COLLECTING SEXUAL ORIENTATION AND GENDER IDENTITY DATA FROM OLDER ADULTS AND CAREGIVERS TO IMPROVE SERVICES

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OUTLINE

I. Why collect sexual orientation and gender identity (SO/GI) data in elder service settings?
   A. Understanding LGBT older adults
   B. State LGBT Aging Commission recommendation, recent federal policy developments

II. How to collect SO/GI data to improve services
   A. Understanding SO/GI terminology
   B. The new SO/GI questions
   C. How to ask SO/GI Questions

III. How to use the data to improve caregiver services for LGBT older adults and their caregivers

IV. Questions, discussion
PART I: WHY COLLECT SO/GI DATA?
UNDERSTANDING LGBT OLDER ADULTS
LGBT PEOPLE LIVE EVERYWHERE

- Not only in Boston and Northampton, but in every part of the Commonwealth, including rural areas
- LGBT elders come to your senior center, meal program, and live in your nursing home or long-term care facility
- It’s important to create a welcoming, affirming environment in which people are comfortable being “out”
- Being “closeted” causes minority stress
LGBT ELDERS

Collecting SO/GI information is important because LGBT elders experience unique disparities and challenges:

- May be more likely to be single and/or live alone
- Less likely to have children, grandchildren
- May be more in need of formal caregiving support, elder services than others
LGBT ELDERS

- LGBT elders came of age under conditions of intense homophobia
  - Homosexuality criminalized in 50 states
  - Categorized as a mental illness; electroshock therapy used as treatment
  - Condemned as sin by all major religions
  - Legitimate cause for being fired or denied employment

- Many LGBT elders thought of non-disclosure as a survival strategy
SOCIAL ISOLATION MAY BE GREATER FOR LGBT ELDERS

- Older gay/bi men, bisexual women in Mass. more likely to live alone, according to BRFSS—could indicate social isolation

- Lower parenting rates for same-sex partners, LGBT elders have implications for caregiving in old age (Gates & Cooke, 2011; de Vries, 2006)
LIFE EXPERIENCES SHAPE LGBT ELDERS’ ACCESS TO HEALTH CARE, SUPPORT NETWORKS

- For many older gay men, AIDS decimated their social networks, increasing social isolation.
- Older Americans more likely to hold antigay views, morally disapprove of homosexuality.
- Ex: 63% of Americans 70+ believe homosexuality “always wrong” vs. 41% of 30-39 year olds.
- Many older Americans believe wrongly that HIV is casually transmitted.
STATE COMMISSION RECOMMENDATION, RECENT FEDERAL REGULATORY DEVELOPMENTS
SPECIAL LEGISLATIVE COMMISSION ON LESBIAN, GAY, BISEXUAL AND TRANSGENDER AGING

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1. DATA COLLECTION

Exec. Office of Health & Human Svcs., Exec. Office of Elder Affairs, Dept. of Housing & Community Development should collect voluntary and confidential sexual orientation and gender identity data as a standard practice for:

- Individual assessments
- Program monitoring data systems
- Consumer satisfaction surveys
- Public health surveillance
- Research and evaluation

“If you don’t count us, we don’t count.”

- Massachusetts Special Legislative Commission on LGBT Aging Recommendations, September 2015
FEDERAL REGULATORY DEVELOPMENTS

Stage 3 Meaningful Use Guidelines 2015

- According to Centers for Medicare and Medicaid Services, Office of Health IT, SO/GI data fields must be incorporated in EHR software certified under the Meaningful Use incentive program HRSA to require SO/GI data collection by CHCs for 2016 in Uniform Data System

- “Improving the health of the nation’s underserved...is a priority of the Health Center Program”

- “Sexual orientation & gender identity can play significant role in determining health outcomes”
FEDERAL REGULATORY DEVELOPMENTS

Center for Medicare/Medicaid Services Equity Plan, 2015

- Encourages health care providers to collect SOGI data from Medicare beneficiaries.
- “Comprehensive patient data, including...sexual orientation, gender identity...are required to plan for quality improvements, and to address changes among the target populations over time.”
PART II: SO/GI DATA COLLECTION

- Basic SO/GI terminology
- The new FCSP Assessment Questions
- How to ask these questions
- Framing
- Pushback
RECAP

- **LGBT Elders** –
  - lifetime of discrimination
  - Invisible in aging service demographics

- **Current Data Collection** –
  - Inadequate to meet needs of this population

- **EOEA Massachusetts**
  - working to make entire elder service network safe, welcoming and inclusive for all older adults and caregivers
  - Asking demographic questions on SO/GI
SEXUAL ORIENTATION

Sexual orientation: how a person identifies her/his physical, emotional attraction to others:

- **Heterosexual (straight):** describes someone who is attracted to people of a different sex
- **Gay:** someone who is attracted to people of the same sex; gay is usually used to describe men attracted to other men
- **Lesbian:** describes a woman who is attracted to other women
- **Bisexual:** individuals who are attracted to both men and women
GENDER IDENTITY

- A person’s internal sense of gender (do I consider myself male, female, both, neither?)
- All people have a gender identity
THE T IN LGBT: TRANSGENDER

Transgender

- Gender identity not congruent with the assigned sex at birth

- Alternate terminology
  - Transgender woman, trans woman, male to female (MTF)
  - Transgender man, trans man, female to male (FTM)
  - Trans feminine, Trans masculine

- Non-binary, genderqueer
  - Gender identity is increasingly described as being on a spectrum
Sex
• Refers to the presence of specific anatomy. Also may be referred to as “Assigned Sex at Birth”

Gender Identity
• What your internal sense tells you your gender is

Sexual Orientation
• To whom you are physically and emotionally attracted
• With whom you have sex
• How you identify your sexuality

Gender Expression
• How you present your gender to society through clothing, mannerisms, etc.
THE NEW SO/GI QUESTIONS IN
THE FCSP ASSESSMENT
Gender: What was your sex at birth (on your original birth certificate)?

☐  ☐ Male
☐  ☐ Female
What is your current gender identity? (Check all that apply.)

- Male
- Female
- Female-to-male (FTM)/transgender male/trans man
- Male-to-female (MTF)/transgender female/trans woman
- Genderqueer, neither exclusively male nor female
- Additional gender category (or other)
- Did Not Answer
NEW QUESTION 13505:

Do you think of yourself as:

- Heterosexual or Straight
- Lesbian, Gay or Homosexual
- Bisexual
- Not Sure
- Did Not Answer
- Other
HOW TO ASK SO/GI QUESTIONS

Framing the intake interview

- “This is a standardized assessment”
- “It is comprehensive so we can learn as much about each caregiver to provide best possible care”
- “I ask every question to everybody and don’t make any assumptions”
- “I will ask questions that don’t apply to you and questions that are difficult to answer (and for me to ask!”)
- “You can decline to answer anything”
HOW TO ASK SO/GI QUESTIONS

Challenges for Caregiver Advisors

- Uncomfortable asking hard questions (race, education, incontinence, $)
- You are experts in asking difficult questions in a compassionate way
- You will develop your style with practice

Responses

- “We can move on and come back to these questions a little later”
HOW TO ASK SO/GI QUESTIONS

Challenges for non LGBT Clients

- I don’t understand why this is relevant. I just want laundry service.

Responses

- “Some questions are very important to different people and some questions don’t apply to everybody”
- Remember you can choose to not answer anything.
HOW TO ASK SO/GI QUESTIONS

About Confidentiality

- Answering SO/GI information is then available to all ASAPs.

Options

- Make sure they are aware of this if they seem uncomfortable with disclosure
- SO/GI status could be in client notes or kept confidential with Case Manager
- Remind them that having this as part of their care plan improves competent service.
HOW TO ASK SO/GI QUESTIONS

Opportunities for LGBT Clients

- So many LGBT older adults have spent their lifetime invisible and yearn to have this question asked.
- Asking SO/GI validates them and shows that the agency is willing to include LGBT people.
- Asking SO/GI creates a safe space that allows LGBT older adults to finally be their authentic selves. That can lead to positive mental/physical health outcomes.
TIPS FOR ASKING SOGI

• We want to be welcoming to everyone
• This is something we are asking all of our clients now
• Some of these questions may be very important to some people, it’s ok if they are not important to you, but I need to ask them
• Some of our clients are LGBT so we are asking everyone to make sure all our clients needs are met
• If you are uncomfortable you don’t have to answer
PART III: HOW SO/GI DATA WILL IMPROVE SERVICES FOR LGBT OLDER ADULTS
PERSON CENTERED CARE:

- The more that providers know about their individual clients, the better services they will be able to provide for them.
- Asking for SO/GI data helps address health/home care disparities for LGBT older adults.
SO/GI DATA WILL HELP PROVIDERS:

- Anticipate critical gaps in caregiving for unbefriended LGBT older adults
- Address social isolation through programming or referrals to LGBT programs
- Monitor bullying/isolation in senior housing towards LGBT residents
SO/GI DATA WILL HELP PROVIDERS:

- Build skills in cultural competency to provide safe, competent services for vulnerable populations – such as home care aides for a transgender elder.

- Enable I&R staff to provide specific resources for new LGBT clients such as locations for LGBT-friendly congregate meal sites.
Massachusetts LGBT Meal Site Locations
(As of March 2016)

Legend
- Meal Site
- Town

- LGBT Senior Social Gathering (Merrimac)
- LGBT Lunch Group (Somerville)
- Arlington Lunch Group
- Mystic Tea (Malden)
- Cafe Emmanuel (Boston)
- Out2Brunch (Roslindale)
- Lakeside Cafe (Sharon)
- Out2Brunch (Brookline)
- Out4Supper (Boston)
- South Shore LGBT Brunch (Braintree)
- Lower Cape LGBT Seniors (Orleans)
- South Coast LGBT Seniors (Fairhaven)
- Over The Rainbow Supper Club (Salem)
- Kate's Cafe @ Ryles (Cambridge)
SO/GI DATA WILL HELP PROVIDERS:

- Identify the needs of LGBT older adults in their area.
- Develop programming to meet those needs.
- Help inform an ASAP’s need for additional resources and cultural competency training as more LGBT clients come into their case load.
LGBT ISSUES AND CAREGIVING: IMPACT OF STRESS

- Similar themes in caregiving, often deeper issues underneath of privacy, secrecy, fear of discrimination from providers
- Increased stress caregiving plus fears of discrimination for care recipient
LGBT ISSUES AND CAREGIVING: LACK OF CAREGIVING SUPPORT

- Lack of caregiving supports and resources (especially family supports)
- Fewer people to share tasks of caregiving
  - Many do this 100% on their own
  - Increased risks of suicide ideation
- Many LGBT older adults have no one to call upon for caregiving help
LGBT ISSUES AND CAREGIVING: FAMILY DYNAMICS

- Challenging family dynamics
  - Caring for non supportive parents
  - Leaving caregiving to LGBT adult children
  - Immediate family not acting in best interest of care recipient
  - Importance for advance directives
FREQUENTLY ASKED QUESTIONS

Isn't asking SOGI intrusive or offensive?
Do you have a plan for proper translations?
Can I just skip these questions?
How do I respond when a client asks why these questions are being asked?
Dear Ethos client,

Your Ethos Case Manager visits you to see how you are doing and if you have any changes that affect your need for services. During these visits we ask questions in order to determine eligibility, understand your needs, and determine which services to provide.

We are writing to let you know that the assessment form has new questions about gender identity and sexual orientation. We will be asking everyone these questions. Whether or not you choose to answer these will not affect your services. The questions are to help us better understand the people we work with. Your Case Manager will be able to explain any questions you may have about this.

Ethos highly values its clients and strives to be inclusive of all people. If you are a person who identifies as gay, lesbian, bisexual, or transgender, be assured that we welcome you and look forward to serving you the best way we can. If you would like to be assigned to a Case Manager who has a focus on working with these groups, please contact Margery Gann, Care Management Director.
RESOURCES

http://www.lgbthealtheducation.org/topic/sogi/

http://issuu.com/lgbtagingcenter/docs/inclusivequestionsolder_adults_guidebook/1?e=0

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THANK YOU. QUESTIONS?

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