ADVANCING EXCELLENCE IN SEXUAL AND GENDER MINORITY HEALTH

LGBT Aging
Change, Challenge and Resilience

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NATIONAL LGBT HEALTH EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE

HARVARD MEDICAL SCHOOL
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: 33,000
(US Census QuickFacts 2019 and MA BRFSS Data 2016-18)

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

Spouse Partner  Children & Grand  Family Of Origin  Faith Community  Local Community  Social Community  Social Services
Aging Supports

- Spouse Partner
- Children & Grand
- Family Of Origin
- Faith Community
- Local Community
- Social Community
- Social Services
Aging Supports: Boomers & Millennials

- Spouse
- Partner
- Children & Grand
- Family Of Origin
- Faith Community
- Local Community
- Social Community
- Social Services
Mainstream Supports

Public Safety
Harassment
Entrapment

Health Care
Mental Illness
(u)ntil 1973
Institutionalization

Military Service
Dishonorable Discharge

Faith Community
Sin
Immoral

Housing
Eviction
Harassment
<table>
<thead>
<tr>
<th>Event</th>
<th>Anna Year</th>
<th>Sarah Year</th>
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<tbody>
<tr>
<td>Born:</td>
<td>1930</td>
<td>1950</td>
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<tr>
<td>McCarthy Trials (1954)</td>
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<tr>
<td>Stonewall (1969)</td>
<td>39</td>
<td>19</td>
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<td>APA/DSM (1973)</td>
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<tr>
<td>Harvey Milk Elected (1977)</td>
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<td>Reagan Mentions AIDS (1987)</td>
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<tr>
<td>“Ellen” Comes Out on TV (1997)</td>
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<td>47</td>
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<td>Marriage Equality in MA (2004)</td>
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<td>Don’t Ask Don’t Tell Repealed (2011)</td>
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<td>DOMA Repealed (2013)</td>
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<tr>
<td>SCOTUS: Marriage Equality (2015)</td>
<td>85</td>
<td>65</td>
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<td>November 2016 ongoing...Today</td>
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Bisexuality and Aging

- Most invisible element in LGBT spectrum
  - assumption of identity based on current partner
  - community based on current partner

- Bisexual older adults vs. lesbian and gay older adults:
  - significant mental/physical health disparities
  - more internalized stigma/less identity disclosure
    - impacting 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
Transgender Aging

- Transition early in life: some lived “stealth” with no history or context; significant losses

- Transition later in life: after milestones
  - Retirement, family grown, deaths

- Selective authenticity: maintaining different identities in different settings
Transgender Aging

- High rates of unemployment, underemployment, violence, denied healthcare

- Reluctance & fear of health & long term care
  - Lack of trans inclusive care
  - Lack of knowledge about long term hormone use

- Isolation from LGB older adults
LGBT Elders of Color and Aging

- Estimated 20% of LGBT community are people of color; double to 40% by 2050
  Adams, Generations 2016 in MAP 2017

- Intersectionality of experiences with multiple minority identities and stressors
  - What does it mean to be LGBT in one’s racial/ethnic/faith 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?

- LGBT Elders of Color/Flashback Sunday: community to welcome all identities
HIV/AIDS and Aging

- Disproportionally LGBT/MSM and People of Color
- Nationally: 50% of all people in the U.S. living with HIV & AIDS are over 50 years old
- Massachusetts: 62% of all people living with HIV/AIDS are over 50 years old

CDC

MA Department of Public Health, 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)
- Importance of LTS peer groups
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
HIV and Aging

- 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
- Under ACA, annual testing covered until age 65
HIV and Aging

- HIV Longterm 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
HIV and Co-Morbidity/Multimorbidity

- Liver Disease

- Non-HIV Malignancies:
  - HPV related - especially anal squamous cell cancer
  - Liver/cirrhosis related (due to hepatitis, EtOH, fatty liver)
  - Lymphoma and other hematologic illness
  - Smoking related

- Depression/Anxiety/PTSD

- Substance Use
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)
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
Dementia & LGBT Patients/Loved Ones

- 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 HCP or POA
  - 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 ADLs:
  - managing medication
  - managing finances
  - managing shopping and cooking
  - Driving/transportation

- 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 social isolation and potential sources of support
- Assess for sensory problems: hearing and vision
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
  - STIs (syphilis, HIV)
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

<table>
<thead>
<tr>
<th>General Population</th>
<th>LGBT Population</th>
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<tbody>
<tr>
<td>women</td>
<td>men/women</td>
</tr>
<tr>
<td>90% birth/marriage</td>
<td>35% partner/spouse</td>
</tr>
<tr>
<td></td>
<td>16% parent</td>
</tr>
<tr>
<td></td>
<td>9% other relative</td>
</tr>
<tr>
<td>10% non relative</td>
<td>32% friend</td>
</tr>
<tr>
<td></td>
<td>7% non relative/neighbor</td>
</tr>
</tbody>
</table>

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
Aging and Autonomy: Advanced Directives

- 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

- MOLST/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
Case Example: Emily Blake*

- 76 year old retired elementary school teacher
- Never married, came out as lesbian late in life, never had a same sex partner
- Lives alone, managing well, large and supportive network of friends
- Medical history: breast cancer, asthma, coronary artery disease, heart failure
- Last year: ovarian cancer with surgery and chemotherapy (atrial fibrillation and heart failure)
- Follow up scans: no cancer
- Currently: friends concerned about forgetfulness and disorganization and safety at home
Case Example: Emily Blake*

- Bloodwork: unrevealing for reversible causes of cognitive decline
- CNS imaging: some small vessel disease
- Medication regimen reviewed and simplified to eliminate any potential medication contributors to her cognitive changes

- Increasing:
  - Frequent EMT assistance for falls at home
  - Difficulty with self-care, finances
  - Repeatedly changing mind about whom she names as health care proxy

- Emily is aware that she is having difficulty managing, and she appreciates her friends help, but she is not sure that she needs as much assistance as they are telling her.
Individual Practice

- Challenge heterosexual/cisgender 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; Gender diverse
Individual Practice

- **Open ended questions:**
  - Who else lives in your home? Who do you consider your family?
  - What else would be helpful for me to know?
  - Anything about your body you would like us to know about?

- **Affirming environment without naming it:**
  - You two make a great team
  - How long have you lived together/know each other?
  - We work with all kinds of people and it’s important to us that you feel comfortable here, please let us know if we can do anything differently for you
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
Resources for LGBT Older Adults and Caregivers

- Social Organizations
  - The Prime Timers, OLOC, RALLY, LGBT Elders of Color, 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)
What Supports Resilience?

Ability to be Authentic

LGBT inclusive and affordable health care
Safe and affordable housing
Social network and community
Meaningful engagement
Livable income
Resilience

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

Merriam Webster Learners Dictionary
Q & A

Are there any questions that you would like to ask?

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