

# FOSTERING END-OF-LIFE CONVERSATIONS, COMMUNITY AND CARE AMONG LGBT OLDER ADULTS



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# UNIQUE CHALLENGES FACING OLDER LGBT ADULTS

## 1. Effects of stigma, past and present

- 1.6 million LGBT elders; largely closeted
- A psychiatric disorder (*until 1973*)
- Criminal (*until 2003*)
- Limited legal protections
- Fear accessing health and community services



## 2. Need to rely upon “families of choice” for care and support



- Twice as likely to be single; age alone
- Four times less likely to have children
- Rely on friends (70%) who lack legal and social recognition
- Uncertain “who caregiver will be”

## 3. Unequal treatment under laws, programs and services for older adults



- Design safety nets around marriage, then exclude LG couples
- Over 80% of LGBT adults report they “can not be out” in LTC settings

## **SOCIAL CONTEXT**

Relative to heterosexual men and women of comparable age, LGBT older adults are:

More likely to live alone (especially gay men—2-3X: ref: Fredriksen-Goldsen et al., 2010; Wallace, Cochran, Durazo & Ford, 2011)

Less likely to have a partner/spouse (especially gay men—2-3X: ref: MetLife Mature Market Inst., 2010)

Less likely to have children (especially gay men—~4X: ref: Fredriksen-Goldsen et al., 2010)

More likely to rely on formal services and informal supports in non-traditional ways (i.e., friends)

# BACKGROUND

**“It’s too early—until it’s too late.”**

**Not talking about our future care need = a failed experiment**

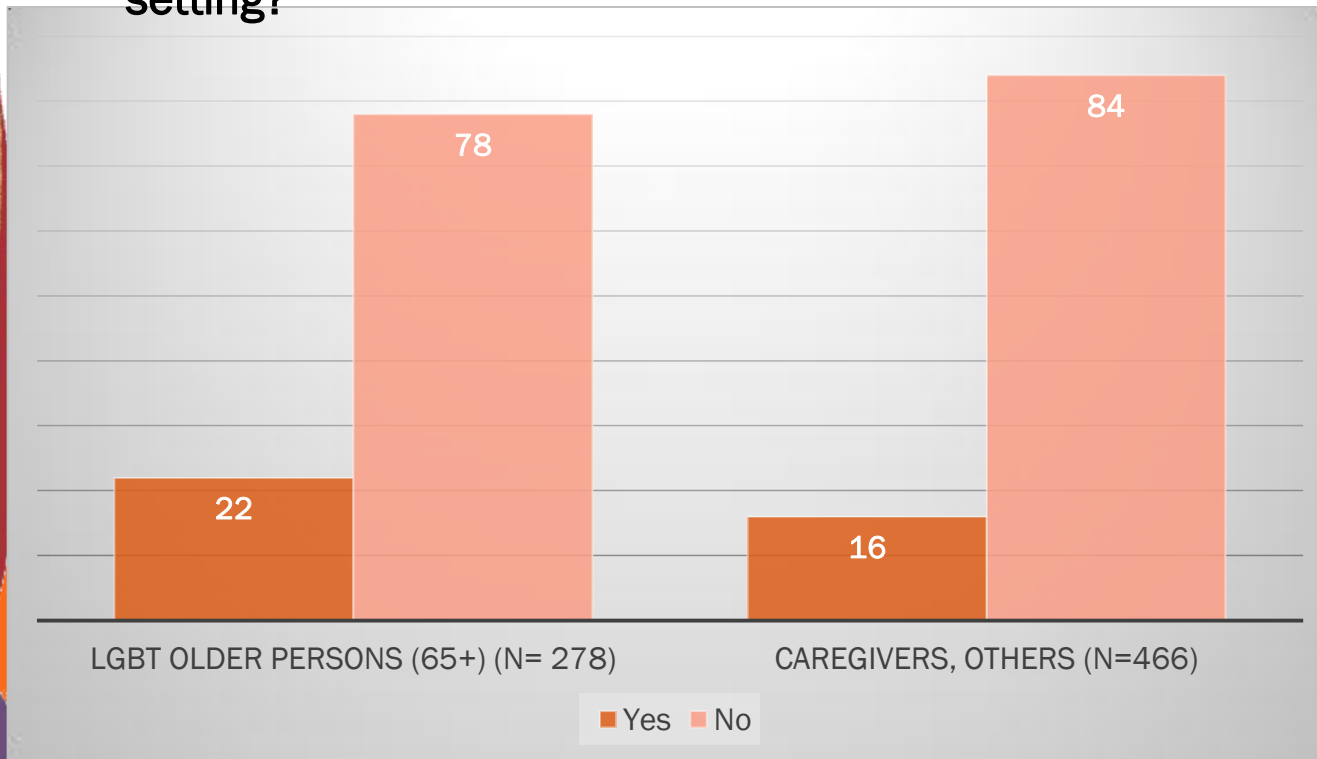
**Consider the following:**

- More than 90% think it is important to talk to loved ones about end-of-life wishes—less than 30% have had such discussions (Conversation Project, 2013; national sample)
- 60% of people report it is “extremely important” that their loved ones are not burdened by tough decisions; almost 60% have not communicated their wishes (CA Healthcare Foundation, 2012, n=1669 adults)
- 70% of people say they would prefer to die at home; 32% of deaths take place at home (CA Healthcare Foundation, 2012, n=1669 adults; CA DPH, Death Records, 2011)

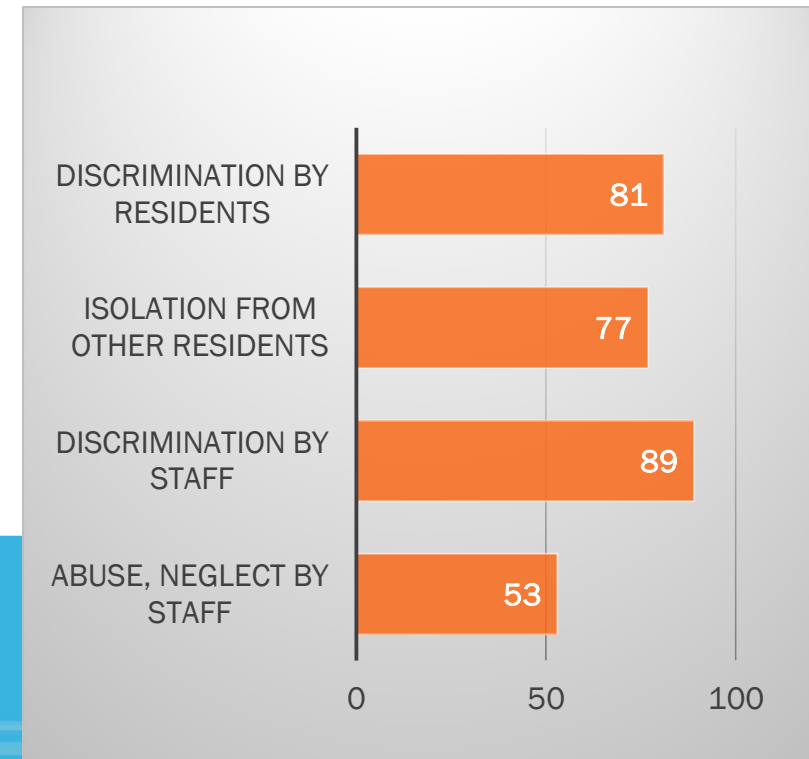
# LGBT PERSONS IN LONG-TERM CARE SETTINGS

(SOURCE: SAGE (2011). LGBT OLDER ADULTS IN LONG-TERM CARE FACILITIES.)

### Can LGBT older persons be “out” in LTC setting?



### Fears/expectations of LGBT older persons in LTC settings:



# PROJECT DETAILS

## Three-part national project

- Focus groups with LGBT older adults and care providers in Vancouver, Edmonton, Toronto, Montreal, and Halifax to understand issues/extent of end-of-life planning (e.g. document completion, care planning, discussions)
- Town hall meetings to raise awareness of need for planning and to highlight local resources
- Create proof-of-concept pilot web-based platform to provide supportive environment for information sharing and community building:

<http://sfu.ca/lgbteol>

# STUDY SAMPLE

	Bisexual & Gay Men	Bisexual & Lesbian Women	Transgender Individuals	Sub-Total	Service Providers
Age range 57-89 years; M = 69					
<b>Total</b>	<b>39</b>	<b>29</b>	<b>23</b>	<b>91</b>	<b>26</b>
Vancouver	15	12	9	36	7
Edmonton	5	2	1	8	3
Toronto	5	4	9	18	7
Montreal	6	5	2	13	5
Halifax	8	6	2	16	4



# FOSTERING END-OF-LIFE CONVERSATIONS – FOCUS GROUPS

## Four Focus groups at each site:

- Gay and bisexual men
- Lesbians and bisexual women
- Trans\* identified persons
- Service providers

## Requirements for LGBT groups:

- English or French speaking
- 60 years of age or older
- One or more chronic conditions
- Some internet experience

## Content:

- Preparations, plans for later life care
- Issues, concerns about aging
- Role of community and support
- Role of technology in assisting LGBT persons better prepare
  
- Group discussions recorded, transcribed, coded (by two persons)

## FOCUS GROUP PARTICIPANTS CHARACTERISTICS

	N	% Single	% Live Alone	% No Children	% No Caregiver
Gay Men	39	62	72	77	32
Lesbians	29	48	45	48	30
Trans*	23	70	54	33	38

# FOCUS GROUP THEMES - EDUCATION

Bisexual & Gay Men	Bisexual & Lesbian Women	Transgender Individuals	Service Providers
<ul style="list-style-type: none"><li>• Education of service providers about LGBT issues</li><li>• Politicize issues</li><li>• Educate younger persons</li></ul>	<ul style="list-style-type: none"><li>• LGBT individuals need to self-educate about aging &amp; about palliative care</li><li>• Plans change when partner gets sick</li></ul>	<ul style="list-style-type: none"><li>• Intentional, specific education</li><li>• Need “bottom-up” education</li><li>• Need to educate medical residents, care facility staff, and other older adult LTC residents</li></ul>	<ul style="list-style-type: none"><li>• Diverse backgrounds of care providers</li><li>• Learning diversity of language (e.g. LGBTQ, 2-spirit, intersex)</li></ul>

# EXCLUSION IN HEALTHCARE SETTINGS

Bisexual & Gay Men	Bisexual & Lesbian Women	Transgender Individuals	Service Providers
<ul style="list-style-type: none"><li>• Concern about having to “go back into the closet” to receive care</li></ul>	<ul style="list-style-type: none"><li>• Residential services not LGBT-affirmative, and “more focused on wealthy gay men”</li><li>• Concern about having to “go back into the closet” to receive care</li></ul>	<ul style="list-style-type: none"><li>• Anxieties of having to “out self” in each new medical environment; having to educate health providers</li><li>• Forms that don’t describe “who I am”</li></ul>	<ul style="list-style-type: none"><li>• No one knows what happens “behind closed doors”</li></ul>

# LANGUAGE

Bisexual & Gay Men	Bisexual & Lesbian Women	Transgender Individuals	Service Providers
<ul style="list-style-type: none"><li>• End-of-life planning resources focus on heterosexual scenarios</li></ul>	<ul style="list-style-type: none"><li>• Need to recognize within group diversity (“I’m a gay female; the one word I don’t use is lesbian”)</li></ul>	<ul style="list-style-type: none"><li>• No consideration for long-term needs for transgender individuals in healthcare materials</li></ul>	<ul style="list-style-type: none"><li>• Difficulty balancing changing language (e.g. “queer”) with client needs and preferences</li></ul>

# STIGMA, DISCRIMINATION, STEREOTYPING

Bisexual & Gay Men	Bisexual & Lesbian Women	Transgender Individuals	Service Providers
<ul style="list-style-type: none"><li>• Impact of living with HIV/AIDS</li><li>• Re-experiencing death of friends; grief; some experiencing survivor's guilt</li><li>• Some but not all estranged from family – a finding common across groups</li></ul>	<ul style="list-style-type: none"><li>• Impact of living with HIV/AIDS (e.g. “I lived my life dying of AIDS. Literally, that’s the way the world looked at me – dying. .... the medical profession still views me as a body with AIDS rather than an aging female.”)</li></ul>	<ul style="list-style-type: none"><li>• Discrimination from within as well as outside the LGBT community</li></ul>	<ul style="list-style-type: none"><li>• Diverse background &amp; training of care providers</li></ul>

## END-OF-LIFE PLANNING TO DATE - VANCOUVER FOCUS GROUPS (%)

	Gay men	Lesbians	Trans
Will	73	67	89
Living will	33	58	22
Durable POA	40	50	33
Representation Agreement	7	42	11
Pre-paid Funeral	27	8	0
LTC Insurance	13	0	11
Critical Care Insurance	13	0	0
Informal care arrangement	40	0	11
Explicit care discussion	47	75	78
Explicit EOL discussion	40	67	78

# LONELINESS & ISOLATION: THE BEST LAID PLANS

“But what did shock me... I had 6 close teaching friends, all my age, we all retired exactly the same day, and within 2 years all of them were dead.... And so whatever retirement I thought I was going to have involving those people, and we were all single just went, and so I had to invent, I had to figure out a new way of doing it because I just had counted on those people being around.” (Edmonton)

...and my partner passed away a year and a half ago so, this is, we thought we had everything covered, when it was the two of us, but now everything has changed.  
(Vancouver)



# SUMMARY

- Many similarities; important differences between gays, lesbians and trans persons
- Lack of, and need for, conversations about end-of-life care with non-traditional caregivers
- Attend to the differences within the LGBTQ population
  - Legacy of HIV
  - Differential access to resources (economic, social)
  - The “hidden T”
- Attend to heteronormativity of health care settings
- Service providers “got it;” not sure how to “act on it” and know they can do better

# CONCLUSIONS

Older LGBT adults face significant and unique challenges in planning later-life and end-of-life. Recognizing and addressing these challenges may redress the exclusion of LGBT persons as well as others who age alone, support better preparation and person-centered approaches to care.

Older LGBT adults have additional/unique end-of-life planning challenges

Inclusive education and policies may redress

## **IMPACT ON POLICY**

**Policies for aging and older adults need to consider issues of sexual orientation and gender identity**

**Service provider education needs to include cultural competence (including knowledge and understanding of socio-political history and context)**

**Resources need to be inclusive and accessible to older LGBT adults**