Fenway Health

May 15, 2023

Senate Chair Patricia Jehlen
House Chair Thomas Stanley
Joint Committee on Elder Affairs
State House Rooms 424 and 167
24 Beacon Street
Boston, MA 02133

Dear Chair Jehlen, Chair Stanley, and Members of the Joint Committee on Elder Affairs,

Fenway Health would like to register our support of H.637 and S.381 An Act establishing an LGBTQI long-term care facility bill of rights and request that the Joint Committee on Elder Affairs report the bill favorably.

Fenway Health is a federally-qualified health center and Ryan White Part C HIV clinic serving about 35,000 patients in four sites across Boston and Cambridge. Roughly half of our patients are LGBTQIA+, and over 5,000 are transgender and nonbinary. About 2,200 patients are people living with HIV, and about 3,000 are on PrEP for HIV prevention. The Fenway Institute is the research, training, and health policy division of Fenway Health. A major focus of our work is HIV and STI prevention and research. The LGBTQIA+ Aging Project, a program of the Fenway Institute, works toward equity, inclusion, and community for LGBTQIA+ older adults ensuring that they can age with the dignity and respect they deserve.

The Massachusetts State Plan on Aging reports an estimate that “70% of all Massachusetts residents who reach the age of 65 will need help with activities of daily living.” However, today’s LGBT older adults are less likely than the general population of elders to have partners, children and family who can provide caregiving supports, and may be estranged from their families of origin. As a result, LGBT people as a group are at higher risk of premature institutionalization. And because of their history of institutional mistreatment, for many LGBT older adults, nursing homes are viewed as “institutional closets”—dangerous and unwelcoming places where, at the end of life, being LGBT reverts to how it began, with bullying, humiliation, and harassment.

Harassment and discrimination are common for older LGBTQ+ individuals and negatively affect their health. This vulnerability is even more dangerous when people already facing health issues are forced into an environment that perpetuates discrimination and is not equipped to provide inclusive and culturally competent care. While Massachusetts law prohibits discrimination on the basis of real or perceived sexual orientation and gender identity (SOGI), SOGI nondiscrimination is not always practiced in the Commonwealth’s long-term care facilities.

A series of seven focus groups was recently conducted with 50 older LGBT people in Massachusetts. The topic was thoughts about entering long-term care. It was led by researchers at Simmons College School of Social Work, the Fenway Institute, and Mount Auburn Hospital Department of Psychiatry. The researchers found that:
Participants seek an inclusive environment where they will be safe and feel connected to a community. They fear dependence on healthcare providers, dementia, mistreatment, and isolation. Importantly, these fears can lead to identity concealment and psychological distress, including suicide ideation.iii

Among the unique concerns and hopes of LGBT older adults in relation to long-term care were:

healthcare providers who are knowledgeable and skillful in LGBT-specific needs; providers who are responsive to LGBT older adults’ historical context and possible history of victimization; visible mission statements that are LGBT affirmative; agency forms that gather information about SOGI and do not presume heterosexuality or cisgender identity; and finally, LGBT-inclusive activities and programming.iv

At the September 13, 2022 Massachusetts Special Legislative Commission on LGBT Aging quarterly meeting, a public meeting under the Commonwealth’s open meeting law, Alejandro Marcel spoke about his experiences at a Cape Cod nursing home and those of other LGBT residents there. A transgender man of Mexican descent, Marcel spoke of systemic but “nuanced” discrimination against LGBT residents of his nursing home. He described patients not having their beds changed for long periods of time, being brought to the toilet and then “they let you sit there for one hour if they don’t like you,” “waiting two weeks to take a shower,” staff not answering bell calls, and other forms of neglect and bias.

He spoke of the trauma of body dysphoria, and how someone will just show up and say “let’s take a shower.” “I felt like a dead man walking—I begged for it not to be a man” giving me the shower, Marcel said. Sometimes staff don’t want to change him because his body looks different. Disclosure is a big issue. One person learns that a patient is LGBTQI+ and the next thing the whole place knows. They put “transsexual” on his EHR so he has to disclose to every health care provider, even ones who he thinks don’t need to know.

Marcel said that training of nursing home staff in LGBTQI+ cultural competency was not sufficient to improve quality of care for LGBTQI+ patients, because the staff are “overwhelmed, overworked,” the nursing home runs on a “skeletal staff” that moves around a lot from facility to facility. Traveling agency nurses don’t come to staff trainings. Marcel said that the only thing the nursing home management cares about is its quality rating, and that LGBTQI+ content must be incorporated into its quality rating process. In Marcel’s view, this is the solution to getting the nursing home to improve its treatment of LGBTQI+ patients.

The Massachusetts Special Legislative Commission on LGBT Aging held listening sessions across the Commonwealth in 2014 and again in 2019-2020. LGBT elders at these listening sessions told equally compelling stories experiences of discrimination in senior housing, including long-term care, as well as in health care facilities and private businesses. These are included in two reports which are available on the Fenway Health website.v

While Massachusetts law requires the state network of elder care providers to take trainings on providing LGBTQ inclusive care,vi that training is not required of all long term care facilities. This bill
would require that training for individual staff and also outline clear policies for long-term care facilities to adopt along with guidance on how to enforce nondiscrimination protections.

Many pieces of legislation begin with definitions. It is especially important and relevant to do so here. The prevalence of discrimination and harassment in long-term care settings requires a response that begins with education and information. An Act establishing an LGBTQI long-term care facility bill of rights outlines what constitutes bullying, harassment, and discrimination based on a person’s actual or perceived sexual orientation, gender identity, gender expression, intersex status, or HIV status:

- denial of admission
- denial of a request to share a room
- where rooms are assigned by gender, refusal to assign based on gender identity
- prohibition of using a restroom in accordance with gender identity, or harassment (for example requiring identity documents to gain entrance) for accessing a restroom in accordance with gender identity
- repeatedly or intentionally failing to use a resident’s chosen name or pronouns
- denial of clothing, accessories, cosmetics or grooming practices that are permitted to any other resident
- restriction of visitors (from outside the facility or within) and consensual sexual relationships where these would not be restricted if the participants were heterosexual or married
- denial or restriction of medical or nonmedical care
- refusal of care or reasonable accommodation

Additionally, facilities would be required to

- distribute a statement that identifies discrimination and harassment (by staff, residents or visitors) and provides contact information for filing a complaint if it occurs
- keep records with residents’ gender and the name and pronouns by which the resident would like to be identified
- protect the privacy of its residents by not disclosing sexual orientation, gender identity, transition status, intersex status, or HIV status
- provide privacy barriers (doors, curtains, screens) for bodily privacy for all residents
- provide informed consent in relation to any non-therapeutic examination, observation, or treatment of a resident of the facility
- facilitate access to transgender-related medical care, including hormone therapy and supportive counseling
- provide LGBTQI-related programming, such as an LGBTQI Pride Month event or a Transgender Day of Remembrance event

Unlike current statute, this bill enables enforcement of these protections by civil penalties or other administrative action for cases of violation. It also requires inclusive and cultural competence training of staff that covers definitions, care, best practices, the unique challenges of LGBTQIA+ people, and strategies to provide an affirming environment. Finally, it requires designated employees responsible for compliance and training.
LGBTQI+ older adults experience discrimination and unequal treatment in long-term care in Massachusetts and around the country. This harassment and fears of this mistreatment lead to poor mental health outcomes\textsuperscript{vii} and need to be addressed through public policy. This bill provides a framework for facilities to create an inclusive environment. Many problems and fears related to entering long-term care are unfortunately universal. However, LGBTQI+ older adults are more vulnerable to discrimination, neglect and abuse and need the explicit protections that H.637 and S.381 offers. Please support and report favorably \textit{An Act establishing an LGBTQI long-term care facility bill of rights}. 

Thank you.

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\textsuperscript{4} Ibid.  