

**AMERICAN MEDICAL DIRECTORS ASSOCIATION
WHITE PAPER
RESOLUTION A-12**

**SUBJECT: WHITE PAPER ON THE CARE OF LESBIAN, GAY, BISEXUAL, AND
TRANS-GENDER PERSONS IN THE LONG-TERM CARE SETTING**

INTRODUCED BY: BOARD OF DIRECTORS

INTRODUCED IN: MARCH 2012

Introduction:

As a group, Lesbian, Gay, Bisexual and Transgender (LGBT) older adults are members of a minority and historically disadvantaged sector of society. Most have spent the majority of their lives hiding sexual orientation and gender identity to avoid stigmatization and discrimination which continues to impact all facets of their lives. While research on sexual orientation has been identified by the Centers for Disease Control (CDC) as “one of the most pronounced gaps in health disparities research”¹, the absence of information regarding LGBT older adults is profound, with their health and aging-related needs among the least well understood of all groups.² Given the history of social ostracism and lack of knowledge regarding their global biopsychosocial needs, particularly in comparison to other aging groups, LGBT elders have been rendered a largely invisible population.³

In light of advancing age, those considered among the “Greatest Generation”, “Stonewall Generation” and “Baby Boomers”, LGBT elders will require increasing involvement with physicians and institutions specializing in long term care. Of paramount importance, yet least well understood, the needs of advanced aged LGBT elders must be identified to facilitate culturally competent and appropriate care, as well as eliminate disparities in the long term care environment.

Increased sensitivity and interest in the LGBT elder community has sparked relatively recent financial support to identify and document the unique social and health-related needs of LGBT elders. Given the mandate of the Older Americans Act, several federal agencies (Administration on Aging, National Institutes of Health, and National Institute on Aging)⁴, as well as private organizations, have allocated recent funding to focus on the unique needs of LGBT elders, recognizing their challenges in accessing appropriate health care and social service needs. Ultimately, it is this groundbreaking research, as well as support by medical and other organizations vested in the work of long term care, that will integrate and sustain the compassionate, culturally competent, and non-discriminatory care afforded LGBT and all elders at the far end of their life continuum.

Background:

This AMDA—Dedicated to Long Term Care Medicine (AMDA) White Paper is developed to improve care of sexual orientation and gender identity minorities- Lesbian, Gay, Bisexual, and

Transgender (LGBT) elders residing in Long-Term Care (LTC) environments such as skilled nursing facilities (SNFs), assisting living facilities (ALFs), and continuing care retirement communities (CCRCs). While confronted with the same challenges that face all people as they age, LGBT elders face substantial barriers to health care and optimal health, characterized in a 2010 report from the LGBT Movement Advancement Project⁵, as well as other current research projects.

The LGBT Movement Advancement Project report indicates that LGBT elders suffer an excess burden of chronic disorders, yet are more likely to delay seeking needed care due to “inhospitable healthcare environments characterized by healthcare professionals and staff that are not accepting of, or trained to work with, LGBT elders.” Further attention is called to barriers in LTC such as hostility of staff, other patients, and exclusion of non-spousal, non-biological “family of choice” caregivers. Together, these barriers, social stigma, negative stereotypes, and legal constraints laws render LGBT elders an underserved minority suffering from multifaceted health disparities.

Recognition of the need to bridge these disparities is gaining momentum in American society in general and more specifically within the healthcare community. One factor in this process is the aging of LGBT baby boomers, who bring a legacy of advocacy to the issues of later life. Attention has also been focused by a variety of other recent events such as repeal of “Don’t ask, don’t tell” in the military, and the legalization of same-sex marriage in an increasing number of states. Elimination of LGBT disparities is now an objective of Healthy People 2020.⁶ Further attention is underscored in recent Institute of Medicine reports in general, in Retooling for an Aging America: Building the Health Care Workforce (2008)⁷, and in particular in The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding (2011).⁸ In addition, a March, 2010 survey “Improving the Lives of LGBT Older Adults”⁹ provided a firsthand perspective of LGBT elder experiences in long term care facilities. Most recently, the “Caring and Aging with Pride” project¹⁰, completed in 2011 with over 2,500 participants, represents the first federally-funded study conducted on a national level to examine aging and health disparities experienced by older adults aged 50-95 in the LGBT community. Collectively, all contribute to a growing body of work which supports the rights of LGBT elders to equitable and responsible care.

Despite these positive changes and statements, healthcare providers and institutions remain impacted by the legacy of negative stereotypes (e.g. LGBT lifestyles as mental illness, criminal behavior, or immoral conduct). Consequently several major medical and other professional organizations have gone on record with strongly-worded, non-discrimination policies with regard to sexual orientation or self-perceived gender status. The American College of Physicians (ACP) calls for “elimination of disparities in the medical care of patients based on social, ethnic, racial, gender, sexual orientation, and demographic differences”.¹¹ The American Academy of Family Physicians “opposes all discrimination in any form, including but not limited to, that on the basis of actual or perceived race, color, religion, gender, sexual orientation, gender identity, ethnic affiliation, health, age, disability, economic status, body habitus or national origin”.¹² The American Medical Association (AMA) opposes any discrimination based on an individual's sex, sexual orientation, gender identity, or other attributes such as race, religion, disability, ethnic origin, national origin or age. The AMA notes further that “physicians who offer their services to

the public may not decline to accept patients because of race, color, religion, national origin, sexual orientation, gender identity or any other basis that would constitute invidious discrimination.”¹³ Similarly proactive statements have also been issued by the American Psychological Association,¹⁴ National Association of Social Workers,¹⁵ American Nurses Association¹⁶ and other organizations representing non-physician professionals in LTC.

AMDA’s position is less defined. The philosophical concept of non-discrimination and elimination of disparities based on sexual orientation or other personal attributes is embodied in AMDA’s model care facility medical staff policies and procedures (Policy number : [Admin.QUA.06](#)), which includes a generic, non-discrimination clause in its medical staff code of conduct but does not spell out specifics (e.g. nondiscrimination based on social, ethnic, racial, gender, sexual orientation, cultural, or geographic attributes).¹⁷ The registration brochure for “AMDA Long Term Care Medicine – 2012” includes a statement: “AMDA is committed to the policy that all persons shall have equal access to all of its programs, facilities and employment without regard to race, color, creed, religion, national origin, sex, age, marital status, disability, public assistance, veteran status or sexual orientation.”¹⁸ However, there is no formal White paper or policy statement that provides specific guidance on this issue for the medical director or other members of the LTC interdisciplinary/interprofessional team.

Rationale:

It is germane that AMDA delineate a formalized position regarding LGBT elders in long-term care. Support for this position is presented in the paragraphs to follow, which examine prevalence issues, clinical and quality of life considerations, evidence of current disparities & barriers to care, regulatory aspects, and ethical imperatives.

Prevalence:

First is the weight of numbers. In keeping with the growth of the United States elderly population, growth of the LGBT population occurs apace. In 2010, approximately 40 million US residents are age 65 or above; this figure is projected to reach 70 million by 2030 and approaching 80 million by 2050.¹⁹ Estimates of the elderly LGBT population are less precise, as data on sexual orientation and gender identity are not requested on census or other data collection instruments. However, using an estimate that 8 percent of the overall population identifies as lesbian or gay,²⁰ it is thought that there are approximately 3 million lesbian and gay elders at this time, with projections of 5.6 million and 6.4 million by 2030 and 2050 respectively.²¹ These figures do not include bisexual and transgendered individuals. Based on a current LTC population of 1.5 million, a population of 120,000 LGBT elders in LTC at this time is a conservative estimate. LGBT-targeted LTC facilities are starting to appear, current economic issues and other factors preclude widespread availability.²² It is therefore likely that the vast majority of LGBT elders in need of long-term care will reside in facilities designed for the general population now and in the future.²³

Clinical considerations:

Second, LGBT elders face specific challenges that directly impact their clinical care and quality of life. While concerns of LGBT elders mirror those of the non-LGBT majority (e.g. concerns about illness, functional decline, and finances) LGBT elders face additional issues. Many have experienced rejection and discrimination from the healthcare community. Issues of distrust and fear of openness remain. In addition, LGBT elders are also less likely to have children or biological family who can assist with access to care, advocacy, and navigation of the health care system.²⁴ Non-recognition or exclusion of family-of-choice (vs. biologic or traditional families) has major implications for elicitation of advance directives, delineation of substitute decision-makers, person-centered care (Medical Director function 9), care preferences in general, and end-of-life care preferences specifically.

Barriers such as stigmatization, “non-biologic” family and unequal treatment predispose LGBT elders to financial insecurity, impaired health and access to healthcare, as well as social isolation. Specific constraints include limited access to spousal benefits under health insurance, bias or lack of acceptance by health care providers and facilities, and isolation from LGBT community and culture.²⁵ Together these factors prompt many LGBT elders in LTC settings to avoid disclosure of sexual orientation or gender preference. This non-disclosure, which encompasses a loss of one’s identity, culture, and self-worth, negatively impacts mental health and quality of life. Non-disclosure also has important clinical ramifications, as LGBT elders may have specific health conditions that could be overlooked if LGBT patients do not feel it is safe to reveal sexual orientation or gender identity.

With regard to health conditions impacting clinical management of LGBT elders in LTC, HIV/AIDS is increasingly a major issue and one that is not confined to LGBT elders. One quarter of the 1.1 million Americans infected by HIV are over age 50 and the number of new HIV diagnoses among people age 50 to 59 increased 32% from 2004 to 2007.²⁶ This influx will be seen in nursing homes and other long-term care venues in the foreseeable future. HIV/AIDS is associated with accelerated cognitive impairment, dementia, and other manifestations of premature and unsuccessful aging such as osteoporosis. Glucose intolerance, hyperlipidemia, nephropathy, malignancies, and HIV drug side effects and interactions are additional concerns.²⁷ HIV related co-infections also have ramifications for infection control in LTC facilities.

LGBT elders are reported to suffer higher levels of substance use (smoking, alcohol use, and illicit drugs), depression and suicide, smoking, and obesity relative to non-LGBT peers.²⁸ These latter issues contribute to development of diabetes and atherosclerotic cardiovascular disease. Long-term effects of hormone use in transgender individuals can impact risk of cancer, diabetes, heart disease, and thromboembolic disorders.²⁹ Lesbians and bisexual women may have higher rates of breast cancer than heterosexual women.³⁰

In addition to the factors listed above, ethnicity and diversity likely also play a significant role in the social and health-related needs of LGBT older adults in long term care. While the global negative experiences of the aggregate LGBT older adult community have been more widely recognized, research points to the fact that marginalized LGBT elders of color experience additional layers of disparities across similar areas with related consequences.³¹ These include

discrimination across the lifespan, economic vulnerability, higher poverty rates, inequities in health care and service provision, increased social isolation, and cultural and linguistic incompetence of care providers, all of which become magnified with the aging process. For example, when evaluated by ethnic groups, research indicates that older LGBT Asian/Pacific Islanders and Native Americans experience higher financial barriers in accessing physician care, while Native Americans, Hispanics and African Americans experience greater barriers to affording medication than White LGBT elders. Of all groups, Native American LGBT elders are most negatively impacted in terms of access to and provision of good care outside of the LGBT community, which may have implications for providers and LTC patients in more rural or outlying communities.³²

Perceptions and Experience:

Third, data on the experience of LGBT residents in LTC is limited but that which is extant points to concerns. A small-sample (n=29), 1996 survey of nursing home social workers' perceptions identified negative staff attitudes toward LGBT residents.³³ Although no studies explore how older lesbians and gay men negotiate their transitions from the community to LTC, fear of discrimination and fear of disclosure appear paramount.³⁴ An older study (2003) suggests that LGBT elders may be prepared to die at home rather than receive otherwise needed LTC if entering such a facility forced them "back in the closet".³⁵

A 2010 online survey³⁶ was conducted by a broad coalition of several advocacy organizations (National Senior Citizens Law Center, National Gay and Lesbian Task Force, Services & Advocacy for GLBT Elders (SAGE), Lambda Legal, National Center for Lesbian Rights, National Center for Transgender Equality), with additional support of the Arcus Foundation, the National Council on Aging, AARP, Family Caregiver Alliance, and Old Lesbians Organizing for Change. Though an opinion survey rather than a formal research study, there were 744 respondents, of whom 278 self-identified as LGBT. More than 80 percent of respondents did not feel LGBT older adults could be open with facility staff. A majority (89%) predicted that staff would discriminate against an openly LGBT elder, that other residents would discriminate, and that staff would abuse or neglect the person (346 or 53%).

In terms of actual experience, 328 respondents (124 LGBT), reported 853 instances of mistreatment. Specific instances include verbal or physical harassment from other residents (23%), refused admission, readmission, or attempted abrupt discharge (20%), verbal or physical harassment from staff (14%), refusal of partner's medical POA (11%), restriction of visitors (11%), staff refusal to refer to transgender patient by preferred name or pronoun, (6%), refusal of basic services (6%), and denial of medical care (6%).

Regulatory Aspects:

Regulatory aspects are a fourth consideration. Nursing home residents, regardless of sexual preference or gender, are protected by the federal Nursing Home Reform Act (NHRA).³⁷ The NHRA is a comprehensive federal statute that creates a minimum set of standards of care and rights for people living in federally certified nursing homes, including the obligation of the facility to "provide services and activities to attain or maintain the highest practicable physical,

mental, and psychosocial well-being of each resident.” This includes the right to be treated with “dignity” and “respect,” “to be free from physical or mental abuse” or “involuntary seclusion,” and to make personal decisions. Discrimination, abuse, or neglect against LGBT older adults would violate the NHRA’s standards of care, as would restriction of visitors who are non-biologic family of choice. Facilities that can be shown to have discriminated are vulnerable to survey citations based on failure to comply with F-tags 279 and F280.³⁸ Moreover, the Centers for Medicare & Medicaid Services (CMS) have issued rules for Medicare- and Medicaid-participating hospitals that protect patients’ right to choose their own visitors during a hospital stay, including a visitor who is a same-sex domestic partner.³⁹ It is likely that such regulation will extend to Medicare- and Medicaid-participating nursing facilities as well. State and local laws in some jurisdictions may further prohibit discrimination based on sexual orientation and gender identity in housing and/or public accommodations including LTC.

Ethical Imperatives:

Lastly, improving nursing facility care of LGBT elders is in keeping with universal ethical principles of medical care.⁴⁰ Non-discrimination, acceptance, and non-restrictive visitation policies are consistent with the principles of Beneficence, the obligation to act in best interests of patients, and Non-Maleficence, the obligation to do no harm. However, Justice, the duty to treat individuals fairly and without discrimination, is the paramount ethical principle surrounding this issue. Quite simply, it is no more appropriate to limit care based on sexual orientation or gender identity than it is to limit care based on any other human attribute such as race, gender, or national origin. AMDA has long been an advocate of equity and quality for all and for care of vulnerable seniors, as evidenced in its own ethics, mission, and values statements.^{41,42} Advocacy for LGBT LTC residents is also consistent with AMDA medical director functions 1, 3, 7, 8, and 9.⁴³ Speaking clearly on the issue of best-practice, LTC for LGBT elders is an opportunity to sustain organizational leadership and commitment in advancing these values.

Summary:

This White Paper briefly summarizes disparities faced by LGBT seniors and recommends that AMDA formulate policies of acceptance, equality and non-discrimination in keeping with societal evolution, federal laws, and ethical guidelines established by other professional organizations vested in the provision of long term care. Such a policy takes into account the number of LGBT elders at risk, clinical considerations, reports of current inequities, regulatory concerns, and ethical imperatives. Accordingly, it is suggested that AMDA advocate and support the following recommendations, divided by Clinical Practice and Policy, Education, and Research. While neither policy statement nor practice recommendations can quickly and easily effect pervasive individual, institutional or organizational culture change, advocacy for all elders, regardless of sexual orientation, gender identify, or other human attributes, supports the best interest and optimal practice of all long term care stakeholders.

Recommendations:

This report concludes with presentation of recommendations as follows:

Clinical Practice and Policy:

1. By virtue of this White Paper, AMDA recognizes and addresses the need to provide ethical, responsible, and equitable treatment and quality care to LGBT and all other individuals in LTC.
2. AMDA will partner with the American College of Physicians (ACP), American Association of Family Practitioners (AAFP), American Medical Association (AMA), and other professional organizations fostering non-discrimination based on sexual orientation or gender identity.
3. AMDA will seek input on LGBT LTC issues from LGBT advocacy organizations including Services and Advocacy for LGBT Elders (SAGE), National Senior Citizens' Law Center, National Center for Transgender Equality, Lambda Legal, National Gay and Lesbian Task Force, and others.
4. AMDA will encourage facilities to recommend revision of admission and procedure forms to incorporate congruent and appropriate language respectful of LGBT family configurations. As such, it is suggested that forms include the terms "lover, domestic partner, significant other, life partner" and others to be determined, as well as "spouse" & "marital status".
5. AMDA encourages facilities to assist LGBT elders with durable power of attorney (POA) for health care, hospitalization visitation authorization form, and other documents that enfranchise "family of choice" members, whether a legally recognized relationship or not.
6. AMDA encourages facilities, medical directors, attending physicians, and all members of the interdisciplinary team to include pertinent discussion of new resident's spouse/life partner/ significant other during the initial assessment. In addition, AMDA recommends that this individual be invited and welcomed to participate with the patient and treatment team in family meetings, treatment planning, or other meetings relevant to the care of the patient.
7. In accordance with federal guidelines and ethical treatment of all patients, AMDA strongly recommends non-restriction of visitation based on sexual orientation or gender identity of visitors.
8. AMDA respects the privacy of all residents as well as their choice in sharing personal information regarding sexual orientation and gender identity. It therefore strongly

encourages facilities, physicians, and LTC care providers to create this as an optional demographic information category on the new patient intake form, as well as all other documents.

9. AMDA recommends the use of LGBT friendly community services to meet the needs of LTC patients both within and outside the facility itself.
10. AMDA recommends that medical directors and attending physicians work collaboratively with administrators and all LTC staff to create programs facilitating respect, cultural competency, and genuine inclusion for LGBT residents, thus reducing isolation and engendering an atmosphere of inclusivity.
11. AMDA recommends that policies regarding the ethical and equitable care and treatment of LGBT residents be formalized in writing and included in the organizational Policy and Procedure Manual.
12. It is strongly recommended that AMDA form a Diversity Committee charged with facilitation, leadership, and ongoing education to ensure access to culturally competent LTC for all ethnic, cultural, and sexual orientation/gender identity minority groups.

Education:

1. Through ongoing training and educational opportunities for its members, AMDA promotes recognition that sexual orientation and gender identity transcend sexual practices to incorporate unique multifaceted cultural, spiritual, and other diverse life experiences.
2. In an effort to create a supportive environment for all residents, as well as meet federal guidelines for LTC operation contained in the Nursing Home Regulation Act (NHRA), AMDA encourages ongoing didactic and experiential training for all LTC staff and providers regarding diversity issues relevant to LGBT residents. Through this training, LTC team members will be encouraged to develop awareness and sensitivity to overt and covert attitudes and behaviors which may disenfranchise LGBT and other ethnoculturally diverse patients.
3. In concert with educational materials and training opportunities available through LGBT advocacy programs (National Resource Center on LGBT Aging, etc.), AMDA encourages and supports the development of a Standardized Diversity Education Program (SDEP) created through the Diversity Committee (once established), to facilitate acceptance and inclusion of LGBT residents by all providers and stakeholders in respective LTC facilities.
4. In accordance with AMDA's mission and policies, the Standardized Diversity Education Program (SDEP) (once created) and other focal diversity-related content programs will be included in future Long Term Care Medicine annual conference programs, as well as AMDA publications.

5. In an effort to expand the knowledge and resources relevant to the culturally competent care of LGBT individuals in LTC, AMDA's Standardized Diversity Education Program (SDEP) will develop a compendium of additional available resources. These will include, but will not be limited to Appendices (Publications, glossary of terms germane to the LGBT community, online resources, hyperlinks for local and state organizations offering assistance, multimedia training resources, culturally competent form samples, and additional materials/references) deemed appropriate and pertinent to the needs of AMDA members.
6. In advancing the educational initiative for AMDA members, it is suggested that AMDA create an online repository/bibliography of relevant books, articles, research studies and other resources for use by its members to enhance their knowledge and expertise in working with LGBT elders in LTC.
7. It is suggested that the AMDA Core Curriculum be expanded to incorporate salient material and experiential training for Certified Medical Director candidates that is relevant to the ethical and equitable care of LGBT elders and other ethnoculturally diverse LTC patients.

¹ Fredriksen-Goldsen. K.(2011) Resilience and Disparities among Lesbian, Gay, Bisexual, and Transgender Older Adults. In Hudson, R. B. (Ed.) Public Policy & Aging Report: Integrating Lesbian, Gay, Bisexual, and Transgender Older Adults into Policy and Practice, SAGE 21(3). Summer 2011 <http://www.sageusa.org/uploads/PPAR%20Summer20111.pdf> Accessed November 25, 2011.

² Hudson, R. B. (Ed.) Integrating Lesbian, Gay, Bisexual, and Transgender older Adults Into Long Term Care Policy and Practice. In Public Policy & Aging Report: Integrating Lesbian, Gay, Bisexual, and Transgender Older Adults into Policy and, SAGE 21(3). Summer 2011, http://www.sageusa.org/uploads/PPAR_Summer20111.pdf Accessed November 25, 2011.

³ LGBT Older Adults in Long Term Care Facilities: Stories from the Field. Arcus Foundation, et al. (2011). <http://www.lgbtlongtermcare.org>. Accessed November 25, 2011.

⁴ Fredriksen-Goldsen, K. I., Kim, H.-J., Emler, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., Goldsen, J., Petry, H. (2011). *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle: Institute for Multigenerational Health. <http://caringandaging.org/wordpress/wp-content/uploads/2011/05/Executive-Summary-FINAL-11-16-11.pdf>

Accessed November 25, 2011.

⁵ LGBT Movement Advancement Project. Improving the Lives of LGBT Older Adults. 2010. <http://www.lgbtmap.org/file/improving-the-lives-of-lgbt-older-adults.pdf>. Accessed 11-13-11.

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⁷ Institute of Medicine. Retooling for an Aging America: Building the Health Care Workforce. Washington, DC: National Academy Press; 2008. PP 4, 21, 155-157.

⁸ Institute of Medicine. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Washington, DC: National Academies Press; 2011. Chapter 6. Late Adulthood. PP. 251-92.

⁹ LGBT Movement Advancement Project. Op Cit.

¹⁰ Fredriksen-Goldsen. K.(2011). Op Cit.

¹¹ <http://www.acponline.org/ppvl/policies/e001287.pdf.P.73>. Accessed October 27, 2011.

¹² <http://www.aafp.org/online/en/home/policy/policies/d/discrimination.html>. Accessed November 16, 2011.

- ¹³ <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-t-advisory-committee/ama-policy-regarding-sexual-orientation.page>. Accessed November 16, 2011.
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- ¹⁶ American Nurses Association <http://gm6.nursingworld.org/MainMenuCategories/Policy-Advocacy/Positions-and-Resolutions/ANAPositionStatements/Position-Statements-Alphabetically/Copy-of-prtetdisrac14448.html> Accessed November 25, 2011.
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FISCAL NOTE: Long term initiative that that will require funding (possibly a grant) and is currently outside the resources of AMDA's staff and workplan strategies

RESOLUTION RESULTS: PASSED