Transforming Your Practice To Be Welcoming and Inclusive of People at Risk for HIV

Harvey J Makadon, MD, FACP

Professor of Medicine (part time), Harvard Medical School
Division of General Medicine and Primary Care, Beth Israel Deaconess Medical Center
Why Programs for LGBT Health Education....
The Impact of Stigma on Health

- Interpersonal Stigma
- Structural Stigma
- Intrapersonal Stigma

Minority Stress/Anxiety/Depression

Health Disparities
Interpersonal Stigma
Structural Stigma

Structural, or institutional stigma results from the policies of private and governmental institutions that intentionally restrict the opportunities of certain people, as well as policies that unintentionally restrict these opportunities.

Courtesy of Fenway Health
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 Live, 1959
Stigma in Health Care
Stigma and Health

- LGBT individuals face health disparities linked to societal stigma, discrimination, and denial of their civil and human rights.
- Discrimination against LGBT persons has been associated with high rates of psychiatric disorders, substance abuse, and suicide.
- Experiences of violence and victimization are frequent for LGBT individuals, and have long-lasting effects on the individual and the community.
- Personal, family, and social acceptance of sexual orientation and gender identity affects the mental health and personal safety of LGBT individuals.

Studies 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. (White, Reisner et. al. 2015)
Creating a Culture of Resilience!

- “We’re so focused on risk factors...that we forget about resilience,...It seems a smarter way...would be to look at the guys who are thriving in spite of the adversities, how they pulled that off, see what the lessons learned are, and apply that to the interventions we already use and have developed.” Ron Stall

- “If we can identify programs that engage youth so they feel good about themselves...there will be fewer problems down the road.” Ken Mayer

Who are LGBTQ People: The Basics!
Sex and Gender

- Often used synonymously
- Understanding increasingly divergent
- Sex relates to one’s biology (anatomy, genes)
  - Male or Female
  - Intersex, Indeterminate, Unspecified
- Gender refers to the attitudes, feelings, and behaviors that a given culture associates with a person’s biological sex
  - Increasingly Expansive Individual Identities Come from Within
    - Cisgender (Not Transgender) and Transgender
      - Men, Women (male, female)
    - Gender Non-binary
      - Masculine, Feminine
Understanding Gender Identity and Sexual Orientation:

- Everyone has one of each!
- Independent variables, they are not related.
- How people identify themselves can change over time.
- Terminology varies and evolves.
- Concepts can be more complex than reality!
Gender Identity and Gender Expression

- **Gender Identity**: One's innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.

- **Gender Expression**: Relates to external appearance generally expressed through behavior, clothing, haircut or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.

VICTORY: Nevada passes the most progressive birth certificate gender change policy in the nation!

By: Arli Christian
Gender Expansive!
Beyond the Binary
Thinking about Sex and Gender
Shannon Dea
Gender Neutral Emojis

- A 2013 community-based survey of 452 transgender adults in Massachusetts, 40.9% of respondents described themselves as having a “non-binary gender identity.”

Oregon court rules that ‘nonbinary’ is a legal gender

BY CORINNE SEGAL  June 11, 2016 at 3:27 PM EDT

An Oregon circuit court has ruled that a resident can change their legal gender to “nonbinary,” a gender identity that is neither male nor female.
Oregon Becomes First State to Issue Gender Non-Binary ID Cards

Those who do not identify as male or female will be able to select “X” for non-specified gender when applying for IDs.
Transgender/Gender Non-binary

- **Transgender**
  - Umbrella term for people whose gender identity is not congruent with the sex they were assigned at birth.
    - Alternate terminology:
      - Transgender woman, trans woman, male to female (MTF)
      - Transgender man, trans man, female to male (FTM)

- **Gender Non-Congruent, Non-Binary**
  - Identify outside the male/female binary
  - Terminology varies
    - Genderqueer, Gender expansive, Gender fluid

- **Trans masculine, Transfeminine**
Sexual Orientation

- Describes ones emotional, romantic and/or sexual attraction to other people.
- Three dimensions:
  - Desire
    - attraction
  - Behavior
    - MSM(MSMW)
    - WSW(WSWM)
  - Identity
    - Straight,
    - Gay,
    - Lesbian,
    - Bisexual,
    - Queer
    - SGL (Same gender loving)
What Does the ‘Q’ Stand For?

- ‘Q’ may reflect someone who is ‘questioning’ their sexual orientation, attraction to men, women, both, or neither, or their gender identity, considering whether they are transgender or gender non-binary.

- ‘Q’ may stand for ‘queer,’ a way some people identify to state they are not straight but also don’t identify with gay, lesbian or bisexual identities, or genderqueer, a term used to identify as non-binary. The term queer is particularly common among younger people and also used by people of all ages.
Intersectionality
Intersectionality

- It's been around since the late 1980's but *intersectionality* is a word that's new to many of us. It's used to refer to the complex and cumulative way that the effects of different forms of discrimination (such as racism, sexism, and classism) combine, overlap, and yes, intersect—especially in the experiences of marginalized people or groups. (https://www.merriam-webster.com/words-at-play/intersectionality-meaning)
Intersectionality

- Race
- Ethnicity
- Education
- Employment
- Gender Identity
- Literacy
- Sexual Orientation
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
Issues for Discussion

- Ending LGBT Invisibility
- Environments for Inclusive Care
- Communications
Invisible Unless Counted!
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>
</tr>
</thead>
<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>

(Adapted from *Am J Public Health*, 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
Collecting SO/GI Data in EHRs
Many Have Concerns About Asking?

Gay and Transgender Patients to Doctors: We’ll Tell. Just Ask.

By JAN HOFFMAN  MAY 29, 2017
Patient Centered Approaches to Sexual Orientation and Gender Identity: The Equality Study, AH Haider et al.

- **Results**
  - Mean (SD) age of patient and clinician participants was 49 (16.4) and 51 (9.4) years, respectively. Qualitative interviews suggested that patients were less likely to refuse to provide sexual orientation than providers expected.
  - Nationally, 154 patients (10.3%) reported that they would refuse to provide sexual orientation; however, 333 (77.8%) of all clinicians thought patients would refuse to provide sexual orientation.
  - After adjustment for demographic characteristics, only bisexual patients had increased odds of refusing to provide sexual orientation compared with heterosexual patients (odds ratio, 2.40; 95% CI, 1.26-4.56).

- *JAMA Intern Med.* Published online April 24, 2017.
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 LGBTQ people.”
Advances in SO/GI Data Collection

- The U.S. Centers for Medicare and Medicaid Services and the Office of the National Coordinator for Health Information Technology announced October 6, 2015 that they will require that all EHR systems certified under the Meaningful Use incentive program have the capacity to collect sexual orientation and gender identity information from patients.

- In March 2016, HRSA announced in a program assistance letter that all FQHC’s were required to routinely collect and report data on sexual orientation and gender identity as part of their uniform data system.
Preparation for Collecting Data in Clinical Settings

- **Clinicians**: Need to learn about LGBT health and the range of expression related to identity, behavior, and desire. Staff needs to understand concepts.

- **Non-clinical staff**: Front desk and patient registration staff must also receive training on LGBT health, communicating with LGBT patients, and achieving quality care with diverse patient populations.

- **Patients**: Need to learn about why it is important to communicate this information, and feel comfortable that it will be used appropriately.
Providing Information to Patients

Thank you for taking the time to complete these questions. If you have additional questions, we encourage you to speak with your provider.

We recently added new questions about sexual orientation and gender identity to our registration forms.

Our health center thinks it is important to learn this information from our patients. Inside are some frequently asked questions about why we are asking these questions and how the information will be used.
Gathering LGBTQ Data During the Process of Care

DATA INPUT AT HOME

ARRIVAL

REGISTER ONSITE

SO/GI DATA REPORTED

INFORMATION ENTERED INTO EHR

PROVIDER VISIT
INPUT FROM HISTORY

YES

NO

INFORMATION ENTERED INTO EHR

SELF REPORT OF INFORMATION ON SEXUAL ORIENTATION (SO) AND GENDER IDENTITY (GI)
Collecting Demographic Data on Sexual Orientation (Example)

<table>
<thead>
<tr>
<th>1. Which of the categories best describes your current annual income? Please check the correct category:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ &lt;$10,000</td>
</tr>
<tr>
<td>□ $10,000–14,999</td>
</tr>
<tr>
<td>□ $15,000–19,999</td>
</tr>
<tr>
<td>□ $20,000–29,999</td>
</tr>
<tr>
<td>□ $30,000–49,999</td>
</tr>
<tr>
<td>□ $50,000–79,999</td>
</tr>
<tr>
<td>□ Over $80,000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Employment Status:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Employed full time</td>
</tr>
<tr>
<td>□ Employed part time</td>
</tr>
<tr>
<td>□ Student full time</td>
</tr>
<tr>
<td>□ Student part time</td>
</tr>
<tr>
<td>□ Retired</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Racial Group(s):</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ African American/Black</td>
</tr>
<tr>
<td>□ Asian</td>
</tr>
<tr>
<td>□ Caucasian</td>
</tr>
<tr>
<td>□ Multi racial</td>
</tr>
<tr>
<td>□ Native American/Alaskan Native/Inuit</td>
</tr>
<tr>
<td>□ Pacific Islander</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Ethnicity:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Hispanic/Latino/Latina</td>
</tr>
<tr>
<td>□ Not Hispanic/Latino/Latina</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Country of Birth:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ USA</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Language(s):</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ English</td>
</tr>
<tr>
<td>□ Español</td>
</tr>
<tr>
<td>□ Français</td>
</tr>
<tr>
<td>□ Português</td>
</tr>
<tr>
<td>□ Русский</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. Do you think of yourself as:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Lesbian, gay, or homosexual</td>
</tr>
<tr>
<td>□ Straight or heterosexual</td>
</tr>
<tr>
<td>□ Bisexual</td>
</tr>
<tr>
<td>□ Something Else</td>
</tr>
<tr>
<td>□ Don’t know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. Marital Status:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Married</td>
</tr>
<tr>
<td>□ Partnered</td>
</tr>
<tr>
<td>□ Single</td>
</tr>
<tr>
<td>□ Divorced</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. Veteran Status:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Veteran</td>
</tr>
<tr>
<td>□ Not a veteran</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1. Referral Source:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Self</td>
</tr>
<tr>
<td>□ Friend or Family Member</td>
</tr>
<tr>
<td>□ Health Provider</td>
</tr>
<tr>
<td>□ Emergency Room</td>
</tr>
<tr>
<td>□ Ad/Internet/Media/Outreach Worker/School</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

Fenway Health Registration Form
Collecting Data on Gender Identity

- **What is your current gender identity?**
  - Male
  - Female
  - Transgender Male/Trans Man/FTM
  - Transgender Female/Trans Woman/MTF
  - Gender Queer
  - Additional Category (please specify)
    __________

- **What sex were you assigned at birth?**
  - Male
  - Female
  - Decline to Answer

- **What name do you use?**
- **What are your pronouns (e.g. he/him, she/her, they/them)?**
Collecting SO/GI Data During Onsite Registration

- Patients should be asked standardized SO/GI questions as part of the demographic section on registration
- Questions can be included alongside other demographic questions (i.e. race, ethnicity, language)
- Patients should be informed that information will help health care providers to deliver appropriate prevention, screening, and treatment services
  - SOGI information should be updated as needed on an ongoing basis for both new and returning patients
- Patients must be assured information will be kept confidential
Directly Asking SO/GI Questions

- If patients leave SO/GI questions unanswered on registration forms, health care providers should re-ask these questions during the clinical encounter.
- Sexual orientation, sexual behavior, gender identity, name and pronouns questions should be asked during the first clinical visit and on an ongoing basis as indicated.
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
Creating a Welcoming and Inclusive Environment for Caring, Working and Learning
Images on Education and Marketing Materials Should Reflect Population Cared For
Do Ask, Do Tell: Talking to your Provider about being LGBT
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.”
What are your pronouns?

- People may use a range of pronouns, including she/her/hers and he/him/his, as well as less-common pronouns such as they/them/theirs and ze/hir/hirs (pronounced zee/hear/hears). To ask for a patient’s pronouns, remember not to make assumptions and if not already asked simply say: “I would like to refer to you respectfully. What are your pronouns?”

<table>
<thead>
<tr>
<th>Subjective</th>
<th>Objective</th>
<th>Possessive Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>He</td>
<td>Him</td>
<td>His</td>
</tr>
<tr>
<td></td>
<td></td>
<td>He is here</td>
</tr>
<tr>
<td></td>
<td></td>
<td>That is him</td>
</tr>
<tr>
<td></td>
<td></td>
<td>His record is there.</td>
</tr>
<tr>
<td>She</td>
<td>Her</td>
<td>Hers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>She is here</td>
</tr>
<tr>
<td></td>
<td></td>
<td>That is her chart</td>
</tr>
<tr>
<td></td>
<td></td>
<td>These results are hers.</td>
</tr>
<tr>
<td>They</td>
<td>Them</td>
<td>Theirs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>They are late.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>This is for them.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The chart is theirs.</td>
</tr>
<tr>
<td>Ze</td>
<td>Hir</td>
<td>Hirs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ze is waiting for an x-ray.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The therapist is here to see hir.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>That coat is hirs.</td>
</tr>
</tbody>
</table>
Harvey J Makadon, MD, FACP

Professor of Medicine (part time), Harvard Medical School
Division of General Medicine and Primary Care, Beth Israel Deaconess Medical Center