



NATIONAL LGBT HEALTH
EDUCATION CENTER

A PROGRAM OF THE FENWAY INSTITUTE



NATIONAL CENTER
FOR EQUITABLE CARE FOR ELDERLY



LGBT Aging

Change, Challenge and Resilience

.....

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FENWAY HEALTH

- FQHC in Boston
- 32,000 patients
 - About half LGBT, 4,000 trans
 - 2,200 patients living with HIV
 - 1600 patients 65 and over
- Ryan White Part C clinic, HIV research
- Behavioral health integrated with primary care
- Fenway Institute: Research, education & training, policy



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Today's Faculty

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Disclosure

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Learning Objectives

Upon completion of this presentation, participants will be able to:

- 1. Describe health disparities faced by LGBT older adults.
- 2. Explain how policy changes can improve health care and elder services for this population.
- 3. Describe how health centers can advocate and care for their LGBT older patients.

How Many LGBT Older Adults?

Today: 1.4 to 3.8 million in U.S.
(Harley & Teaster, 2016)

2030 estimate: 3.6 to 7.2 million in U.S.
(Harley & Teaster, 2016)

MA Estimate: 65,000

Three Generations: Invisible -- the oldest old
Silenced -- greatest generation
Proud – baby boomers and beyond



What's So Different?

Elder Issues

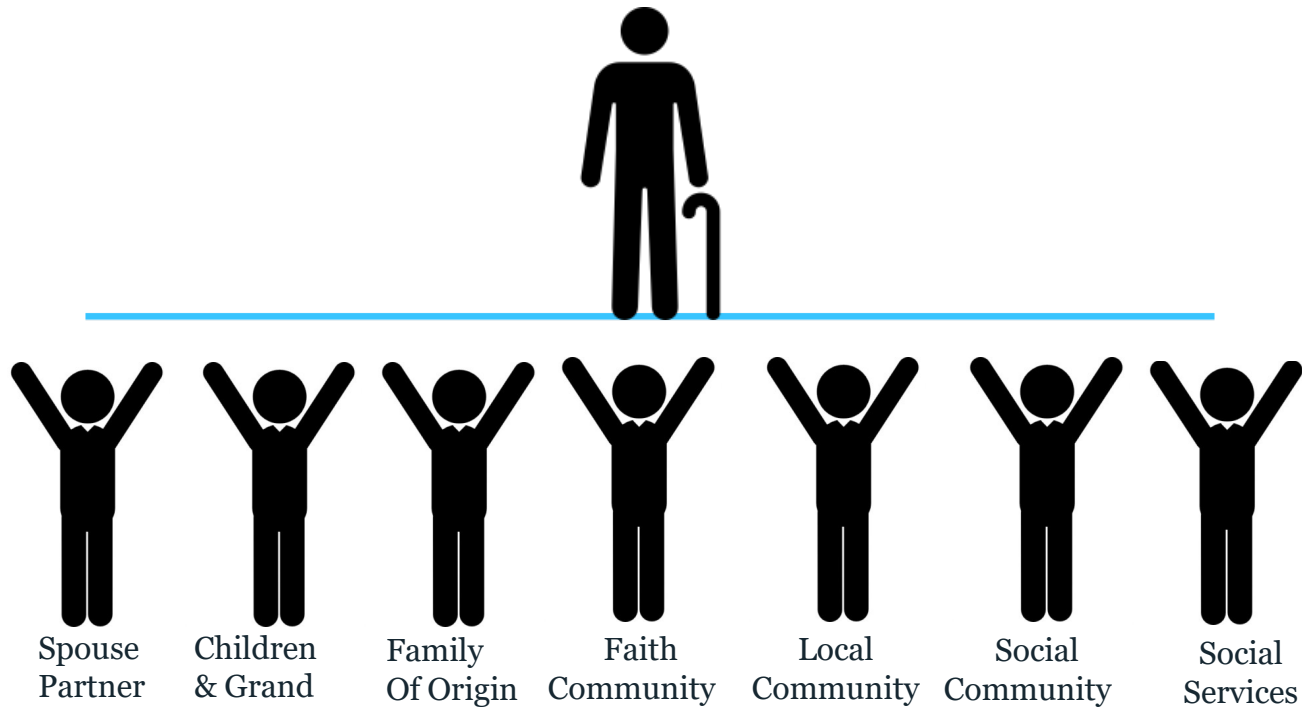
- Healthcare
- Housing
- Medication Costs
- Social Network: Family, Friends
- Income
- Retirement / Work
- Social / Recreational Activities

LGBT Elder Issues

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Aging Supports



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LGBT Aging Supports



Spouse
Partner

Children
& Grand

Family
Of Origin

Faith
Community

Local
Community

Social
Community

Social
Services



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Aging Supports: Boomers & Millennials



Spouse
Partner



Children
& Grand



Family
Of Origin



Faith
Community



Local
Community



Social
Community



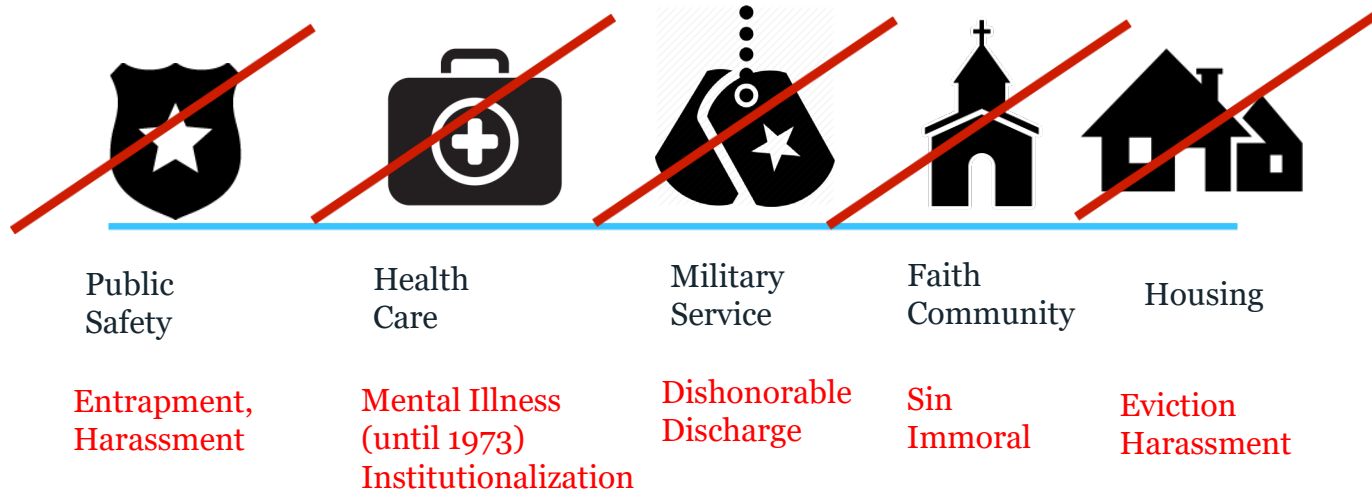
Social
Services



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Mainstream Supports





Anna Sarah

Born:	1930	1950
McCarthy Trials (1954)	24	4
Stonewall (1969)	39	19
American Psychiatric Association (1973)	43	23
Harvey Milk Elected (1977)	47	27
Reagan Mentions AIDS (1987)	57	37
“Ellen” Comes Out on TV (1997)	67	47
Marriage Equality in MA (2004)	74	54
Don’t Ask Don’t Tell Repealed (2011)	81	61
Defense of Marriage Act Repealed (2013)	83	63
SCOTUS: Marriage Equality (2015)	85	65
November 2016 ongoing.....Today	89	69



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Elders of Color & Aging

- Estimated 20% of LGBTs are people of color: estimated to double to 40% by 2050.
Adams, Generations 2016 in MAP 2017
- Lifetime experience with minority stress (multiple minority identities – multiple stressors).
- What does it mean to be LGBT in one's racial/ethnic community? What does it mean to be old?
- What does it mean to be a person of color in the LGBT community? What does it mean to be old?
- Flashback Sunday – community for LGBT Elders of Color



Bisexuality and Aging

- Most invisible element in LGBT spectrum assumption of identity based on current partner community based on current partner
- Bisexual older adults: significant mental/physical health disparities compared with lesbian & gay older adult peers
- More internalized stigma and less identity disclosure which impact social network and social support

Fredriksen-Goldsen et al., 2017

- Bisexuals 45+ less likely to be “out” with healthcare providers than lesbian/gay peers
- 59% have children/grandchildren
- 74% *do not* live in big cities

AARP, 2018



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Transgender Aging

- Transition early in life: some lived “stealth” with no history or context; significant losses
- Transition later in life: after milestones
- High rates of unemployment, underemployment, violence, denied healthcare
- Reluctance & fear of health/long term care
- Isolation from LGB age peers



HIV/AIDS and Aging

- Disproportionally LGBT/ Men who have Sex with Men (MSM) and People of Color
- Nationally: 50% of all people in the U.S. living with HIV & AIDS will be over 50 years old (by 2017)

CDC, 2015

- Massachusetts: 62% of all people living with HIV/AIDS are over 50 years old

Cahill et al, 2018

HIV and Aging

- Long-term Survivors
 - as long as 25 years or more with HIV infection
 - almost 70% live alone
 - impact of stigma persists
 - impact of losses of late 1980s/early 1990s persists
 - HIV supports of early era now gone
 - increased poverty (early disability)



HIV and Aging

- New infections/New diagnoses in older adults
 - more likely to present with advanced disease
 - less likely to achieve CD4/immune recovery with ARVs
 - more rapid progression to AIDS and shorter survival
 - increased risk of IRIS (immune reconstitution)

HIV and Aging

- new and newly identified infections - late diagnosis
- providers underestimate risk: ageism, lack of knowledge about past and present risk history
- patient lack of risk and prevention knowledge, increased risk behavior due to stigma, substance use
- stigma leading to: failure to engage in care, fear of disclosure
- missed diagnosis: symptoms which would be striking in younger adults attributed to other aging conditions
- CDC recommends annual testing age 13-64
- annual testing covered until age 65



HIV and Aging

- HIV Long-term Survivors

- increased inflammation even with viral load control
- immune senescence
- controversy about whether HIV itself accelerates aging process

Co-morbidities/Multimorbidity

- for many conditions, older people with HIV have greater incidence of co-morbidities but not at an earlier age
- Polypharmacy
 - 55% of people with HIV over 50 are on at least 5 medications



HIV and Co-Morbidity /Multimorbidity

- Lipodystrophy /Metabolic Issues: due to HIV, antivirals
- Cardiovascular Disease
- Chronic Kidney Disease
- Osteoporosis
- Liver Disease
- Peripheral neuropathy and associated complications
- Non-HIV Malignancies:

HPV related - especially anal squamous cell cancer

Liver/cirrhosis related(due to hepatitis, alcohol, fatty liver)

Lymphoma and other hematologic illness

Smoking related



HIV and Co-Morbidity /Multimorbidity

- Neurocognitive dysfunction
 - Risks of HIV Associated Neurocognitive Disorders (HAND) increase with age
 - HIV dementia in effective antiretroviral era much less common
 - HAND prevalent and has impact on attention, working memory, processing speed and motor skills
 - HAND therefore has significant impact on medication adherence and other activities of daily living essential to independence (medication management, finances, shopping and cooking)
 - Depression/Anxiety/PTSD
 - Substance use



Dementia & LGBT Patients /Loved Ones

- Diagnosis – When and by whom?
 - Diagnosis could be delayed due to lack of socialization/family support and/or fear of doctor visits
- Care – Primary contact? Who manages? Who is informed?
 - Family may be estranged = partner may be ousted
 - May not have family or emergency contact information
- Legal Issues – “next of kin” vs. “family of choice”
 - Estranged/unaccepting family member may not respect relationship or wishes
 - LGBT friends may end up being health care proxy or power of attorney
 - Legal documents for providers



Aging and Cognitive Decline

- Fear of loss of autonomy and fears of vulnerability/abuse are more acute: “I have taken care of myself my entire life!”
- Early stages of cognitive decline affect instrumental Activities of Daily Living (ADLs):
 - managing medication
 - managing finances
 - managing shopping and cooking
- —> can easily be missed in an office visit <—
- —> highest risk for people living alone without supports <—



Aging and Cognitive Decline

Useful Interventions Which Do Not Require a Neurologist!

- Assess for safety: driving, cooking, finances, wandering
- Assess for sources of support

Aging and Cognitive Decline

Useful Interventions Which Do Not Require a Neurologist!

- Assess particularly for modifiable contributors to cognitive decline:
 - polypharmacy - de-prescribe when possible
 - medication adherence/confusion
 - medication interactions and side effects
 - sleep disorders
 - behavioral health especially depression and anxiety
 - sexually transmitted infections (syphilis, HIV)
 - sensory: hearing, vision, neuropathy
 - social isolation



Aging and Cognitive Decline

Useful Interventions Which Do Not Require a Neurologist!

- Assess particularly for modifiable contributors to cognitive decline:
 - substance use:
 - smoking which is higher in LGBT adults
 - alcohol: higher in LGBT adults, increase after retirement
 - marijuana???
 - methamphetamine
 - benzos/sleep medications
 - opioids



Caregiving and Care receiving

Most LGBT Caregiving is HORIZONTAL

General Population

Women

90% birth/Marriage

10% non relative

LGBT Population

Men/Women

35% partner/spouse

16% parent

9% other relative

32% friend

7% non relative/Neighbor

*The Aging and Health Report: Disparities and Resilience in
Lesbian, Gay, Bisexual and Transgender Older Adults, 2011*

LGBT Caregiver Support: Safe space for unique experience

LGBT Bereavement Group: Current & Previous Losses; Broader range of losses

Aging and Autonomy: Advanced Directives

- People express concern about autonomy and control of end of life care
- Over half of people with advanced illness have not completed advanced directives
- Many people who complete advanced directives do not share these with their physician
- Health care proxy may not be sufficient if proxy not aware of wishes and comfortable respecting these wishes
- Health care proxy needs to be reviewed regularly especially when same aged peer is the proxy
- Medical Orders for Life Sustaining Treatment (MOLST) and Physician Orders for Life Sustaining Treatment (POLST) sometimes helpful
- LGBT individuals may have complicated relationships with family of origin and detailed advance directive may be enormously helpful to the health care proxy



Individual Practice

- **Challenge heterosexual assumptions about older adults**
- **Language of the times:**
 - Homosexual vs. Gay/Lesbian
 - Lifestyle vs. Orientation; Gender Identity/Expression
 - Friend, lover, partner, spouse, husband/wife
 - Euphemisms -- friend, roommate, cousin
- **Newer language:**
 - Queer
 - Ally
 - Non-binary; Gender non-conforming
- **Open ended questions:**
 - Who else lives in your home? Who do you consider your family?
 - What else would be helpful for me to know?
- **Affirming environment without naming it:**
 - You two make a great team
 - How long have you lived together/known each other?



**SPECIAL
LEGISLATIVE
COMMISSION ON
LESBIAN, GAY,
BISEXUAL AND
TRANSGENDER
AGING**



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An Act Relative to LGBT Awareness Training for Aging Service Providers

SECTION 1. Chapter 19A of the General Laws is hereby amended by inserting after section 41 the following section:

Section 42. The department shall **develop a curriculum and training program** on the prevention and elimination of discrimination based on sexual orientation, gender identity and expression and on improving access to services for lesbian, gay, bisexual and transgender elders and caregivers. The training program shall be completed by **all providers of services who contract with or receive funding from the department, Aging Service Access Points or the MassHealth Office of Long Term Care**, or whose services are certified by the department.

July 2018



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Resources for LGBT Older Adults and Caregivers

- Social Organizations
 - The Prime Timers, Older Lesbians Organizing for Change (OLOC), RALLY, Flashback Sunday, Griot Circle
- LGBT Friendly Community Cafes - 23 statewide in MA
- LGBT Friendly Senior Housing - 10 currently; 20 pending in US
- LGBT Bereavement Groups
- LGBT Senior Pride Coalition
- LGBT Aging Project Newsletter (lgbtagingproject.org)
- SAGE – NY and national affiliates
- National Resource Center on LGBT Aging (lgbtagingcenter.org)



Resilience



able to return to an original shape after being
pulled, stretched, bent or pushed

Merriam Webster Learners Dictionary



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Thank you!

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