



ADVANCING EXCELLENCE IN SEXUAL  
AND GENDER MINORITY HEALTH

## LGBT Aging

Change, Challenge and Resilience



Elizabeth Kass, MD  
Fenway Health

Lisa Krinsky, MSW, LICSW  
Director, LGBT Aging Project



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: 65,000

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



# What's So Different?

## Elder Issues

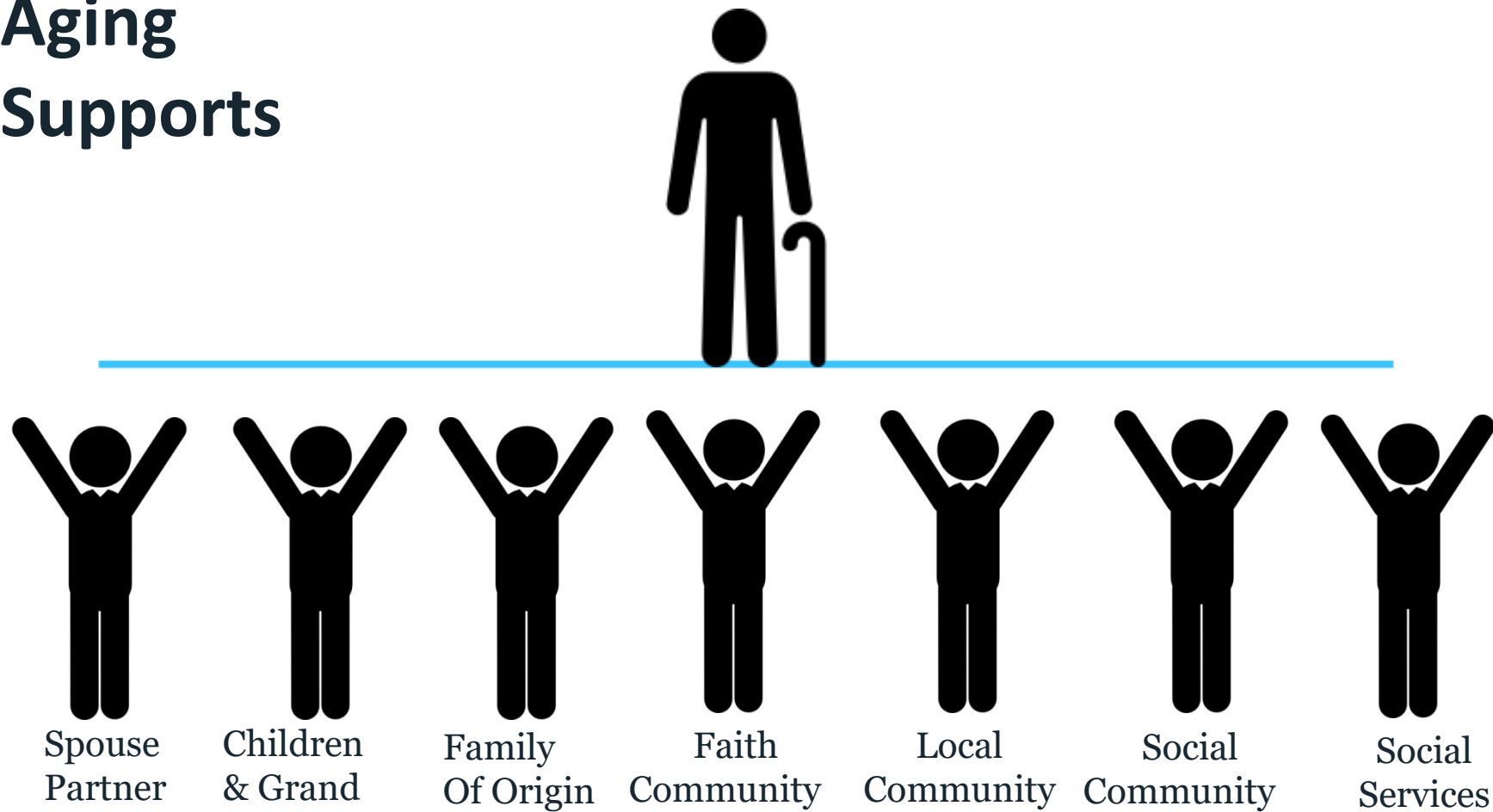
- Healthcare
- Housing
- Medication Costs
- Social Network: Family, Friends
- Income
- Retirement / Work
- Social / Recreational Activities

## LGBT Elder Issues

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



# Aging Supports



# 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



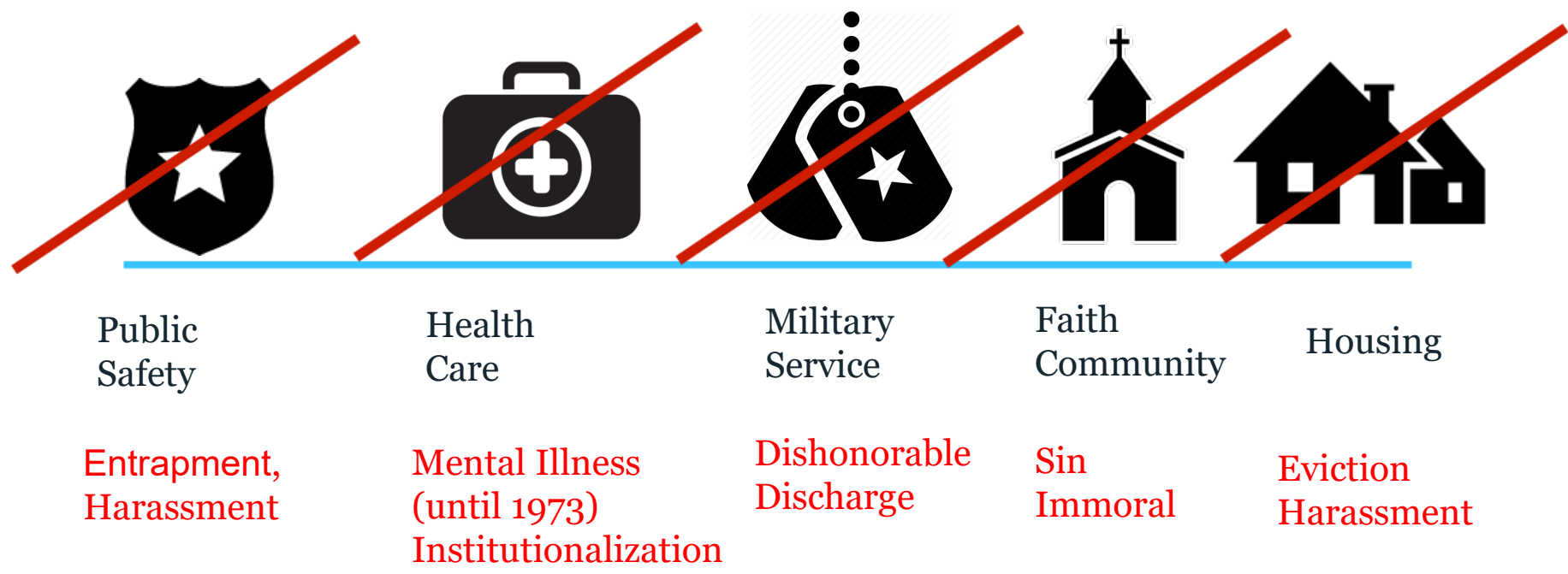
Social  
Community



Social  
Services



# Mainstream Supports





## Anna

## Sarah

Born:	1930	1950
McCarthy Trials (1954 )	24	4
Stonewall (1969)	39	19
APA/DSM (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Don’t Ask Don’t Tell Repealed (2011)	81	61
DOMA Repealed (2013)	83	63
SCOTUS: Marriage Equality (2015)	85	65
November 2016 ongoing.....Today	89	69





# 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 EOC



# 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



# 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/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
- 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
- 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



# 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 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
- —> 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
  - STIs(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
- 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

- Emily is a 76 yr old retired elementary school teacher who never married and came out as a lesbian late in her life but never has had a same sex partner. She has lived alone and until last year seemed to be managing quite well independently despite multiple medical problems that included breast cancer, asthma, coronary artery disease and heart failure. Ms Blake has had a large and supportive group of close friends.
- Last year she had an ovarian cancer diagnosis and underwent surgery followed by chemotherapy, which was complicated by episodes of atrial fibrillation and heart failure. Though followup scans showed no evidence of cancer, and she re-gained appetite, weight and energy, her friends began to express concerns about Ms Blake's increased forgetfulness and disorganization.
- Bloodwork for reversible causes of cognitive decline was unrevealing.
- CNS imaging showed some small vessel disease.
- Medication regimen was reviewed and simplified to eliminate any potential medication contributors to her cognitive changes.

# Case Example cont.

Emily Blake

- Despite this, over time Ms Blake seems to have had increasing difficulty with keeping her medication straight, with managing her finances and self-care, and she has begun to have frequent falls, with EMTs called to her home numerous times to assist her.
- Her friends have been doing their best to pitch in and help out, but they are becoming increasingly concerned that she can not remain safely at home. Ms Blake repeatedly changes her mind about whom she wishes to be her health care proxy. She told one of her friends that she has long term care insurance as it had been offered through her work benefits, but she is not sure what this will cover.
- She 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 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/know each other?



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



# 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, 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](http://lgbtagingproject.org))
  
- SAGE – NY and national affiliates
- National Resource Center on LGBT Aging ([lgbtagingcenter.org](http://lgbtagingcenter.org))



# 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?

Elizabeth Kass, MD

[Ekass@fenwayhealth.org](mailto:Ekass@fenwayhealth.org)

Lisa Krinsky, MSW, LICSW

[Lkrinsky@fenwayhealth.org](mailto:Lkrinsky@fenwayhealth.org)

