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# Time for **Transformation**: Public Policy Must **Change** to **Achieve** Health **Equity** for **LGBT** Older Adults

The marriage equality movement and the Affordable Care Act have enormous potential to reduce health disparities in LGBT elders, but more data and additional policy changes are sorely needed.

**T**he influence of social context in health is profound. Lesbian, gay, bisexual, and transgender (LGBT) older adults, compared to older adults in the general population, are at elevated risk of health disparities. Such risks include higher rates of disability, mental distress, poor general health, and living alone (Fredriksen-Goldsen et al., 2013a; Fredriksen-Goldsen et al., 2013c; Wallace et al., 2011). If public policies are to address these health disparities, they must take into account the historic as well as current obstacles that affect the health and well-being of LGBT older adults and their families.

The landscape of public policy and laws surrounding the lives of LGBT older adults is changing rapidly.

Research has found that psychological distress among lesbian, gay, and bisexual people has declined significantly in states that have passed legislation advancing the legal rights of LGBT populations; and in the general population, psychological distress, even at low levels, has been found to increase the risk of cardiovascular disease and premature mortality (Russ et al., 2012).

Promoting health equity for LGBT older adults requires a comprehensive approach to public policy to ensure high-quality care, responsiveness in service delivery, and a comprehensive knowledge base to support the development and evaluation of policies and interventions (Fredriksen-Goldsen et al., in press).

This article examines recent LGBT-related policy changes, including marriage equality and employment non-discrimination, as they relate to the health and well-being of LGBT older adults and their families. We investigate how the Affordable Care Act (ACA) and its implementation at federal and state levels can respond to the needs of LGBT older adults, as well as those living with HIV, and we outline important next steps to advance policies that proactively promote health equity and the needs of the growing number of LGBT older adults.

## **The Marriage Equality Legal Landscape**

Historically, and even today, LGBT older adults are restricted from full participation in many societal institutions, though the number of states that have legalized same-sex marriage continues

to grow at a rapid rate. Currently, more than thirty states and the District of Columbia grant same-sex marriages, with legislation pending in all other states (Freedom to Marry, 2014). The 2013 *Windsor v. United States* ruling extended many federal benefits to LGBT adults in legally recognized same-sex marriages. The ruling also recognizes the right of states to not allow same-sex marriage and to refuse recognition of marriages performed in states where they are legal (Freedom to Marry, 2014). Legal marriage can provide access to significant economic benefits; for example, those who are married and reside in states with legal same-sex marriage have access to spousal and survivor benefits through Social Security. Until recently, these were not available to same-sex couples.

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***There are no federal laws that prohibit sexual identity– or gender identity–based discrimination in housing or public accommodations.***

LGBT older adults who live in states that prohibit legal same-sex marriage cannot be legally married unless they travel to, and are married in, a state sanctioning same-sex marriages. Section II, the “full faith and recognition” clause of the Defense of Marriage Act remains intact; states also are not required to recognize same-sex marriages performed in other states. And, in determining spousal retirement and survivor benefits, currently the Social Security Administration considers the state of residence, not the state in which the marriage was performed, in deciding whether or not a marriage is legally valid (Johnson, 2014). Applications for Social Security benefits submitted by individuals in same-sex marriages who reside in states that do not recognize such marriages are currently on hold (Johnson, 2014).

Yet, socially integrated relationships, including marriage, play an important role in better health, including among older adults in same-

sex relationships (Williams and Fredriksen-Goldsen, 2014). Such findings are similar to the large body of research documenting that marriage is protective for both physical and mental health in the general population (Coombs, 1991; Manzoli et al., 2007; Waite and Lehrer, 2003). Research suggests that lesbian, gay, and bisexual adults in legally recognized relationships have significantly better physical and mental health than those who are single or are in a committed, but not legally recognized, relationship (Riggle, Rostosky, and Horne, 2010; Wight et al., 2012), including older adults in same-sex marriages (Williams and Fredriksen-Goldsen, 2014).

### **Non-Discrimination in Employment Laws**

Discrimination and victimization are strong predictors of poor physical and mental health among LGBT older adults (Fredriksen-Goldsen et al., 2013b), yet discrimination based on sexual orientation is still legal in twenty-nine states, and discrimination based on gender identity is allowed in thirty-two states (Human Rights Campaign, 2014).

The Obama Administration has signed legislation adding sexual orientation and gender identity to Executive Order 11246, which prohibits federal contractors (with contracts exceeding \$10,000 in a year) from discriminating on the basis of race, color, religion, sex, or national origin (The White House, 2014); this affects about 20 percent of the American workforce. It is estimated that discrimination results in lower income and education, poorer health, shorter life expectancy, and costs an estimated \$2 billion to \$31 billion annually in health and employment related costs (Smialek, 2014).

The Employment Non-Discrimination Act (ENDA) is proposed legislation that would prohibit discrimination in employment on the basis of sexual orientation and gender identity (Human Rights Campaign, 2014). ENDA has yet to be passed and would not apply to religious organizations or businesses with fewer

than fifteen employees (Human Rights Campaign, 2014), which constitutes about 90 percent of small businesses in the United States (Farley, 2013).

LGBT older adults also report experiencing discrimination in housing and public accommodations, such as senior centers (Brotman, Ryan, and Cormier, 2003; Fredriksen-Goldsen et al., 2011). Yet there are no federal laws explicitly prohibiting discrimination in housing or public accommodations based on sexual orientation or gender identity.

Both marriage equality and non-discrimination laws are critically important to address the health and well-being of LGBT people. As a result of discrimination, older LGBT adults may be fearful of accessing health and other support services, and they may postpone or even forgo much-needed care (Brotman, Ryan, and Cormier, 2003; Fredriksen-Goldsen et al., 2011). It is also important to recognize that many policy advocacy efforts are addressing the needs of LGBT people in committed relationships, those who reside in states that have legalized same-sex marriage, and those who are in the workforce. Such policies may not adequately address the needs of the most vulnerable LGBT older adults, including those who are single, residing in states with strong biases against LGBT people, and who are retired or disabled and not working.

The majority of lesbian, gay, and bisexual mid-life and older adults are single, and are more likely to be single than married or partnered compared to heterosexuals of similar age (Fredriksen-Goldsen et al., 2013b). But even within the general population, the number of single, unmarried adults continues to rise; currently about 51 percent of U.S. adults are married and it is projected that within the next few years the number of those married will drop below half (Pew Research Center, 2011). It is critical that families of choice, informal caregivers, and people in other mutually dependent relationships are considered in policy advocacy efforts so they, too, are protected. Extending

paid leave laws to friends and other caregivers in alternative family structures is necessary.

### **The Affordable Care Act and LGBT older adults**

The March 2010 Affordable Care Act (ACA) benefits LGBT older adults in multiple ways. The ACA prohibits health insurers from denying coverage or charging higher premiums based on a person's sexual orientation or gender identity, or a pre-existing condition, such as HIV status, which disproportionately affects LGBT people (Cray and Baker, 2013). Early data show that the ACA already has enhanced health coverage for millions of Americans. As of April 2014, the U. S. Department of Health and Human Services (HHS) reports that more than 8 million people had enrolled in the Health Insurance Marketplaces established through the ACA, though it remains unclear how many of these enrollees are LGBT, because the marketplaces did not collect demographic information on sexual orientation or gender identity (HHS, 2014; Kellan Baker, senior fellow, Center for American Progress, personal communication to Robert Espinoza, May 28, 2014).

Yet a recent report from Out2Enroll—a coalition of organizations that formed in 2013 to support LGBT peoples' access to healthcare coverage under the ACA marketplaces—has found mixed results in regards to the experiences of LGBT people during the first open enrollment period from October 2013 to March 2014 (Out2Enroll, 2014). According to Out2Enroll's study, states varied in their outreach and enrollment efforts aimed at LGBT people, with some dedicating much more attention to these issues than others; and many LGBT people reported not having the information they needed to understand how their states addressed relationship recognition, transgender issues, HIV coverage, and more discreet concerns. Further, it appeared that a number of statewide coalitions focused on ACA outreach and enrollment did not engage LGBT organizations, and

many ACA assistors requested more training on LGBT-specific concerns, which speaks to the lack of information they had to support LGBT people. Future efforts will need to address these questions to support LGBT people who qualify for marketplace coverage.

The ACA has enormous potential for reducing the profound health disparities facing LGBT people ages 50 and older, and enhancing health coverage and outcomes in the short and long term. Fredriksen-Goldsen et al., in their 2011 report, *The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults*, uncovered several areas of concern related to physical and mental health of LGBT older adults, including obesity, high blood pressure, cardiovascular disease, and diabetes. More than half of the study's respondents had been told by a doctor that they had depression, among other mental health concerns.

Research has shown that health disparities occur in LGBT people across the life span and intensify in later life. Durso, Baker, and Cray (2013) posit that the ACA addresses three health-related concerns among LGBT adults: a lifetime of discrimination that engenders higher rates of physical and mental health disparities; lower rates of insurance coverage among LGBT people, coupled with barriers that prevent same-sex partners and others from accessing health insurance plans for their loved ones; and, differential treatment from healthcare providers who provide substandard care. Research from health and aging professionals also has documented numerous incidents of LGBT older adults encountering discrimination in long-term-care settings. Many LGBT elders report delaying care for fear of differential treatment (Fredriksen-Goldsen et al., 2011; National Senior Citizens Law Center, 2011; National Resource Center on LGBT Aging, 2011).

### Federal and state policy reforms

While the ACA stands to improve dramatically the health of LGBT older adults, additional



policy reforms are needed to better evaluate its effect on LGBT people, as well as policy interventions that require community engagement with LGBT people and their nonprofit advocates at the local and state levels. Recent studies have found that 34 percent of LGBT people—including 28 percent of people ages 50 to 64—were uninsured in October 2013, when the open enrollment period began for the ACA's marketplaces (Center for American Progress 2013). At that time, two-thirds of uninsured LGBT people had lacked coverage for more than two years, and 68 percent expressed an interest in obtaining support while seeking new insurance options from workers who are familiar with LGBT concerns, such as options for same-sex couples and transgender-specific concerns (Center for American Progress, 2013).

A variety of policy reforms could speak to these health coverage needs. Federal regulations could require that the marketplaces collect demographic data on LGBT people that would measure the extent to which LGBT people, including those ages 50 and older, enroll in new health insurance options, and identify where gaps in coverage are more pronounced. The ACA initiatives, such as

Community Assistance Programs, Health Navigator Programs, and Dual Eligible Demonstration Projects, could work with LGBT organizations in states to ensure their outreach and enrollment efforts effectively recognize LGBT people, including older adults (Services and Advocacy for GLBT Elders [SAGE], 2013). Finally, the marketplaces and consumer-related information could speak to LGBT people's unique needs, such as family considerations and coverage concerns, as well as legal protections under the ACA (Durso, Baker, and Cray, 2013).

### ***New research shows that 48 percent of uninsured LGBT people live in states that are not expanding Medicaid.***

State policy reform and implementation also will be instrumental in shaping health outcomes for marginalized people, including LGBT older adults. As of June 2014, twenty-one states have opted not to expand Medicaid under the ACA, which could broaden health coverage for low-income people, including LGBT people and those living with HIV. New research shows that 48 percent of uninsured LGBT people live in states that are not expanding Medicaid (Durso, Baker and Cray, 2013). And, if Medicaid were expanded in all states (and all eligible people were accessing care), approximately 200,000 people with HIV would benefit from increased access to healthcare (Diverse Elders Coalition, 2014). In its broadest sense, policy reform should ensure that all states expand Medicaid.

Federal initiatives to work closely with LGBT organizations and programs, in particular those with an aging focus, could provide incentives for mainstream consumer groups working to implement the ACA at the state level. The infrastructure of LGBT organizations working on health reform implementation in all fifty states—including states that have opted out of Medicaid expansion—is thin and under-resourced. For example, the latest research on

the infrastructure of statewide LGBT organizations found that 33 percent had no paid full-time staff and nearly 85 percent had less than six full-time staff (Equality Federation, 2011). This means that the nonprofit organizations that are best poised to engage LGBT people of all ages regarding new health insurance options remain ill-equipped to meet the high demand.

### **HIV and Aging**

The HIV/AIDS epidemic has disproportionately affected LGBT people since its onset in the early 1980s. As a policy concern, HIV/AIDS embodies the health inequities facing marginalized people in the United States, including LGBT older adults. Moreover, addressing the epidemic among LGBT older adults requires a range of policy interventions across disciplines, with an emphasis on responding to multiple forms of stigma and discrimination in later life (Cahill et al., 2010; Centers for Disease Control and Prevention [CDC], 2013; Emlet, Fredriksen-Goldsen, and Kim, 2013).

Research estimates suggest that by 2015, 50 percent of people with HIV in the United States will be ages 50 and older; by 2020, this percentage will increase to nearly 70 percent (Diverse Elders Coalition, 2014). New infections are on the rise among older adults; people ages 50 and older are more likely to be dually diagnosed with HIV and AIDS (suggesting they were not screened early enough to prevent more dire health consequences); older people report both knowing less about HIV sources of transmission and being less likely to be screened for HIV by their medical providers; and, medical research shows high rates of comorbidities among people in their 50s who have HIV equivalent to people in their 70s who do not. Men who have sex with men, LGBT people, and people of color represent the majority of HIV/AIDS cases across various indicators, which denote how marginalization affects the spread of HIV and its consequences (Cahill et al., 2010; CDC, 2013; National Resource Center on LGBT Aging, 2011).



New policy analysis from leaders in aging, HIV, LGBT, and racial equity fields (CDC, 2013; Diverse Elders Coalition, 2014) offers an array of recommendations to improve the health of older adults with HIV. Advocates propose that older adults with HIV and LGBT elders be specified as a population of “greatest social need” in the Older Americans Act, and that HIV and aging be prioritized in the discussion topics and official recommendations of the 2015 White House Conference on Aging.

Policy advocates also propose the Ryan White Program (<http://hab.hrsa.gov/abouthab/aboutprogram.html>) be sufficiently funded to meet the treatment needs of older adults with HIV. They also believe federal agencies should fund an array of approaches, including elder-appropriate HIV prevention campaigns, new research on aging with HIV, and enhanced testing methods and reporting on HIV among older populations; and that HHS should promote clinical care guidelines on treating a growing demographic of older people with HIV, many of whom exhibit multiple age-related comorbidities at an earlier age. Given the scale of the ACA, and the percentage of people with HIV living in states that have opted to not expand Medicaid, policy reformers should ensure that people with HIV have the healthcare and medications they need to age in good health, regardless of income or geographic location.

### **Building the Knowledge Base**

While health disparities are evident among LGBT older adults, significant information gaps remain about LGBT older adult health and well-being. Obtaining quality information on the health and well-being of LGBT older adults is necessary to identify policy initiatives needed to promote health equity. Yet, sexual orientation and gender identity measures rarely are included in public health and aging surveys. Where such measures are included, they often are directed only to younger and middle-age adults, and exclude older adults (Fredriksen-Goldsen and

Kim, 2014; Redford and Van Wagenen, 2012). This is despite the existing research findings that most older adults respond to sexual orientation questions in public health surveys, with a significant increase in response rates over time. Older adults are more likely to respond to a sexual orientation question than they are to one asking about household income (Fredriksen-Goldsen and Kim, 2014).

It is critical to better understand health disparities through the collection of quality data. Population-level data are needed to establish the nature and scope of health disparities. The inclusion of a sexual orientation question in 2013 to the National Health Interview Survey (Brown, 2011) is an important step. In addition, the CDC is encouraging states to include sexual orientation and gender identity questions in the state-added modules of the CDC Behavioral Risk Factor Surveillance System ([www.cdc.gov/brfss](http://www.cdc.gov/brfss)). Other national surveys that gather information on health and aging needs should routinely include questions related to both sexual orientation and gender identity.

It also is critical to gather information on multiple dimensions of sexuality and gender in order to more fully understand the health and aging of LGBT older adults. This includes incorporating well-designed and field-tested questions for older adults on sexuality, including sexual identity, sexual behavior, attraction, and romantic relationships, as well as gender, including biological sex at birth and gender identity (Fredriksen-Goldsen and Kim, 2014).

As research on sexual and gender minorities becomes increasingly sophisticated, it is evident there are important sub-group differences that may be obscured by aggregating data and not examining groups separately. Mounting evidence suggests that bisexual and transgender mid-life older adults may be at increased risk for multiple poor health outcomes relative to lesbians and gay men (Fredriksen-Goldsen et al., 2013b).

Research also has shown that Asian Americans, Hispanics, and African Americans are less

likely to respond to sexual orientation measures compared to non-Hispanic whites, so innovative ways of measuring sexual orientation to reduce racially and ethnically driven bias need to be developed and integrated into health and aging surveys (Kim and Fredriksen-Goldsen, 2013). People of color are less likely than non-Hispanic whites to identify as lesbian, gay, or bisexual, even though they may engage in same-sex behavior (Chae and Ayala, 2010). Rather than identifying as LGBT, many Asian Americans use the term “queer” (Dang and Vianney, 2007), while African Americans often describe themselves as “same-gender loving” (Battle et al., 2002).

Signed into law in 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act is intended to “promote the adoption and meaningful use of health information technology” (HHS, 2010). Among its objectives of meaningful collection and use of data is “. . . Record Demographics, including . . . gender, race, ethnicity . . . date of birth [and] sexual orientation and gender identity . . .” in electronic health records (EHR) (Institute of Medicine, 2011). The Office of the National Coordinator for Health Information Technology has signaled its intent to include sexual orientation and gender identity in the 2017 Edition Certified EHR Technology (Bradford and Mayer, 2014).

As data relevant to sexual orientation and gender identity become increasingly available, it will be crucial that the translation gap be minimized. Work is needed to find effective ways to reduce time from “bench-side to bedside,” so collected data can be translated and used in developing healthcare and aging-related services and policies that dismantle obstacles leading to health disparities in LGBT older adults.

### **Moving Forward: A Renewed Call to Advocacy**

In order to respond effectively to the aging and health needs of LGBT older adults, we need a

comprehensive approach to public policies. While many important policy changes are underway, we need additional policy advocacy to adequately take care of the needs of LGBT people who are most vulnerable, including those who are old, single, living alone, and those with insufficient resources. As with any policy change, it is vital to consider quality of life, the need for quality care, responsiveness of service delivery, and to continue to build a comprehensive knowledge base to support the development, implementation, and evaluation of policies and interventions.


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***Applications for Social Security benefits by individuals in same-sex marriages, and who reside in a state not recognizing such marriages, are on hold.***

Policy innovations are needed to ensure accessibility to services and information as well as to the development and integration of innovative preventive health initiatives. To support such efforts, there must be greater opportunities for LGBT older adults, as consumers, to be actively involved on boards and commissions that plan and develop services and programs.

It is estimated that by 2030, there will be more than 5 million LGBT older adults (Fredriksen-Goldsen and Kim, 2014). The ever-shifting patchwork of policies and services designed to address the needs of the growing number of LGBT elders often varies by government level (i.e., city, county, state, and federal) and by geographic location. To reduce fragmentation, healthcare providers, researchers, advocates, and policy makers must work across levels to ensure streamlined access and better care integration. Both upstream and downstream interventions that promote prevention and wellness for LGBT people across the life span are needed.

Policy changes must be made to support the safety and economic security of all LGBT older adults, including the most vulnerable. In the reauthorization of the Older Americans Act, LGBT older adults need to be targeted for social and health services and programs as a potentially vulnerable group, recognizing that bisexual and transgender older adults are critically underserved. As we move forward in policy advocacy, families of choice, and others in mutually dependent relationships, must be afforded the rights and protections enjoyed by

other family caregivers. Promoting health equity requires attention to the economic, physical, and social well-being of all LGBT older adults, their families, and communities. 

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## Authors Note

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