

WELCOME!



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TODAY'S SESSION

- 1) Short group discussion about your experiences serving LGBT older adults
- 2) Discussion of these Elders as a unique cohort
- 3) Brief review of health disparities
- 4) Monmouth University OAP research findings
- 5) Jenny's dissertation findings
- 6) Implications for providers
- 7) Reconvene with your small group to see if your thoughts or perceptions have changed in any way

WHO ARE LGBT ELDERS?

WHAT WE DO AND DON'T KNOW



AN UNDERSTUDIED POPULATION

- 2011: The Institute of Medicine report entitled
 - *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*
- Lacking foundation in what we know about LGBT health overall
- Even less attention paid to LGBT elders than other age groups
- Few large-scale studies have included older LGBT persons
- Aging is infrequently considered in LGBT research [and] the field of gerontology has infrequently considered LGBT aging issues

These surveys

- ***Don't ask***
- ***Have only recently begun to ask***
- ***Or module is optional***

With regards to sexual orientation or gender identity.

- The **Census Bureau's** decennial count and **American Community Survey** are the premier sources of demographic data in this country.
 - these topics have never been listed & there are still no plans to do so
- The **National Health Interview Survey & BRFSS** are primary source of information about American's health
- The **Current Population Survey** is the preeminent source of information about the nation's economic well-being.

RESEARCH & THE LGBT POPULATION

- According to the Census Bureau, there is “no federal data need” to ask about sexual orientation & gender identity
- Department of Health and Human Services eliminated questions about L.G.B.T. people from drafts of two critical surveys: the National Survey of Older Americans Act Participants, which helps inform social and nutritional support programs for seniors; and the Centers for Independent Living Annual Program Performance Report, which helps inform programs designed to allow people with disabilities to live independently.

RESEARCH AND THE LGBT POPULATION

- For years, LGBTQ groups lobbied to have surveys include questions that would help identify the amount of lesbian, gay, bisexual and transgender elderly people who live in the U.S. and participate in services.
- **In 2014, questions about sexual orientation and gender identity were added to the survey**
- The Trump administration released a draft of the 2017 survey: The LGBTQ questions were erased
- In June, as a direct result of the overwhelmingly critical reaction, the ACL announced that it would restore the question about sexual orientation **but not gender identity**

ESTIMATES

- Recent estimates show that **between 5.2 and 9.5 million** adults in the U.S. identify as lesbian, gay, bisexual, or transgender
- Currently, more than 2.4 million adults age 50 and older in the US identify as LGBT, which is about 2.4% of the population
- ***By 2030, LGBT adults ages 50 and older will number more than 5 million***



**TWO IMPORTANT THINGS TO
KNOW ABOUT LGBT OLDER
ADULTS**

1) A UNIQUE COHORT

- As older LGBT adults came of age, many hid their sexuality due to fear of discrimination, shame, and violence
- Many were afraid for their safety and often remained silent and isolated to survive
- It is important to know that hiding and concealment of identity is one characteristic of this group
- That means you have to work extra hard to 1) reach them and 2) earn their trust

Historical Timeline of LGBT Elder “Ms. Anna”	Years Old
Born:	1936 (81 years old in 2017)
1940’s: Could be involuntarily committed, subjected to electric shock, lobotomies	4-13 years old
McCarthy Era: banned from working for Fed Gov’t	14-23 years old
Homosexuality classified as mental disorder in DSM (1952-1973)	16-37 years old
1969: Stonewall Riots, “birth” of the LGBT civil rights movement	33 years old
1980s: AIDS Crisis: lack of Fed response	43-53 years old
1996: Defense of Marriage Act signed by President Clinton (marriage b/w one man & one woman)	60 years old
1998: Matthew Shepard tortured and left tie die	62 years old
2008: Prop 8 invalidates legal same-sex marriages in CA	72 years old
Section 3 of DOMA Repealed (2013)	77 years old
2015: Supreme Court rules states can not ban same-sex marriage	79 years old
2016: Pulse Nightclub Shooting: killed 49 people and wounded 53 others	80 years old

WHAT DOES THIS MEAN FOR PROVIDERS?

- When taken as a whole, Ms. Anna's life is not one in which policy, law, medicine, culture, etc. tell her it is safe to be out and be who you she is.
- All of us as service providers have to own this history
- They need to know we're aware of it, and we're not blaming them for being hesitant or afraid to come forward when they need help.

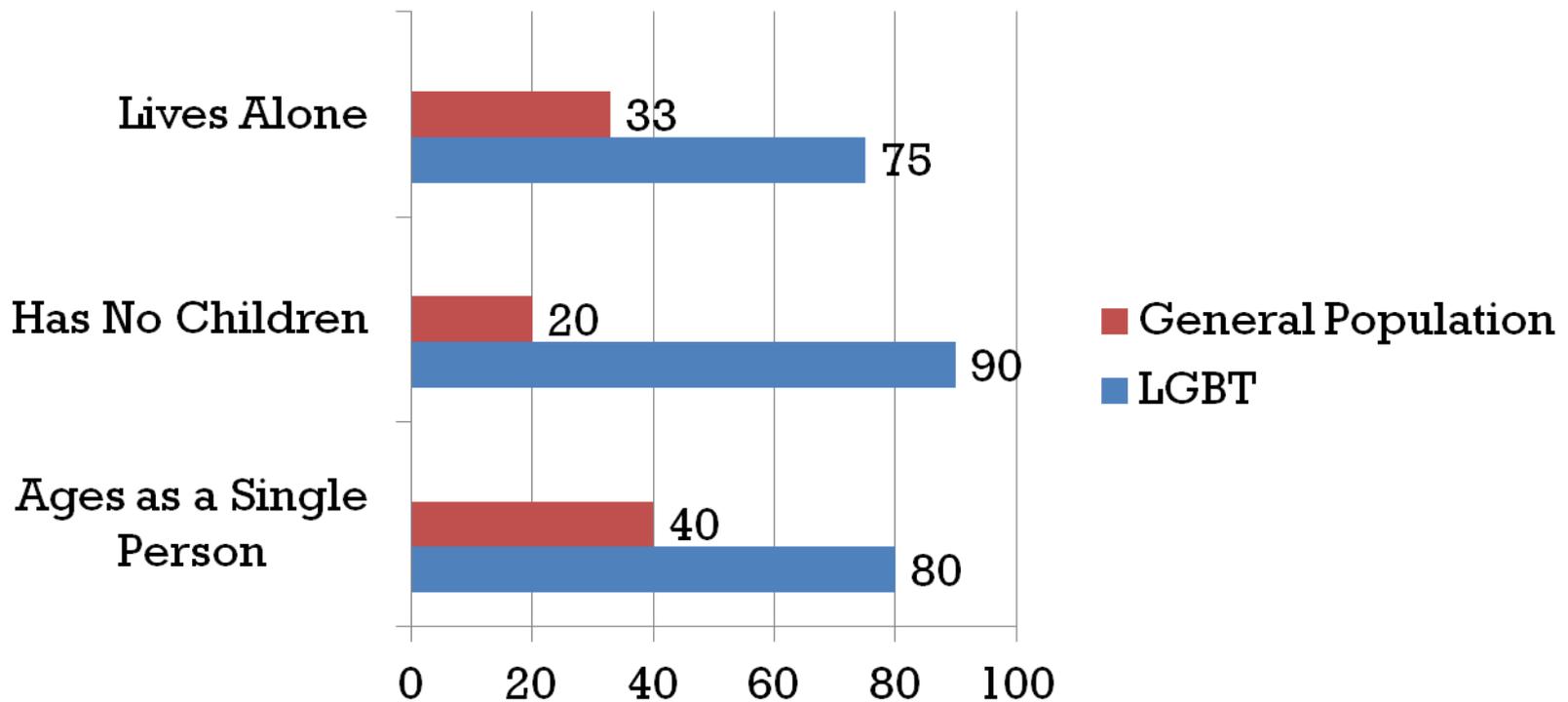
WHAT DOES THIS MEAN FOR PROVIDERS?

- You may be serving currently Elders who are hiding their identity from you and other residents/patients/clients
 - *Introducing their spouse as “friend” “neighbor” “cousin” etc. is quite common*
- There may be seniors who need services but are afraid to come forward
 - *That is the last thing we want—for people to delay or not get needed care*

2) AGING ALONE

- LGBT Elders are:
 - Twice as likely to live alone
 - Twice as likely to be single
 - And three times less likely to have children
- than heterosexual older adults

LGBT VS. GENERAL POPULATION





WHAT ARE THE IMPLICATIONS FOR PROVIDERS?

- *Why do you think so many are aging alone?*
- *What do you think are some implications of that fact that many elders may aging alone?*

DOCUMENTARY: GEN SILENT



GEN SILENT

Gen Silent is the critically-acclaimed documentary from filmmaker, Stu Maddux, that asks six LGBT seniors if they will hide their friends, their spouses—their entire lives in order to survive in the care system.

- [Trailer](#)
- More information at [GenSilent.com](#)



GEN SILENT

- *We have seen the experiences of those in the film expressed over and over again by residents of Central New Jersey*

DATA TIME:
**A BRIEF OVERVIEW OF HEALTH
DISPARITIES**



THE AGING AND
HEALTH REPORT

*Finally, a
national
study.*

- ***The Aging and Health Report (2011)* was the first nationwide study of LGBT elders**
- Surveyed over 2,500 Elders
- Funding by the The National Institutes on Health and the National Institute on Aging
- Resilience, Risk, Physical Health, Mental Health, Health Care Access, Health Behaviors, Services & Programs, HIV, and caregiving and receiving

FINDINGS OF CONCERN: MENTAL HEALTH

- Nearly 31% of all respondents reported depression
- 25% overall reported anxiety
- **Nearly half (48%) of transgender people reported depression**
- **39% of transgender Elders reported anxiety**

FINDINGS OF CONCERN: MENTAL HEALTH

- 39% of all LGBT elders had thought of committing suicide at some point in their lives
- But that number was 71% looking at just transgender older adults

FINDINGS OF CONCERN: MENTAL HEALTH

- 59% said they lacked companionship
- 53% felt isolated from others
- and 53% felt left out
- *What are some things isolation and loneliness correlate with?*

FINDINGS OF CONCERN: SOCIAL SUPPORT

- 67% said they had someone they could count on for help with daily chores if needed
- 71% said they had someone to make them feel loved and wanted
- 33% do not have someone they can count on
- 29% don't have someone that makes them feel loved

FINDING OF CONCERN: HEALTHCARE ACCESS

- 13% overall had been denied healthcare or received inferior care because they are LGBT
- 15% said they fear accessing care outside of the LGBT community
- 21% said they do not disclose sexual orientation to healthcare providers
- 40% for transgender older adults had been denied healthcare or received inferior care due to being transgender

Did you say 'denied health care'?

**YES, AND WE WILL FOLLOW UP ON THAT
SHORTLY**



SERVICE USE

Only 28% were using any community based aging services

- Participants identified 5 programs & services as most needed:

- Senior housing (66%)
- Transportation (62%)
- Social events (62%)
- Support groups (55%)
- Legal services (53%)

HEALTH DISPARITIES IN THE GENERAL LGBT POPULATION

- **The following are highlights from:**
- *Substance Abuse and Mental Health Services Administration, Top Health Issues for LGBT Populations Information & Resource Kit, 2012 (still the most current report from SAMHSA)*

HEALTH ISSUES FOR LESBIANS

- **Higher risk for breast cancer**: fewer full term pregnancies, fewer mammograms & clinical breast exams, being overweight
- **Obesity**: higher prevalence rates for African American lesbians, those who live in rural areas; lower education; from low SES
- **Injury & Violence**: harassment & violence from family; higher rates of intimate partner violence
- **Mental Health**: More depression, phobia, PTSD than women with “opposite sex partners”; increased rates of suicidal ideation
- **Substance Use**: more likely to smoke, drink alcohol

HEALTH ISSUES FOR GAY MEN

- **Heart Disease**: higher rates of tobacco & alcohol use
- **Cancer**: Increased risk for prostate, testicular, colon cancers; Anal cancer due to HPV
- **Injury & Violence**: criminal violence and from intimate partners
- **Eating disorders**: increased risk for anorexia and bulimia
- **Mental Health**: Higher rates of depression & anxiety; more severe for those not out; higher rates of suicide attempts
- **Substance Use**: higher rates of alcohol and drug use, and tobacco use

HEALTH DISPARITIES IN TRANSGENDER WOMEN

- Potential **cardiovascular risk** related to estrogen use and higher smoking rates
- Potential **breast cancer**
- Uninsured & more likely to use street hormones – increasing risk for HIV, Hep C
- **Long term study of hormone** use is on-going in terms of health risks (meaning a lot is unknown)
- Osteoporosis- linked to high rates of tobacco use
- Street silicone injections
- Prostate exams and symptom review

Screen and treat the body parts that they have!

HEALTH DISPARITIES IN TRANSGENDER MEN

- Hormone Replacement Therapy Risks
- Polycystic ovaries
- Unknown whether risk for ovarian cancer is increased, decreased, or unchanged in transgender men on testosterone
- Excess testosterone can convert to oestrogen, potentially increasing risk for breast cancer
- Increased liver enzymes
- Worsened migraines

Screen and treat the body parts that they have!

SERVING TRANSGENDER PEOPLE

- Extremely limited data
- Unknown effects of long-term hormone use
- Sampling challenges
- Increased risks for:
 - Increased risk for physical assault and abuse
 - Increased risk for sexual assault
 - High rates of suicidal ideation and suicide attempts
 - High rates of anxiety and depression and other clinical conditions
 - Increased substance use

OTHER ISSUES TO CONSIDER

- ***Screen and treat the body parts that they have!***
- **But where?**
 - Where does someone who identifies as a man get a pap smear?
 - Where does someone who identifies as a women get a prostate exam?
- What services are adequate training on trans health issues and really ready to treat trans folks with dignity and respect?

**MANY LGBT PEOPLE ARE NOT
AWARE OF THESE ISSUES...
*NOR ARE PROVIDERS***



PROVIDER EDUCATION

A 2011 study surveyed 176 medical schools in the US and Canada.

- The average amount of time dedicated to LGBT content was 5 hours, with 5 schools reporting having **zero hours** dedicated to LGBT content in both preclinical and clinical hours



So, how will the serious issues be addressed?

- If LGBT people are afraid to disclose their sexual orientation to their healthcare providers,
 - Either because they don't trust the system
 - Or they don't understand why/how their sexual orientation matters to their health
- And if health care providers do not consider it important to ask about sexual orientation/don't know it matters...

THE MONMOUTH UNIVERSITY LGBT OAP





FIRST WE CONDUCTED INTERVIEWS—SUMMER 2012

- First thing many said was “thank you...no one knows about us”
- Some were preparing for old age; some really afraid of what will happen to them because they are alone
- Those with partners and higher incomes less stressed & more prepared

INTERVIEW FINDINGS

- Many worried about acceptance in assisted living facilities, nursing homes, senior centers, etc. if they wanted or need to access services
 - *Could they stay with partner in nursing home?*
- Many knew people who were hiding
 - *said they were sisters in retirement communities, for example*
- Afraid of strangers coming into the home for **in-home care**
- Many were **helping each other** instead of relying on formal services

INTERVIEW FINDINGS

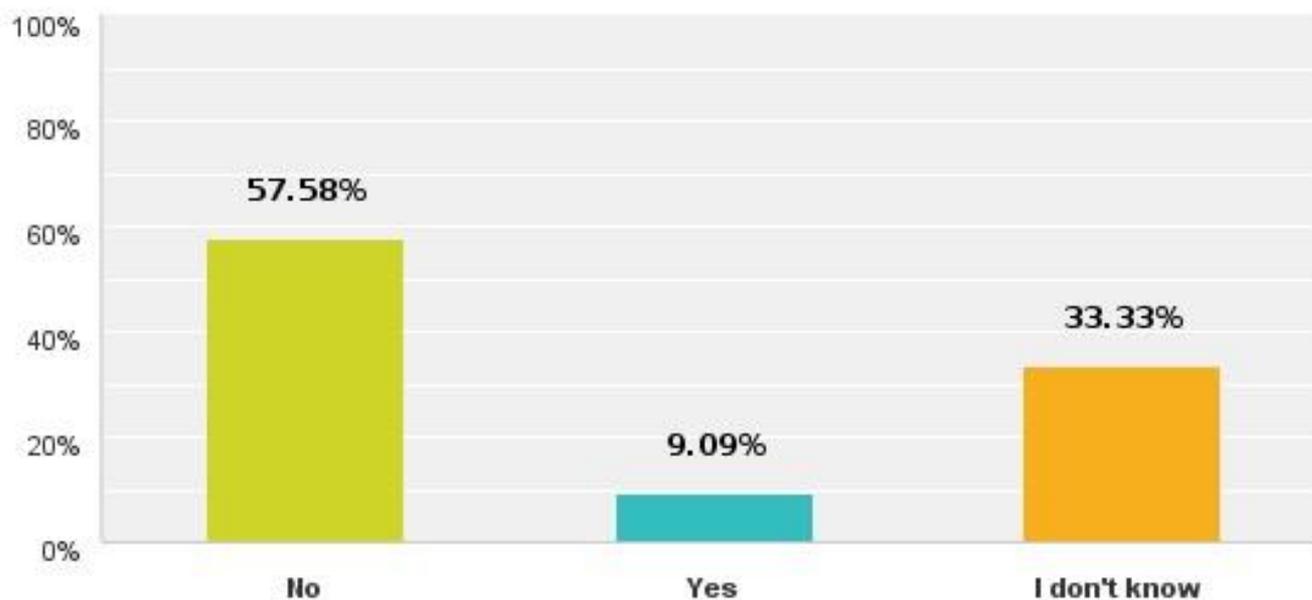
- Most were “ok” now
- A lot of worry about the future
- Most said they just wanted to know they would be treated fairly or find a welcoming environment
- Cited need for LGBT specific senior centers, retirement communities etc., ***if*** existing services were not going to become culturally competent

KEY SURVEY FINDINGS SUMMER 2013

- ***Do you identify as LGBT to your health care providers?***
 - 11.43% Never
 - 8.57% Rarely
 - 14.29% Often
 - *Think about why that's important in light of the health disparities we just discussed!*

Q9 Do you feel your health care providers have adequate training regarding LGBT issues?

Answered: 33 Skipped: 2



KEY SURVEY FINDINGS

- *Your health care providers understand your needs as an older LGBT adult.*
 - **Agree and Strongly Agree = 12.5%**
 - **Neither Agree nor Disagree = 46.88%**
 - **Strongly Disagree and Disagree = 40.63%**



DO YOU TRUST THE HEALTH CARE SYSTEM TO TAKE CARE OF YOU AS YOU AGE?

- Strongly Disagree: 6.06%
- Disagree: 24.24%
- Somewhat Disagree: 42.42%
- Agree: 18.18%
- Strongly Agree: 9.09%

**ADDING JENNY'S DISSERTATION
FINDINGS TO THE DISCUSSION:
EXPERIENCES WITH AND
PERCEPTIONS OF OLDER
AMERICANS ACT-FUNDED
SERVICES**



EMERGENT THEMES

Four themes emerged as significant:

1. Low expectations of a welcoming service environment
2. The importance of being out
3. Potential need for LGBT-specific services
4. Recommendations on how to create inclusive services

LOW EXPECTATIONS

- Overall, participants had low expectations that OAA-funded services in the study area would provide LGBT-welcoming & knowledgeable environments. What differed was their thoughts about how that would impact service use (theme 2)
- **Due to a combination of interlocking factors that included:**
 1. Participants lived in a conservative area with hidden LGBT population,
 2. Negative experiences with OAA-funded services and other types of services, and
 3. The current political climate.

LOW EXPECTATIONS

- *If they don't want to sell us a wedding cake, they certainly don't want to touch our bodies. They're not going to want to save your life if they don't want to sell you a wedding cake. In urgent situations like if a code was called and you get someone who is homophobic...they might just take their time walking down the hall and say 'I'm letting Jesus do his job' ...it's weird and really scary. (Lesbian, Female participant)*

IMPORTANCE OF BEING OUT

- Participants felt **strongly** about being out in their lives and to service providers
- Many participants stated that if they could not be out to service providers, they'd rather not use the service.
- Some felt they might have to hide when they were older to remain safe and avoid mistreatment in nursing home or assisted living settings
- Others felt they would never hide, no matter what
- Many felt oldest-old were more likely to be hidden

THE IMPORTANCE OF BEING OUT

- “In my mid-30s I lost all of my friends to AIDS. Every. Last. One. Of. Them. And I had a large circle of friends. I think at this point, and pardon my language, I basically said fuck it. This is who I am. I’m a survivor. God knows why. And I’m gonna live a proud and open life.”
 - “I don’t feel victimized. We would be pissed off if we weren’t treated well. We’re not disadvantaged in any way...”
 - “I’m not worried. I don’t care. I will live in senior [housing]...you just deal...I wouldn’t worry about being isolated. I would make sure I am social”
- “If I went into a nursing home or assisted living, I wouldn’t tell them I was gay because you probably end up with the shitty room overlooking the garage!”
 - “I wouldn’t tell them because I don’t know what would happen to me”
 - “You could be 90 and perfectly lucid but frail. And you know when someone is not taking good care of you and that is why I would not say it.”

LGBT SPECIFIC SERVICES

- ***If*** existing services will not become inclusive
 - The sense was that if 'we're not welcome, we'll ***have to*** create our own.'
- But are there enough out people in CNJ to use such services?
- Most discussed services was need for LGBT-specific housing—worry about treatment in assisted living or nursing homes, hiding in retirement communities (saying they're sisters, cousins—everyone seemed to know someone doing this)
- Also a debate about whether LGBT-specific services are actually good for the LGBT community

LGBT SPECIFIC SERVICES

- “A nightmare in the back of my head is that someday if we land in a nursing home...our relationship would not be respected. By the time that occurs, you might be separated or [encounter a] lack of respect for your relationship”
- “I’m not making any plans yet. I see there are places for gays and lesbians in New York, SAGE, Los Angeles, and Portland...it’s a relief.”

- “Are we building a wall to keep them out or us in?”
- “setting up our own centers are great. But are we separate but equal? Or separate but not equal?”
- But do you ever feel that your choices are limited, having to plan around gay-friendly communities? Do we just run our lives around making sure we're in gay friendly communities, or are there other things that take precedence over that?

CREATING INCLUSIVE SERVICES

- Creating them is the provider's responsibility—part of ethical, holistic care
- Providers must “own” history of poor treatment & learn about LGBT health & health disparities
- Training is needed at all levels of an organization, from the top admin to the housekeeping and office staff
- Visible signs of inclusivity would be a source of reassurance & comfort to those out and those not
- Why can't providers “reach in” or tap into existing LGBT networks/organizations

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IMPLICATIONS FOR SERVICE PROVIDERS

CARING FOR EACH OTHER

- Older LGBT adults are providing a lot of care to friends and loved ones
 - ***So: what we have is an aging population looking after itself***
- Interview participants were concerned with what would happen when helping a friend was putting themselves at risk
 - ***What will they do when they can no longer help each other? To whom will they turn?***

CARING FOR EACH OTHER

- Strong networks of friends and families of choice are considered protective factors, associated with increased mental and physical health outcomes
- Long history in the LGBT Community
- **BUT!! This population must also have culturally competent services available to them.**
- If networks are being relied on due solely to lack of culturally competent services--that is not acceptable!

PROVIDERS:

- There is a dual issue to consider:
- 1) Are you already serving elders and do not know who they are—they have not disclosed their identity to you?
- 2) Who in the community needs services but are not sure if they will be culturally competent so they stay away?



REMEMBER WHEN WE SAID
LGBT OLDER ADULTS HAD
REPORTED BEING DENIED
HEALTH CARE?

MARRIAGE EQUALITY

- As of June 26th, 2015, the Obergefell et al. v. Hodges, Director, Ohio Department of Health, et al. ruling requires that all 50 states uphold and sign marriage certificates of same-sex couples.
- Unfortunately, some government officials still fight the Supreme Court decision and refuse to honor these marriages.
- And, we should not assume that all older LGBT adults are going to get married even though it is now legal
- Interviewees were unsure of benefits should marriage equality become legal
- ***AND, we must not assume that all is well now that marriage equality is the law of the land!***

NO FEDERAL PROTECTIONS

- **Anti discrimination laws** in each state protect against discrimination based on
 - race, color, religion, age, sex, and national origin.
- There are no federal protections for LGBT rights.
- Non discrimination laws and protections vary widely from state to state
- http://www.hrc.org/state_maps

ANTI-LGBTQ LAWS

- Over the past several years, individual states have passed discriminatory legislation
- These include the so-called “bathroom bills” and also religious freedom laws that allow someone to discriminate against LGBTQ people on the grounds that their existence violates someone’s faith (*sorry for the sarcasm*)
- *Here are some of the more famous examples*

NORTH CAROLINA

- North Carolina Governor Pat McCrory signed into law an anti-LGBT bill that:
 1. eliminated existing municipal non-discrimination protections for LGBT people;
 2. prevented such provisions from being passed by cities in the future;
 3. and forced transgender students in public schools to use restrooms and other facilities inconsistent with their gender identity
- Was replaced but many advocates feel the replacement was just to attract businesses that protested the bill and that is isn't really any better

GEORGIA

- Following weeks of pressure from the Human Rights Campaign and Georgia Equality, Georgia Gov. Nathan Deal vetoed H.B. 757
- The legislation, which sparked a massive backlash of opposition, would have
 1. Weakened local non-discrimination protections,
 2. Allowed businesses to discriminate and deny service to LGBT people, and
 3. Explicitly empowered discrimination by taxpayer-funded religious organizations

MISSISSIPPI

- On April 5, 2016, Mississippi Governor Phil Bryant signed into law H.B. 1523, "The Religious Liberty Accommodations Act."
 1. Public employees, businesses, and social workers cannot be punished for denying services based on the belief that marriage is strictly between a man and a woman,
 - or people who act on the belief that "sexual relations are properly reserved to such a marriage"
 - and that gender is determined at birth
 2. Government can't prevent businesses from firing a transgender employee,
 - clerks from refusing to license a same-sex marriage,
 - or adoption agencies from refusing to place a child with a couple who they believe may be having premarital sex.

MICHIGAN PHYSICIAN REFUSED TO TREAT
BABY ON THE GROUNDS OF RELIGIOUS
FREEDOM OR LIBERTY



2017 HAS NOT BEEN A GOOD YEAR FOR LGBT RIGHTS

- According to the Human Rights Campaign, there have been 100 anti-LGBTQ bills introduced so far in 2017
- [Let's take a look](#)

TRUMP'S TRANSGENDER BAN

- Trump, via tweet, announced a ban on transgender service members



Donald J. Trump ✓
@realDonaldTrump

Thank you to the LGBT community! I will fight for you while Hillary brings in more people that will threaten your freedoms and beliefs.

6/14/16, 1:31 PM

GREAT PROGRESS HAS BEEN MADE!

- While on the one hand, we have seen progress in many areas
- Unfortunately, a good deal depends on where you live
- For some elders, recent anti-LGBT legislation simply continues a life-long pattern of being forced into second-class citizenship via policy makers and legislators.
- OAP interviewees talked about fears of travelling to less progressive states (or even parts of NJ) and that their rights can be taken away at anytime

THE OLDER AMERICANS ACT

- The revisions of 2006 were signed into law for a 5-year period
- Reauthorized (April, 2016)
- Leading aging organizations call for reauthorization, increased funding, and to include the needs of LGBT Elders in the bill
- The following recommendations are from the National Leadership Council on Aging

CLASSIFY ELDERS AS VULNERABLE POPULATIONS UNDER THE OAA

- OAA services are to be targeted to those with the greatest social and economic need.
- *OAA has been expanded previously to include rural Americans and African Americans.*
- **As we've seen, Elders are a unique and often hidden cohort.**
- **This designation can bring them to the attention of OAA providers**

RECOGNIZE UNIQUE FAMILY SITUATIONS

- Which can include partners, friends, and families of choices, as well as spouses and biological families
- *As we've seen, LGBT Elders often create their own informal support networks of non biological family members*
- *Need to be inclusive of those who might be supporting the Elder*

SENIOR CENTERS

- Senior resource centers are called on to explicitly address minority group needs of LGBT older adults
- Are there Elders hidden that are currently using senior center resources?
- And also recognize who is in need in the community but is not using their services
- *How can services be expanded to be made inclusive?*

ELDERS LEFT OUT OF OAA REAUTHORIZATION

- LGBT-specific language was not included in the Reauthorization
- Organizations like SAGE will continue advocacy efforts to have Elders represented in this important bill
- *“SAGE will continue our advocacy for an LGBT-inclusive Older Americans Act. We must ensure that LGBT Americans, who face higher rates of poverty, pronounced social isolation, and less access to health care, receive the services that they so need and deserve. SAGE will work tirelessly to see that these provisions make it into the next iteration of the Older Americans Act”*



WRAPPING UP AND CREATING INCLUSIVE ENVIRONMENTS

WE'VE COVERED A LOT OF GROUND

- How much of what we presented was new to you?
- Based on this information, can you see things going well in your agency in terms of meeting the needs of LGBT Elders?
- Can you see things that may need development based on what we presented?
- **Take a few minutes to reconvene with your group to think about how you might implement change to help meet the needs of LGBT Elders.**



INCREASING CULTURAL COMPETENCY

- Have a list of LGBT resources available if a provider or patient needs to clarify information
- Include gender identity and sexual orientation on intake forms
- Include LGBT related social activities or photographs on agency website/pamphlets

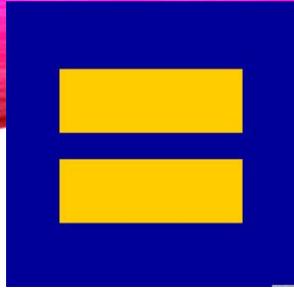


INCREASING CULTURAL COMPETENCY

- Include LGBT health related resources in waiting room, office, or front desk
- Have a zero tolerance policy on LGBT discrimination
- Have Safe Zone/Safe Space stickers in a visible area in waiting room, office, or on desk

RESOURCES TO GO

- Services and Advocacy for GLBT Elders (SAGE) (<http://www.sageusa.org/>)
- Human Rights Campaign (<http://www.HRC.org>)
- Caring and Aging with Pride (<http://caringandaging.org/>)
- Gen Silent (<http://gensilent.com/>)
- Fenway Health (<http://fenwayhealth.org/the-fenway-institute/lgbt-aging-project/>)



Human Rights Campaign symbol



Safe Space/Zone symbol



Pride Flag– representing gay pride



THANK YOU FOR YOUR
ATTENDANCE AND
PARTICIPATION TODAY!

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