LGBT OLDER ADULTS AND INHOSPITABLE HEALTH CARE ENVIRONMENTS

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Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders

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ISSUE SUMMARY

Older Americans are frequently dependent on the assistance of professional health care providers, whether home-based service providers, or doctors, nurses and staff at medical centers and long-term care facilities. LGBT older adults, who are less likely to be able to rely on family members for caregiving, often face hostile or unwelcoming health care providers, or might encounter staff members who are unfamiliar with the needs of the LGBT community. These experience and fears can cause LGBT older adults to delay seeking necessary health care, sometimes indefinitely, and can lead to premature institutionalization in nursing homes and long-term care facilities due to fear of hostile in-home care providers.

HEALTH CARE ENVIRONMENTS ARE OFTEN INHOSPITABLE TO LGBT ELDERS

As with many older adults dealing with the challenges of their aging bodies, LGBT older adults often must rely on professional caregivers during their later years. Such care ranges from home-based services such as health aides or Meals on Wheels, to treatment in clinics, offices, and institutions such as nursing homes or long-term care facilities. Providers along this continuum of caregivers—doctors to pharmacists to hospital and nursing home staff—might be hostile towards LGBT elders, untrained to work with them or unaware that LGBT older adults even exist.

For example, the presumptions of many providers that older adults are cared from by their heterosexual spouses might prevent a gay older adult from talking openly to his service provider. Even when providers are supportive, past experiences of discrimination can still make LGBT elders reluctant to disclose their sexual orientations to health care providers and ultimately not seek the medical care they need.[1] To mitigate harassment, LGBT older adults sometimes "de-gay" their homes before a home-based caregiver arrives (e.g., hide family pictures or ask a same-sex partner to temporarily leave), a process that can have negative emotional and physical outcomes in an older person with serious health care needs.

In a large-scale 2006 study, less than half of lesbian and gay male Baby Boomers were strongly confident that health care professionals would treat them with dignity and respect. Further, a full 12% had absolutely no confidence that the health care system would treat them respectfully.[2] LGBT older adults' concerns about health providers appear well founded:

- A 2008 study by the Public Advocate of New York found that in New York City's health care facilities, "LGBT individuals experience hostility and discrimination in care," and "concerns about homophobia and transphobia keep LGBT individuals from using health care services." The report also notes that health providers "may lack knowledge about transgender and intersex anatomy, health disparities affecting LGBT people, and appropriate behavior dealing with young, elderly and 'closeted' LGBT individuals."[3]
- In a health disparities study conducted with more than 3,500 LGBT people in New York, 8.3% of the LGBT adults surveyed reported being neglected by a caregiver because of their sexual orientations or gender identities, and 8.9% reported financial exploitation or blackmail.[4]
- According to some initial research, at least 39% of transgender people face some type of harassment or discrimination when seeking routine health care.[5]

Transgender people in particular fear discrimination by medical professionals. As noted by the Transgender Aging Network, "Trans individuals' 'non-congruent' bodies may lead to embarrassing, disrespectful, and perhaps even hostile treatment. … Particularly worrisome to many trans older adults is the

[1] R. Klitzman and J. Greenberg, J., "Patterns of Communication between Gay and Lesbian Patients and their Health Care Providers," *Journal of Homosexuality* 42, 2002.
[2] MetLife Mature Market Institute (2006).
[3] Public Advocate for the City of New York, *Improving Lesbian, Gay, Bisexual and Transgender Access to Health Care at New York City Health and Hospital Corporation Facilities*, 2008.
[4] Somjen Frazer for The Empire State Pride Agenda Foundation and the New York State Lesbian, Gay, Bisexual and Transgender Health and Human Services Network, *LGBT Health and Human Services Needs In New York State*, http://www.prideagenda.org/Portals/0/pdfs/LGBT%20Health%20and%20Human%20Services%20Needs%20in%20New%20York%20State.pdf.
[5] Movement Advancement Project, "Advancing Transgender Equality," 2009.

Neglected By A Caretaker Because Of Sexual Orientation Or Gender Identity

Source: See footnote 4

prospect of needing intimate personal assistance from paid aides or, even worse, needing to reside in a nursing home."[6]

FAILURE OF NURSING HOMES TO PROTECT LGBT OLDER ADULTS

Figures show that a little more than 4% of US elders live in an institutional setting[7]—a statistic that is likely higher for LGBT elders. Many health and social service providers have shared stories about LGBT elders' reluctance to use home-based care providers, and how this reluctance can contribute to LGBT elders entering nursing homes or long-term care facilities earlier than their heterosexual counterparts.

The prejudice and hostile treatment of staff, fellow patients and other patients' families can create unwelcoming environments for LGBT elders. In response, they might withdraw or be excluded from social activities, which compounds feelings of isolation and loneliness. Staff might deny visitors of whom they disapprove—or an LGBT older adult might feel uncomfortable having a same-sex partner or LGBT friend visit because it might lead to harassment. Nursing homes also have been known to refuse to allow same-sex couples to share rooms, or to bar partners or other loved ones from participating in medical decision-making. For transgender individuals, staff members might refuse to place them in a gender-segregated ward that matches their gender identities; or staff might refuse to respect the pronoun or clothing preferences of a transgender elder. These issues become even more problematic when patients are mentally or physically incapacitated and unable to advocate for themselves.

Few nursing home and assisted living providers have had any training in how to diffuse and counter patients who are hostile to their fellow patients.[8] Staff might deal with this harassment by placing a harassed patient in isolation from his/her peers. In one example, an openly gay man in a nursing home who was the regular target of protests from other patients (and their family members) was moved to a floor for patients with severe disabilities and/or dementia. Without any family members or friends to advocate for him, he eventually hanged himself.[9]

Patient Sees Pervasive Discrimination in Health Care System

Amirah Watkins-Brown, 62, recalls growing up as a lesbian in Mississippi in the 1960s and 1970s. She remembers the first time she felt discriminated against by a doctor. "We were talking, very cordially and friendly, [but] once he found out I was in a relationship with a woman, his demeanor totally changed," she said. The doctor had been examining Amirah's lymph nodes and neck with bare hands, but immediately put gloves on after learning that she was a lesbian.

Amirah began hearing similar stories from LGBT friends and realized the pervasiveness of discrimination against LGBT people seeking medical care. "These doctors and nurses and aides seriously need sensitivity training," she said. "I've heard it all: 'The reason you have a yeast infection is because you're a lesbian;' or, 'The reason you have eczema or acne is because you're gay.'"

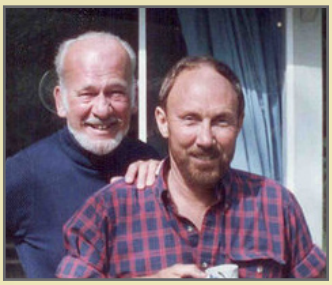
Amirah began volunteering at Chicago's Howard Brown Health Clinic (a hospital specializing in LGBT health care) in the 1990s. She is also an advocate for safer-sex practices, speaking at health fairs in malls, schools, college campuses and diversity expos.

Source: J. Grant, "Outing Age: Public Policy Issues Affecting Lesbian, Gay, Bisexual and Transgender Older Adults," National Gay and Lesbian Task Force, 2010.

Nursing homes are regulated under the federal Nursing Home Reform Act,[10] which requires all nursing homes that receive federal funds[11](usually through Medicare or Medicaid) to make available to their residents written policies (also known as a "resident bill of rights") that describe resident rights. These rights include the right to privacy, the right to be free from abuse and restraint, the right to receive any visitor of one's choosing and the

[6] Loree Cook-Daniels, *Transgender Elders and Significant Others, Friends, Family and Allies: A Primer for Service Providers and Advocates*, Transgender Aging Network, 2007.
[7] In 2007, 4.4% of the 65+ population lived in institutional settings: 1.3% for age 65-74, 4.1% for 75-84 and 15.1% for 85+. *A Profile of Older Americans: 2008*, Administration on Aging, US Department of Health and Human Services, 2008.
[8] SAGE, It's About Time: LGBT Aging in a Changing World; SAGE Fourth National Conference on LGBT Aging Conference Report: Policy Recommendations, 2009.
[9] Jane Gross, "Aging and Gay, and Facing Prejudice in Twilight," New York Times, October 9, 2007.
[10] A more detailed analysis of federal nursing home laws is available from the National Senior Citizens Law Center. See "Legal Protections for LGBT Seniors in Long-Term Care: A Preliminary Analysis of Federal and California Law," NSCLC, 2009.
[11] Almost all nursing homes receive federal funds. The requirements of the Nursing Home Reform Act apply to all residents of the facility, not just those who are the direct beneficiaries of the federal funds.

Gay Man Held Involuntarily in Nursing Home While Partner Dies



Clay, 75, and his partner Harold, 85, had been together for 20 years and shared a home in Santa Rosa, California, with their two beloved cats. Although physically frail, Harold was mentally sharp and living at home until a fall in May 2009 landed him in a nursing home. Although Clay was Harold's designated medical decision-maker, the nursing home and the county workers handling Harold's case refused to keep Clay informed or to consult him about Harold's care.

Soon after, the county went to court to establish control over Harold's financial affairs, ostensibly so they could pay for Harold's care. Although a court granted the county only very limited powers over Harold's estate (and no power over Clay's estate), the county workers took everything both Harold and Clay owned, and sold it all at auction, saying that it was impossible to tell what belonged to whom. Clay, who was home when the apartment was stripped bare, witnessed workers saying things like, "My wife would like this," or "This would look great in my living room." After selling their possessions, the county also gave up their apartment, sold Clay's truck and gave away their cats. When workers came to take the cats, Clay tried to protect them, but the workers laughed at him and pushed him to the ground.

At the same time, the staff at Harold's nursing home stopped putting Clay's calls through to him, isolating Clay from Harold. Soon after, Clay was also taken to the nursing home, where he was isolated from Harold and not allowed to even call him. After several weeks, the county put Clay into a different nursing home against his will, falsely claiming that Clay had dementia. The nursing home staff told Clay that he was not allowed to leave the premises. While Clay was kept in the second nursing home, Harold died. The county worker responsible for informing Clay that Harold had died asked a neighbor of Clay and Harold's to do it for him, saying that he "did not want to deal with a gay boy."

Clay was eventually released from the second nursing home and now lives in a different apartment in another town. He has been unable to get back anything from the home that he and Harold had shared, does not know what happened to their cats, and remains severely traumatized.

The National Center for Lesbian Rights is assisting Clay's attorney, Anne Dennis, with a lawsuit against the county, the auction company that sold Clay's and Harold's belongings, and the nursing home that placed Clay involuntarily.[13]

right to one's own clothing and possessions. While these rights provide some protections, many LGBT older adults nevertheless hide their identities, feel uncomfortable lodging complaints, or are not in positions to advocate on their own behalves.[12] Additionally, many patients, families of choice and facility staff are unaware of these federal protections. Further, note that while President Obama recently mandated that all hospitals receiving Medicare and Medicaid payments grant all patients the right to designate visitors and medical decision makers, this mandate does not apply to nursing homes and long-term care facilities.

POLICY AND ADVOCACY SOLUTIONS

- **Pass non-discrimination acts (NDAs) or ordinances at the state or local level.**[14] NDAs that prohibit discrimination in public accommodations and housing can provide legal recourse for LGBT older adults who experience discrimination in a variety of settings, including senior citizen centers, low-income housing, hospitals, nursing homes, assisted living facilities, senior centers, etc. Note that NDAs should prohibit discrimination based on both sexual orientation and gender identity/expression (not just sexual orientation).
- **Increase awareness and enforcement of existing NDAs.** Many LGBT older adults and aging service providers are unaware of existing laws; do not know that the law applies to them; or have weak enforcement of these laws. The New York State Attorney General provides an example of an effort to create and distribute written guidance to clarify existing laws.
- **Encourage service providers to adopt their own non-discrimination policies.** This can be done by working directly with providers, or through larger initiatives like the Human Rights Campaign's Healthcare Equality Index, which rates health providers on their inclusiveness towards LGBT people and encourages providers to adopt more inclusive policies.
- **Examine state laws on public health, nursing homes and assisted living facilities for opportunities to protect LGBT older adults.** For example, California has a separate state public health law that was amended to include non-discrimination based on sexual orientation. Ideally, any legislation would include funding to pay for related training and enforcement.

[12] Alliance Healthcare Foundation, The San Diego County LGBT Senior Healthcare Needs Assessment, 2003.
[13] www.nclrights.org.
[14] There is no federal law to prohibit discrimination based on sexual orientation or gender identity/expression, and the proposed federal employment non-discrimination act (ENDA) has no provision for public accommodations. Therefore, protections from discrimination must be enacted at the state and local levels.

- **Develop scalable, technology-enabled cultural competency training to reach large numbers of health care providers.** The Administration on Aging's recent announcement that it will fund an LGBT Elder National Technical Assistance Resource Center is a step in the right direction, but the funding is only a fraction of what is needed to bring training efforts to scale.
- **Work with organizations that accredit health service providers to develop standards for serving LGBT older adults.** Accrediting bodies guide providers who receive funds from sources such as Medicaid, Medicare or local providers that receive Administration on Aging funds through government Area Agencies on Aging. For example, the Joint Commission[15] accredits and certifies more than 17,000 health care organizations and programs, including whether a facility is eligible for Medicare reimbursements. In 2009, the Joint Commission released standards stating that patients have a right to care free of discrimination based on sexual orientation and gender identity/expression.[16] Similarly, the American Medical Association has adopted 28 policies indicating the importance of culturally competent care that addresses the needs of the LGBT community.[17]
- **Advocate for better support of, and training for, long-term care ombudsmen.** The Older Americans Act requires every state to create an ombudsman program to "investigate and resolve complaints" of individuals in long-term care facilities." These ombudsmen also train facility staff on resident rights. Unfortunately, many ombudsman programs have limited staff resources, and most rely on volunteers.[18] States should adequately fund these ombudsman programs and educate and work with the programs on meeting LGBT elder needs.
- **Seek to enforce protections for LGBT patients under the federal Nursing Home Reform Act (NHRA)** and to educate providers about their responsibilities under this law. The Civil Rights of Institutionalized Persons Act gives the Department of Justice (DOJ) standing to bring forward cases when NHRA violations occur.[19] Advocates can educate and work with the DOJ and Department of Health and Human Services to more strongly enforce the NHRA.
- **Work with HUD to create regulations that require nursing homes and assisted living facilities to allow same-sex couples and families of choice to share a room.** Creating this regulation within HUD, rather than under the Nursing Home Reform Act, would ensure assisted living and other facilities are also covered.

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[15] www.jointcommission.org.
[16] Facility types include hospitals, medical equipment services, hospice services and other home-based care organizations, nursing homes and other long-term care facilities, behavioral health care organizations, rehabilitation centers, group practices, office-based surgeries, and other ambulatory care providers.
[17] See www.ama-assn.org.
[18] In 2007, for example, about 12,600 people provided 670,000 hours of volunteer time to serve long-term care facility residents through the program. That year, the program also employed 1,300 paid ombudsmen to oversee 16,750 nursing facilities with 1.8 million beds and 47,000 other residential care facilities with 1.1 million beds. Source: *The Basics: Older Americans Act*, National Health Policy Forum, George Washington University, April 21, 2008. FY2008 funding for the program was about $82 million.
[19] http://www.justice.gov/crt/split/documents/philcomp.php.

MODEL PROGRAM: New York Promotes Cultural Competency Training for Aging Service Providers

The City of New York Department for the Aged (DFTA) issued an announcement in 2005 to its aging services network that LGBT issues must be taken into consideration in serving older adults. Since that announcement, DFTA's Requests for Application (RFAs) have included LGBT language. Further, the RFAs include a "point system," by which applications are measured for funding consideration. Points are awarded for LGBT cultural competency training, which improves the likelihood of the applicant being successful. DFTA also offers free trainings to all recipients of agency funding, and works closely with SAGE to ensure that its cultural competency trainings always include LGBT components.

ABOUT THIS BRIEF

This is one of a series of issue briefs based on content from *Improving the Lives of LGBT Older Adults*, a report which provides an in-depth examination of the issues facing LGBT elders, and potential solutions for improving their lives. For more information, visit **www.lgbtmap.org** or **www.sageusa.org**.

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