
- Bisexual
- Queer
- Transgender
- Trans-Man
- Trans-Woman
- MTF
- Straight
- Masculine
- Feminine
- Asexual
- Non-Binary
- MSM
- FTM
- Lesbian
- Gay
- Genderqueer
- Ally
- Desire
- Behavior
Sexual Orientation and Gender Identity are Not the Same

- All people have a sexual orientation and gender identity
  - How people identify can change
  - Terminology varies
- Gender Identity ≠ Sexual Orientation
Gender Identity and Gender Expression

- Gender identity
  - A person's internal sense of their gender (do I consider myself male, female, both, neither?)
  - All people have a gender identity

- Gender expression
  - How one presents themselves through their behavior, mannerisms, speech patterns, dress, and hairstyles
  - May be on a spectrum
A 2013 community-based survey of 452 transgender adults in Massachusetts, 40.9% of respondents described themselves as having a “non-binary gender identity.”
The T in LGBT: Transgender

- Gender identity not congruent with the assigned sex at birth
- Alternate terminology
  - Transgender woman, trans woman, male to female (MTF)
  - Transgender man, trans man, female to male (FTM)
- Non-binary, genderqueer
  - Genderqueer
  - Trans masculine, Trans feminine
- Gender identity is increasingly described as being on a spectrum
Sexual Orientation

- Sexual orientation: how a person identifies their physical and emotional attraction to others
  - Desire
  - Behavior:
    - Men who have sex with men- MSM (MSMW)
    - Women who have sex with women- WSW (WSWM)
  - Identity:
    - Straight, gay, lesbian, bisexual, queer--other

Dimensions of Sexual Orientation:

- Identity
  - Do you consider yourself gay, lesbian, bisexual, straight, queer?
- Behavior
  - Do you have sex with: men? women? both?
- Attraction/Desire
  - What gender(s) are you attracted to physically and emotionally?
A Web of Factors

Intersectionality
Gender Expression
Native Language
Disability
Culture
Food Security
Class
Race
Socio-Economic Status
Gender Identity
Ethnicity
Physical Health
Religious background
Physical Mobility
Mental Health
Level of Education
Legal Status
Housing
Age
Sexual Orientation
Level of Education
Intersectionality

- Intersectional...“theory proposes that we should think of each element or trait of a person as inextricably linked with all of the other elements in order to fully understand one's identity.”
  

- “Intersectional approaches are based on the premise that individual and group identities are complex— influenced and shaped not just by race, class, ethnicity, sexuality/sexual orientation, gender/gender identity, physical disabilities, and national origin but also by the confluence of all of those characteristic

A Black Gay Man

“A gay man has to deal with homophobia. A black man has to deal with racism. But a black gay man will have to deal with homophobia and racism (often at the same time). It is often the case that he will face racism inside the LGBT community and homophobia in the black community”.

See more at: http://www.equality-network.org/our-work/intersectional/#sthash.uUMCTvIX.dpuf
Vulnerability to Poverty

- While children generally have higher rates of poverty than adults, children of LGB parents are especially vulnerable to poverty
  - African American children in gay male households have the highest poverty rate (52.3%) of any children in any household type
  - the rate for children living with lesbian couples is 37.7%
- Transgender respondents to the National Transgender Discrimination Survey (NTDS) were 4 times more likely than the general population to have a household income of less than $10,000

Overcoming Barriers
Population Health: Ending LGBT Invisibility in Health Care

- Has a clinician ever asked you about your history of sexual health, your sexual orientation or your gender identity?
- How often do you talk with your patients about their sexual history, sexual orientation, or gender identity?
Getting to know patients in clinical settings
Proportion of Physicians Discussing Topics with HIV-Positive Patients

<table>
<thead>
<tr>
<th>Topic</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Adherence to ART</td>
<td>84%</td>
</tr>
<tr>
<td>Condom use</td>
<td>16%</td>
</tr>
<tr>
<td>HIV transmission and/or risk reduction</td>
<td>14%</td>
</tr>
</tbody>
</table>

(From AmJPublicHealth. 2004;94:1186-92)
Discomfort as a Barrier

“Ironically, it may require greater intimacy to discuss sex than to engage in it.”

The Hidden Epidemic
Institute of Medicine, 1997
Taking a History of Sexual Health

http://www.lgbthealtheducation.org/publications/
Taking a History of Sexual Health

- The core comprehensive history for LGBT patients is the same as for all patients (keeping in mind unique health risks and issues of LGBT populations)
- Get to know your patient as a person (e.g., partners, children, jobs, living circumstances)
  - “Tell me about yourself”
- Use inclusive and neutral language
- For all patients
  - Make it routine
  - Make no assumptions
  - Put in context and assure confidentiality
Institute of Medicine Reports


- *Collecting SOGI Data in Electronic Health Records* (2013): “…data collection should start now to better understand the health care issues experienced by LGBT people.”
Gathering LGBT Data During the Process of Care

DATA INPUT AT HOME
ARRIVAL
REGISTER ONSITE

SELF REPORT OF INFORMATION ON SEXUAL ORIENTATION (SO) AND GENDER IDENTITY (GI)

SO/GDATA REPORTED
INFORMATION ENTERED INTO EHR

SO/GDATA NOT REPORTED
PROVIDER VISIT INPUT FROM HISTORY

YES
INFORMATION ENTERED INTO EHR

NO
Collecting Demographic Data on Sexual Orientation (Example)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Which of the categories best describes your current annual income? Please check the correct category:</td>
<td>□ &lt;$10,000 □ $10,000-14,999 □ $15,000-19,999 □ $20,000-29,999 □ $30,000-49,999 □ $50,000-79,999 □ Over $80,000</td>
</tr>
<tr>
<td>2. Employment Status:</td>
<td>□ Employed full time □ Employed part time □ Student full time □ Student part time □ Retired □ Other _________</td>
</tr>
<tr>
<td>3. Racial Group(s):</td>
<td>□ African American/Black □ Asian □ Caucasian □ Multi racial □ Native American/Alaskan Native/inuit □ Pacific Islander □ Other _________</td>
</tr>
<tr>
<td>4. Ethnicity:</td>
<td>□ Hispanic/Latino/Latina □ Not Hispanic/Latino/Latina</td>
</tr>
<tr>
<td>5. Country of Birth:</td>
<td>□ USA □ Other _________</td>
</tr>
<tr>
<td>6. Language(s):</td>
<td>□ English □ Español □ Français □ Portugês □ Русский</td>
</tr>
<tr>
<td>7. Do you think of yourself as:</td>
<td>□ Lesbian, gay, or homosexual □ Straight or heterosexual □ Bisexual □ Something Else □ Don’t know</td>
</tr>
<tr>
<td>8. Marital Status:</td>
<td>□ Married □ Partnered □ Single □ Divorced □ Other _________</td>
</tr>
<tr>
<td>8. Veteran Status:</td>
<td>□ Veteran □ Not a veteran</td>
</tr>
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NATIONAL LGBT HEALTH EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE
Collecting Demographic Data on Gender Identity

<table>
<thead>
<tr>
<th>What is your current gender identity?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Male</td>
</tr>
<tr>
<td>□ Female</td>
</tr>
<tr>
<td>□ Transgender Male/Trans Man/FTM</td>
</tr>
<tr>
<td>□ Transgender Female/Trans Woman/MTF</td>
</tr>
<tr>
<td>□ Gender Queer</td>
</tr>
<tr>
<td>□ Additional Category (please specify)</td>
</tr>
<tr>
<td>_________</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>What sex were you assigned at birth?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Male</td>
</tr>
<tr>
<td>□ Female</td>
</tr>
<tr>
<td>□ Decline to Answer</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What is the name you use?</th>
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<table>
<thead>
<tr>
<th>What are your pronouns (e.g. he/him, she/he, they/them)?</th>
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</thead>
</table>
Education About Culturally Appropriate Care
Focus on Specific Issues

- HIV Prevention
- Transgender Health
- Effective Communications
Clinical Practices to Improve HIV Prevention and Care for MSM and Transgender People
HIV Diagnoses by Transmission Category, United States and 6 Dependent Areas, 2014

- Male-to-Male Sexual Contact (MSM): 67%
- Heterosexual Contact: 25%
- Injection Drug Use (IDU): 6%
- MSM/IDU: 3%
- Other: <1%

HIV Incidence in the United States, 2008-2013

There are approximately 50,000 new HIV diagnoses each year in the US.

Incidence among MSM and MSM/IDU increased 15% from 2008 to 2011. Young black MSM accounted for more than half of new infections among MSM aged 13-24 over this time.
Why is HIV incidence highest among black MSM?

- Sexual risk behaviors and substance use do not explain the differences in HIV infection between black and white MSM.

- The most likely causes of disproportionate HIV infection rates are:
  - Barriers to access health care
  - Low frequency of recent HIV testing
  - Delayed treatment of STI’s which facilitate HIV transmission
  - High HIV prevalence in black MSM networks, especially among those who identify as gay.
Transgender Women are also at High Risk

- Estimated HIV prevalence in transgender women
  - 28% in US
  - 56% in African-Americans
  - 18-22% worldwide

- Transgender women are nearly 49 times more likely to have HIV than other adults of reproductive age

- Risk factors for HIV include
  - Social and economic marginalization
  - High unemployment, engaging in sex work
  - Limited health care access
  - Lack of familial support

Baral, 2013; Herbst, 2008; Schulden, 2008
Basic Steps to Improve HIV Prevention in Clinical Settings

Universal HIV Screening

HIV Positive
- HIV care / antiretroviral therapy / Counseling / Adherence

Reduce HIV Incidence

HIV Negative
- Safer sex
- Address STIs
- PEP or PrEP
- Counseling / Adherence

(USPSTF, 2013 and CDC, 2010)
Pre-exposure prophylaxis (PrEP)

- Oral antiretrovirals taken in a continuous or episodic manner
- Once-daily oral tenofovir-emtricitabine approved for PrEP by the FDA
- Does not require the knowledge or cooperation of one’s partners

www.lgbtheatheducation.org
How well do HIV prevention interventions work?

![Bar chart showing Relative Risk Reduction for different HIV prevention interventions.]

- Treatment as prevention: 100%
- Post-exposure prophylaxis: 90%
- Condoms: 80%
- Pre-exposure prophylaxis: 95%

Adherence is crucial for optimal efficacy.

Pearson correlation: 0.86 (P=0.003).


www.lgbthealtheducation.org
PrEP prescribing guidelines

1. Determine eligibility:
   1. Document negative HIV test and high risk of infection
   2. Confirm creatinine clearance > 60 mL/min

2. Assess for conditions of concern:
   1. HBsAg/HBsAb for everyone
   2. Pregnancy test for fertile women

3. Prescribe: Tenofovir-emtricitabine, 1 tablet by mouth daily (≤ 90-day supply)

4. Monitor:
   1. Every 3 months: Check Creatinine*, HIV, pregnancy status
   2. Every 6 months: STI screening

Clinical Care of Transgender People Requires Knowledge of Gender Identity and Sex Assigned at Birth
Appropriate Screening: Jake R’s Story

- Jake R is a 45-year-old man who came in with pain and on x-ray what appeared to be metastases from a unknown primary cancer
- Evaluation ultimately showed that he had developed cancer in his residual breast tissue after surgery to remove his breasts
- No one told Jake that he needed routine breast cancer screening, even though his mother and sister also had breast cancer
Quality Care for Transgender People: Louise M’s Story

- Louise M is a 59-year-old woman who developed a high fever and chills after head and neck surgery.
- The source of infection was her prostate gland (acute prostatitis), but no one knew that she had this anatomy.
- No one asked her about her gender identity or knew she was transgender.
Caring for Transgender People Who Wish to Raise Families

www.lgbthealtheducation.org
Basic Principles

- Counsel on embryo, egg and sperm Banking
  - 5/41 of trans men conceived on hormones
  - 25/41 used testosterone prior to pregnancy
  - 20/25 resumed menstruation within 6 months after stopping testosterone
- For Gestational Pregnancies
  - Pre-Conception Counseling and Ongoing Support (Ellis et.al. J Midwif and Women’s Health 2015, Jan 60 (1)62-69)
    - Testosterone Use
- Alternative methods: Adoption, Surrogacy, IVF
- Should be taught to primary care providers regarding all LGBT couples
- Above all, affirmative care throughout

www.lgbthealtheducation.org
Communications: The Whole Team
Anticipating and Managing Expectations

- You are almost certainly not the first health care staff person an LGBT individual has met.
- If the patient has experienced insensitivity, a lack of awareness, or discrimination, he or she may be on guard, or ready for more of the same from you.
- Don’t be surprised if a mistake, even an honest one, results in an emotional reaction.
- Don’t personalize the reaction.
- Apologizing when patients have uncomfortable reactions, even if what was said was well intentioned, can help de-fuse a difficult situation and re-establish a constructive dialogue about the need for care.
Avoiding Assumptions

- You cannot assume someone’s gender or sexual orientation based on how they look or sound.
- To avoid assuming gender or sexual orientation with new patients:
  - *Instead of:* “How may I help you, sir?”
  - *Say:* “How may I help you?”
  - *Instead of:* “He is here for his appointment.”
  - *Say:* “The patient is here in the waiting room.”
  - *Instead of:* “Do you have a wife?”
  - *Say:* “Are you in a relationship?”
  - *Instead of:*” What are your mother and fathers’ names?”
  - *Say:* “What are your parents’ names.”
Keeping Up with Terminology

- Obvious “don’ts” include
  - Use of any disrespectful language
  - Gossiping about a patient’s appearance or behavior
  - Saying things about someone not necessary for their care
    - “You look great, you look like a real woman/ real man”
    - “You are so pretty I cannot believe you are a lesbian”
Putting What You Learn into Practice....

- If you are unsure about a patient’s preferred name or pronoun
  - “I would like be respectful—what name and pronoun would you like me to use?”

- If a patient’s name doesn’t match insurance or medical records
  - “Could your chart/insurance be under a different name?”
  - “What is the name on your insurance?”

- If you accidentally use the wrong term or pronoun
  - “I’m sorry. I didn’t mean to be disrespectful.”
Creating a Welcoming and Inclusive Environment for Caring, Working and Learning
Adding Affirmative Imagery and Content to Education and Marketing Materials
Do Ask, Do Tell: Talking to your Provider about being LGBT
Our Challenge:
Quality Care for All, Including LGBT People

Data Collection
Clinical Education
Consumer Education
Patient Centered Care

Fenway
GUIDE TO LESBIAN, GAY, BISEXUAL, AND TRANSGENDER HEALTH
2nd Edition
Harvey J. Makaiola, MD
Kenneth H. Mayer, MD
Jennifer Potter, MD
Hilary Goldhammer, MS

Do Ask, Do Tell:
Talking to your health care provider about being LGBT

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The National LGBT Health Education Center provides educational programs, resources, and consultation to health care organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, and transgender (LGBT) people.

The Education Center is a part of The Fenway Institute, the research, training, and health policy division of Fenway Health, a Federally Qualified Health Center, and one of the world’s largest LGBT-focused health centers.