



RUTGERS

# At the End of the Rainbow: Sexual and Gender Minority Well-Being at the End of Life



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(she/her)**

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You have worked so hard to make your practice inclusive!



**Preferred Pronoun:** ☐ He ☐ She ☐ They ☐ Ze ☐ A pronoun not listed ☐ No pronoun preference

We require the following information for the purposes of helping our staff use the most respectful language when addressing you, understanding our population better, and fulfilling our grant reporting requirements. The options for some of these questions were provided by our funders. Please help us serve you better by selecting the best answers to these questions. Thank You.

**Preferred Spoken/Written Language:**

- ☐ English ☐ Spanish  
☐ American Sign Language  
☐ Other: \_\_\_\_\_

Language interpretation services needed?

- ☐ No  
☐ Yes, language: \_\_\_\_\_

**Sexual Orientation**

- ☐ Lesbian  
☐ Gay ☐ Straight  
☐ Bisexual ☐ Something Else  
☐ Queer ☐ Decline to Answer

**Gender Identity:**

- ☐ Male/Man  
☐ Female/Woman  
☐ TransMale/TransMan  
☐ TransFemale/TransWoman  
☐ Genderqueer/Gender nonconforming  
☐ Something Else  
☐ Decline to Answer

**Race:** \*Select all that apply\*

- ☐ American Indian/Alaska Native  
☐ Black and/or African American  
☐ White/Caucasian

Asian:

- ☐ Asian Indian  
☐ Chinese ☐ Korean  
☐ Filipino ☐ Vietnamese  
☐ Japanese ☐ Other

Native Hawaiian/Pacific Islander:

- ☐ Native Hawaiian  
☐ Guamanian or Chamorro  
☐ Samoan  
☐ Other Pacific Islander

☐ Decline to Answer

**Sex Assigned at Birth:**

- ☐ Male ☐ Intersex  
☐ Female ☐ Decline to Answer

**Ethnicity:**

- ☐ Non-Hispanic/Latino  
☐ Dominican  
☐ Cuban  
☐ Mexican, Chicano/a  
☐ Puerto Rican  
☐ Other Hispanic/Latino  
☐ Decline to Answer

**Housing Status:**

- ☐ Stable Housing  
☐ Homeless  
☐ Decline to answer

If homeless,  
select which best applies:

- ☐ Street  
☐ Homeless Shelter  
☐ Transitional  
☐ Doubling Up (not paying rent)

**Veteran?** ☐ Yes ☐ No

**Migrant Worker?**

☐ Yes ☐ No

**How did you first learn of Callen-Lorde?**

- ☐ Friend/Patient  
☐ Referral  
☐ Health Fair/Presentation  
☐ Callen-Lorde Website/Internet  
☐ Callen-Lorde Brochure/Ad  
☐ Facebook/Social Media  
☐ TV/Radio/Print Media

**Do you have a non Callen-Lorde primary care provider that you want to continue to see?**

☐ Yes ☐ No

# Your new patient



## Some questions...?

- What does your patient's SOGI have to do with their health?
- How might their SOGI impact your relationship with them and their support persons?
- What are the “best practices” in caring for LGBTQ+ patients?  
Are there any best practices?

# Agenda

- Introduce commonly used language and concepts re: SGM health
- Discuss health disparities and current issues in the health and care of SGM persons
- Apply content to the special issues for SGM persons and their loved ones at the end of life
- Concrete suggestions for creating an affirming and inclusive environment
- Have an open and honest dialogue



# Happy, Healthy, Fulfilling Lives

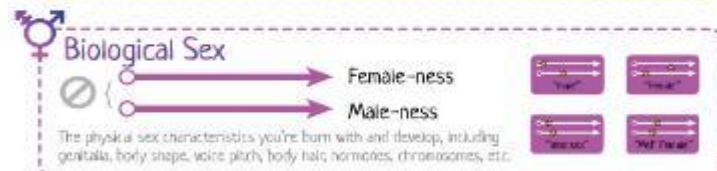
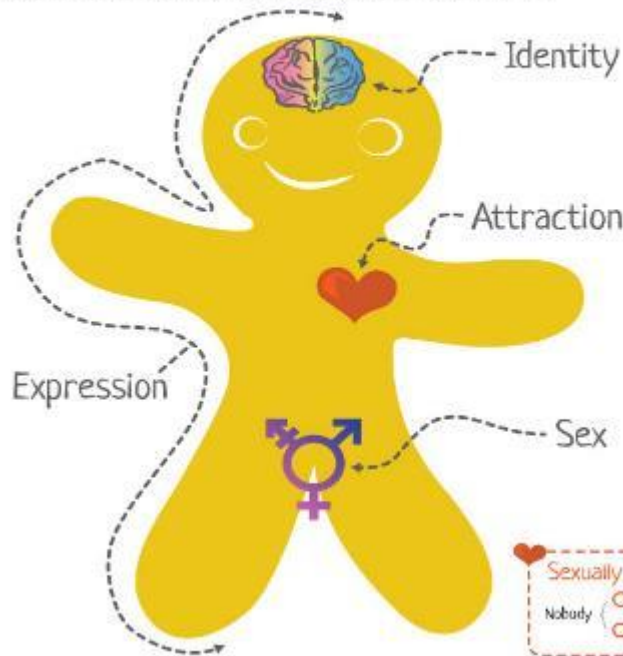


# What is the difference between sexual orientation (SO) and Gender Identity (GI)?

## The Genderbread Person v3.3

by its pronounced **METROsexual**.com

Gender is one of those things everyone thinks they understand, but most people don't. Like Aception, Gender isn't binary. It's not either/or. In many cases it's both/and. A bit of this, a dash of that. This tasty little guide is meant to be an appetizer for gender understanding. It's okay if you're hungry for more. In fact, that's the idea.



For a bigger bite, read more at <http://bit.ly/genderbread>

In each grouping, circle all that apply to you and put a point, depicting the aspects of gender towards which you experience attraction.



# LGBTQ+ health: defining terms

## **LGBTQ+ vs. SGM**

### **Gender identity Terms**

- Transgender
- Cisgender
- Genderqueer
- Non-Binary
- Gender-diverse
- Gender non-conforming
- Two-spirit
- Intersex

### **Sexual Orientation Terms**

- Lesbian
- Gay
- Bisexual
- Pansexual
- Sapiosexual
- Asexual
- Queer
- Same loving

# Identifying the population



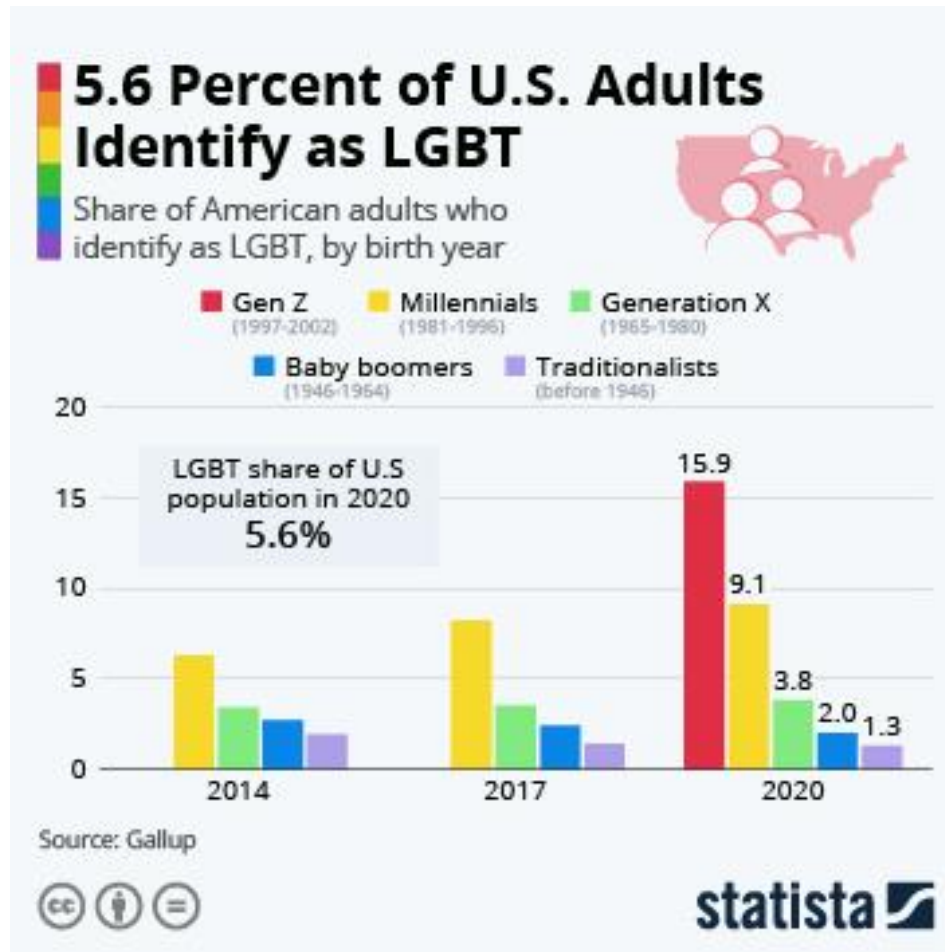
The U.S. Census Bureau in July, 2021 began asking Americans about SOGI

This is the first time the federal government has tried to capture data on LGBTQ+ persons

# Record high of 7.1% of US population



# Changing Demographics of SGM community





# SGM disparities: Are they for real?





# SGM Health Disparities

SGM persons have disparities in most of the leading US health indicators (*Healthy People 2030*):

- Access to and utilization of preventive and primary healthcare
- Chronic diseases including HTN, DM, some cancers
- Depression, anxiety and suicidality
- Reproductive and sexual health
- Substance use including tobacco, alcohol and illicit drugs
- Injury and violence

## A few sobering statistics

- LGB youth 3-6x as likely to attempt suicide than heterosexual peers
  - Transgender youth 6x as likely
- 28% of transgender women are living with HIV
  - 56% of black transgender women are living with HIV
- 2-3x less likely to have health insurance
- Gay, bisexual, and MSM are about 20 times as likely as heterosexual men to develop anal cancer
- 20.5% of lesbian, gay, and bisexual adults smoke (as compared to 15.3% of heterosexual adults)

# Intersectionality

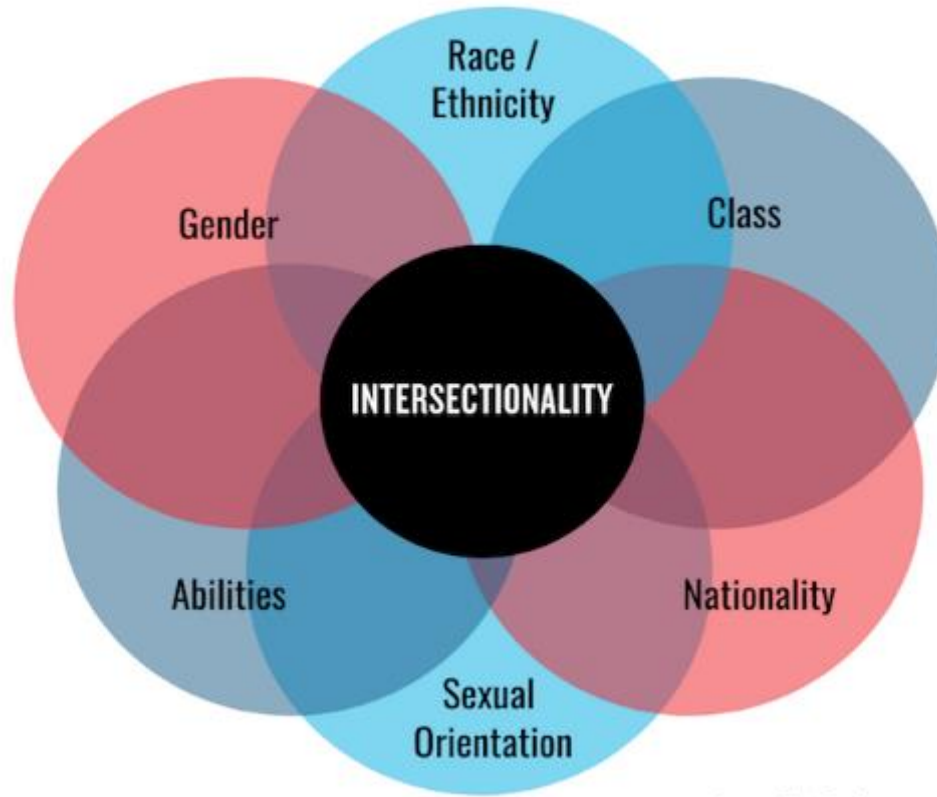
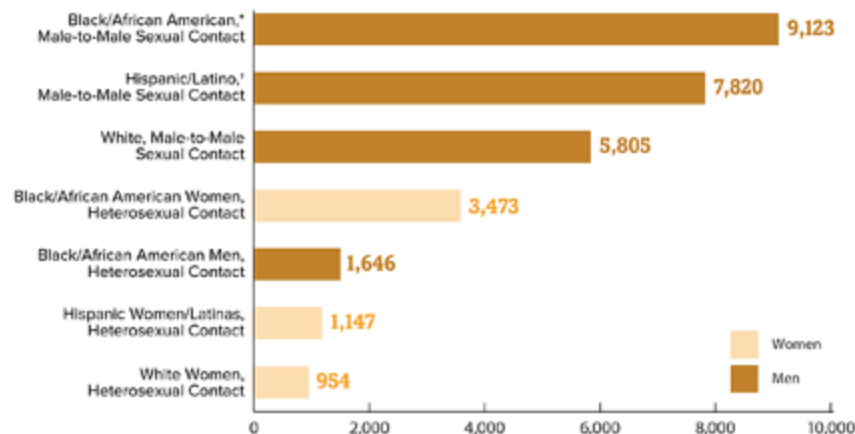


Image: First Book

# HIV Disparities: The picture of intersectionality

## New HIV Diagnoses in the US and Dependent Areas for the Most-Affected Subpopulations, 2019

**Gay and bisexual men are the population most affected by HIV.**



NOTE: Subpopulations representing 2% or less of all people who received an HIV diagnosis in 2019 are not represented in this chart.

\* Black refers to people having origins in any of the Black racial groups of Africa. African American is a term often used for people of African descent with ancestry in North America. Hispanic/Latino people can be of any race.

Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2019. *HIV Surveillance Report* 2021;32.

# Social Determinants of Health

Figure 1

## Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education		Stress	
Support	Walkability				
	Zip code / geography				
<b>Health Outcomes</b> Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations					



# Social Determinant Disparities

- Housing
- Education
- Employment
- Poverty (inclusive of access to food/food insecurity)
- Access to healthcare and health literacy
- Perception/Experience of stigma, discrimination and inequity
- Violence

WPU

# Transgender Day of Remembrance

**Saturday, November, 20th 2021  
5:30PM-6:30PM, Main Lawn**

Join us to commemorate and honor  
the memory of the transgender  
people whose lives were lost in acts  
of anti-transgender violence.



Office of Diversity,  
Equity, & Inclusion  
[diversity@peace.edu](mailto:diversity@peace.edu)

# SGM social disparities during COVID

LGBTQ+ people often reported:  
lost employment,  
not have enough to eat,  
be at elevated risk of eviction or foreclosure, and  
face difficulty paying for basic household expenses

[Census' Household Pulse Survey](#)



## The Common Thread

# STIGMA

**Homophobia, transphobia, heterosexism and heteronormativity**

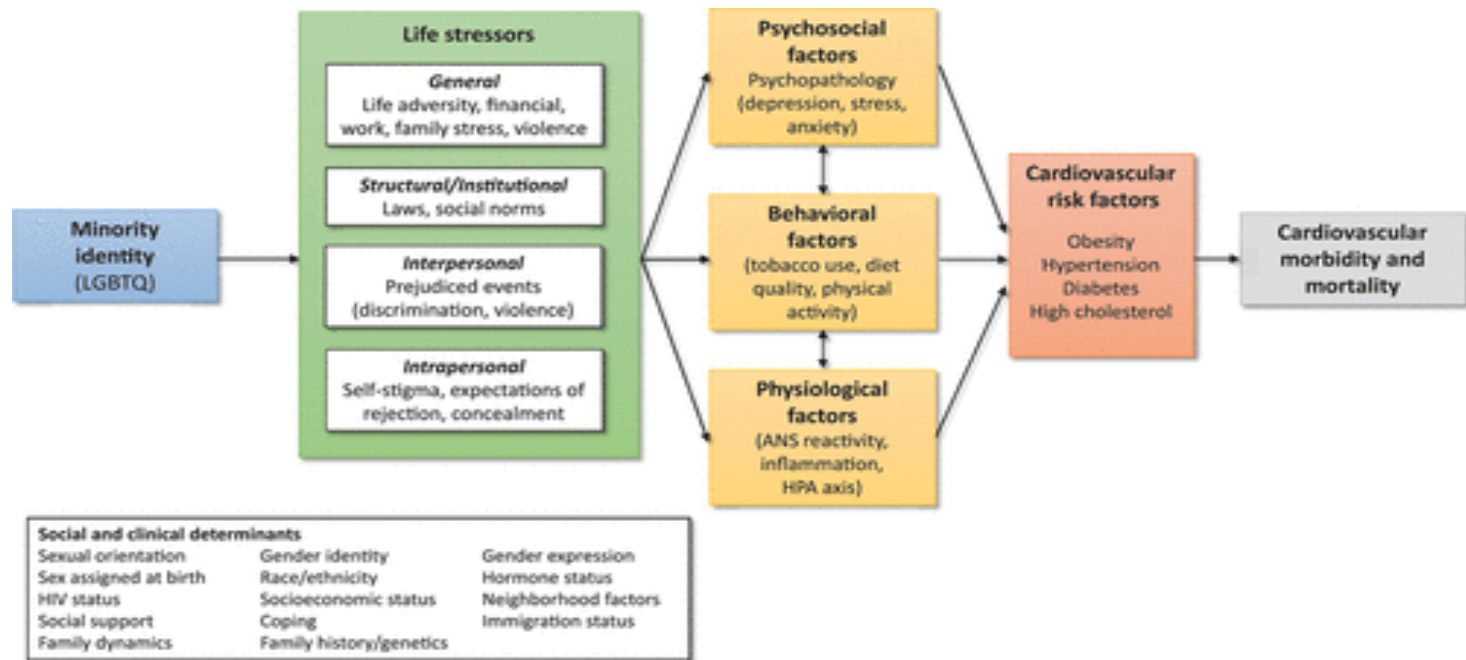
**Compounded by racism, sexism**

**Society at large, within healthcare, within communities & families**



# How does STIGMA impact health?

## Minority Stress Theory



# How does stigma impact access to care?



Delay care due to fear of real or perceived discrimination

Receive inappropriate or inadequate care

Be turned away from care

Less likely to have health insurance

Less likely to have enough healthcare providers, pharmacies

80% first year medical students expressed implicit bias towards LGBTQ persons, and 50% expressed explicit bias



Nearly 56% of sexual minority and 70% of gender minority adults report having experienced some form of discrimination from clinicians (including the use of harsh/abusive language)

≈8% and 25% of sexual minority and transgender individuals, respectively, have been denied health care by clinicians.



LGBTQ+ People of color more than twice as likely to avoid seeing a provider than white counterparts

<http://blog.lighthouse.lgbt/10-stats-lgbtq-healthcare/>

Caceres, B. A., Streed Jr, C. G., Corliss, H. L., Lloyd-Jones, D. M., Matthews, P. A., Mukherjee, M., ... & American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Hypertension; Council on Lifestyle and Cardiometabolic Health; Council on Peripheral Vascular Disease; and Stroke Council. (2020). Assessing and addressing cardiovascular health in LGBTQ adults: a scientific statement from the American Heart Association. *Circulation*, 142(19), e321-e332.

# Let's think about this related to palliative care

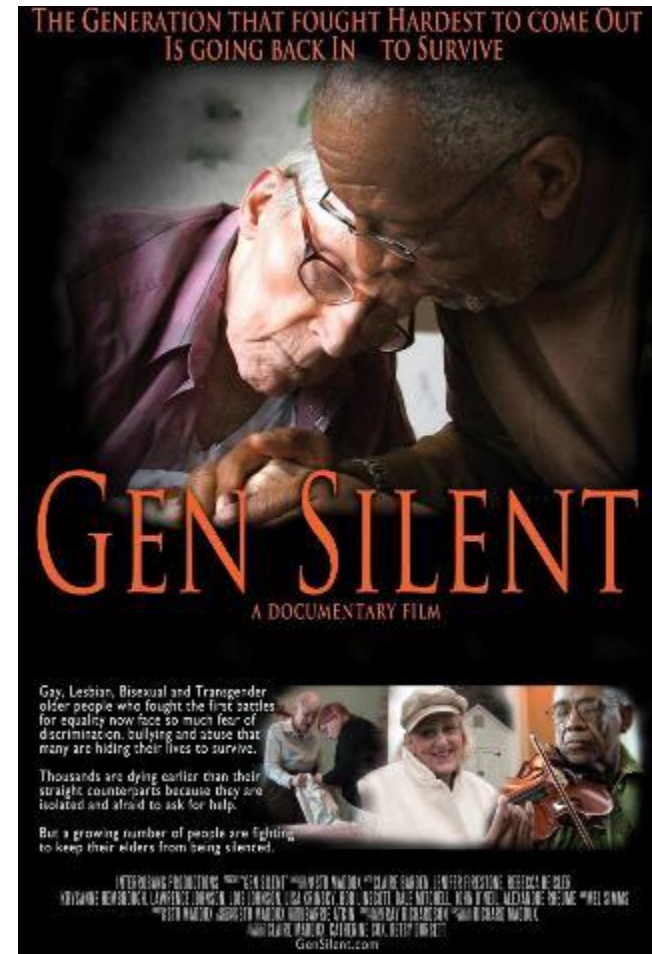
- LGBTQ people may have:
  - Delayed primary and preventative care
  - Later diagnosis of chronic or serious illness
  - Increased risk factors for chronic disease and malignancy
  - Delayed referral to palliative care and/or hospice care
  - Inadequate pain control
  - Lower rates of completion of living wills and other advance care directives
  - Fewer available caretakers and support persons
  - Fewer choices for support services

# Issues for the bereaved

- Disenfranchised grief (not being able to publicly grieve)
- Loss of health insurance, life insurance, housing
- Complicated grief, especially if not allowed to fully participate in care and decision-making of their loved one at the EOL



# LGBTQ “boomers”: The Stonewall Generation



# Younger generations



**THE STATE OF**

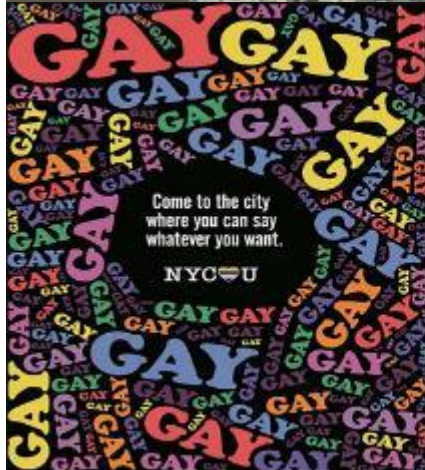
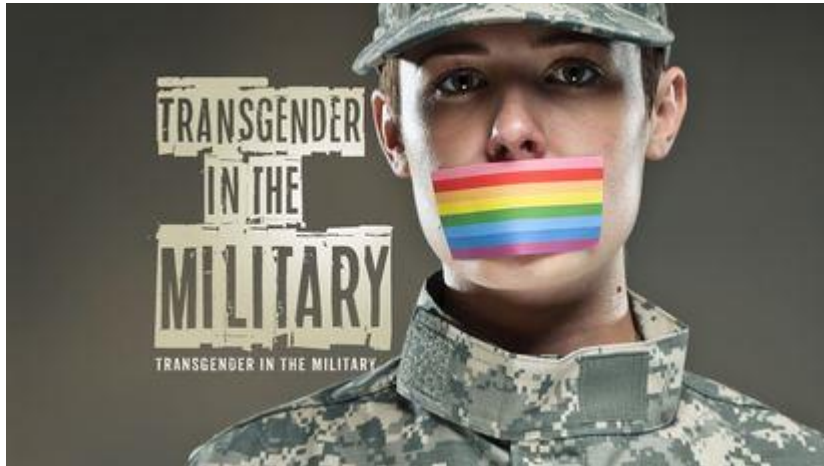
## **ANTI-LGBTQ+ BILLS**

LGBTQ+ people are under a coordinated attack across the country. Over 330 *anti-LGBTQ+ bills* have been introduced this year and a record number may be signed into law.

 HUMAN RIGHTS CAMPAIGN®

**LEARN MORE >**

# What about the US?



# Wisconsin

## Wisconsin's LGBTQ Policy Tally



Sexual Orientation Policy Tally:

12.75/20.5

MEDIUM



Gender Identity Policy Tally:

5.25/22

LOW



Overall Tally:

18/42.5

FAIR



 [VIEW METHODOLOGY/MORE INFORMATION](#)

See how Wisconsin compares to the rest of the country on the [Snapshot](#) page.

[https://www.lgbtmap.org/equality-maps/profile\\_state/WI](https://www.lgbtmap.org/equality-maps/profile_state/WI)



# LGBTQ Global Health

## GAY RIGHTS WHERE HOMOSEXUALITY IS ILLEGAL



SOURCE: ILGA





# What can you do? Attitudes and Knowledge

- Learn about the culture and healthcare needs of the LGBTQ+ community
  - History of LGBTQ civil rights struggles
  - Role of religion and spirituality in LGBTQ community
  - Mental and physical health disparities
  - Past experiences with healthcare providers and institutions, including any concerns about medical mistrust
  - Places of joy and resilience
- Know the legal landscape for your state and community
- Consider LGBTQ patients top concerns
  - Hormones
- Assess your IMPLICIT BIAS

# Nurses' Knowledge and Attitudes

A 2019 review of top 20 nursing journals found:

- 2009 and 2017 only 0.19% of the literature in the top 20 nursing journals focused on SGM health.

A 2015 study on health care provider's implicit and explicit attitudes towards lesbian women and gay men:

- Online survey 2338 MDs, 5379 nurses, 8531 mental health
- Heterosexual nurses held the strongest implicit preferences for heterosexual men and women

A 2013 survey of over 1,000 nursing faculty teaching in BSN programs indicates:

- The median time devoted to teaching LGBT health is 2 hours.

# Hospice and Palliative Care Providers (2018)

N= 865 interprofessional hospice and palliative care providers  
23.7% observed discriminatory care;  
64.3% reported that transgender patients were more likely than cisgender patients to experience discrimination;  
21.3% observed discrimination towards transgender patients;  
15% observed the spouse/partner of LGBTQ+ patients having their treatment decisions disregarded or minimized;  
14.3% observed spouses/partners or surrogates being treated disrespectfully

Stein, G. L., Berkman, C., O'Mahony, S., Godfrey, D., Javier, N. M., & Maingi, S. (2020). Experiences of lesbian, gay, bisexual, and transgender patients and families in hospice and palliative care: perspectives of the palliative care team. *Journal of Palliative Medicine*, 23(6), 817-824.

# What can you do? Environment

Non discrimination statements

Intake forms and processes

Posters, pamphlets, PR and marketing

In New York City, it is illegal to discriminate on the basis of a person's sexual orientation, gender identity or gender expression in public accommodations, including in health care settings.

.....

You have the right to:

1. Be treated with dignity, respect and professionalism in all health care settings by all providers and all staff
2. Receive compassionate, judgment-free and comprehensive care that is mindful of your sexual orientation, gender identity and gender expression for all health services
3. Respectful discussions with providers about your health and health care needs, including your sexual history and current sex life
4. Have your gender identity and gender expression recognized, affirmed, documented and accommodated in all health care interactions
5. Clear explanations of providers' requests for your health information
6. Clear explanations of all medical procedures and risks, and the right to choose or refuse any treatment
7. Access health insurance coverage and benefits without discrimination based on sexual orientation, gender identity and gender expression
8. Choose who will make medical decisions for you if you are unable; and, if you are a minor, the right to have your voice and best interests included in these decisions
9. Decide who may and may not visit you if you are admitted to a health care facility
10. Privacy and confidentiality



HEALTH CARE BILL OF RIGHTS

Mistreated or denied care because of your sexual orientation, gender identity or gender expression?  
Call 311 or 718-722-3131 to file a complaint with the New York City Commission on Human Rights.



# Creating an inclusive environment

> [Nurs Forum](#). 2022 Jan;57(1):34-41. doi: 10.1111/nuf.12648. Epub 2021 Sep 17.

## What does gender affirmation mean to you? An exploratory study

[Caroline G Dorsen](#)<sup>1</sup>, [Noelle Leonard](#)<sup>2</sup>, [Lloyd Goldsamt](#)<sup>3</sup>, [Amy Warner](#)<sup>3</sup>, [Kevin Gomez Moore](#)<sup>4</sup>,  
[Nathan Levitt](#)<sup>5</sup>, [Peri Rosenfeld](#)<sup>6</sup>

Affiliations + expand

PMID: 34535901 DOI: [10.1111/nuf.12648](#)

# Pronouns!



# Basic inclusive and affirming history questions

- Ask of ALL patients. You do not know who will benefit from your inclusivity.
- LGBTQ+ Inclusive Palliative Care Interview Questions:
  - What name would you like me to call you?
  - What gender pronoun do you go by? (e.g., he/him, she/her, them/their, ze/zir, etc. [Ensure subsequent use of the patient's preferred pronouns.]
  - Who do you consider to be your family?
  - Who is available to help you at home with your everyday needs when you are sick?
  - Chochinov's dignity question:
    - What should I know about you to help me provide the best care for you?



# What to do if you misgender someone?

- Brief apology
- Move on
- Try harder next time!

# What can you do? Be an ally



The truth is, no one of us can be  
free until everybody is free.

— *Maya Angelou* —

AZ QUOTES

