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## Integrating Lesbian, Gay, Bisexual, and Transgender Older Adults into Aging Policy and Practice



## Integrating Lesbian, Gay, Bisexual, and Transgender Older Adults into Aging Policy and Practice

Robert B. Hudson, Editor

Given the voluminous gerontological literature that has built up over the past half-century, it is hard to imagine that any set of aging populations has been largely ignored or under-investigated. Yet, this clearly appears to be true in the case of lesbian, gay, bisexual, and transgendered (LGBT) older people. These individuals have remained nearly invisible to the community of advocates, researchers, practitioners, administrators, and politicians who associate themselves with the modern aging enterprise.

This issue of *PP&AR* takes a step toward filling that void. Topics explored here include the absence of research devoted to LGBT populations; the higher economic, health, and social risk profile of these individuals; the absence of public policies directed to their specific concerns; the failure of existing broad-based aging policies to incorporate LGBT needs and interests; the lack of cultural competency training among services personnel; the failure of public agencies to address bias-based victimization suffered by LGBT communities; the stealth realization that half of Americans living with HIV will be over the age of 50 by 2015; and the void in the gerontological literature speaking to diversity *within* the LGBT population, rendering it a residualized demographic held together, in the words of Brian de Vries, by "otherness."

Yet, forward steps are being taken to address this array of overlapping concerns. SAGE (Services and Advocacy for GLBT Elders) has pressed for involvement and inclusion in a host of associational and political events. More recently, The Diverse Elders Coalition has come into existence, combining resources of the LGBT and elders of color constituencies with particular attention to influencing the mainstream aging debate rather than remaining as isolated and segregated sub-populations positioned on the outside looking in. These advocacy activities have led to the formation of the first National Resource Center on LGBT aging, funded through the Older Americans Act. At the local level, an Innovative Service Center devoted to the LGBT community in New York City is about to open its doors. More broadly, the Affordable Care Act holds the promise of extending coverage and easing access to health care by the LGBT community.

We bring to this topic a committed and articulate group of authors: Karen Fredriksen-Goldsen (University of Washington); Robert Espinoza (SAGE); Kellan Baker and Jeff Krehely (Center for American Progress); Hilary Meyer (SAGE); Daniel Tietz (AIDS Community Research Initiative of America); Nathan Schaefer (Gay Men's Health Crisis); Harper Jean Tobin (National Center for Transgender Equality); Lilliam Barrios-Paoli (New York City Department for the Aging); Catherine Thurston (SAGE); Michael Adams (SAGE); and Brian de Vries (San Francisco State University). We would especially like to thank Robert Espinoza for his generous and timely assistance in helping us organize this issue and SAGE for sponsoring this issue.

Fostering inclusion and eliminating disparities are ascendant concepts in contemporary health and social policy, and we hope these articles addressing policy concerns of the LGBT community further such efforts.

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# Resilience and Disparities among Lesbian, Gay, Bisexual, and Transgender Older Adults

*Karen I. Fredriksen-Goldsen*

## Introduction

Increasing diversity is a defining feature of the growing older adult population across the globe. The expanding multicultural older adult population presents both opportunities and challenges in healthcare and gerontological research and public policy. Despite tremendous advancements in health, minority and historically disadvantaged communities bear higher levels of illness, disability, and premature death. A primary commitment of the National Institutes of Health (2010) is to reduce and eliminate health disparities, which are defined as differences in health impacting communities that have, as a result of social, economic, and environmental disadvantage, systematically encountered obstacles to good health (Department of Health and Human Services, 2010). Yet, the unique health and aging needs of lesbian, gay, bisexual, and transgender older adults are rarely addressed in research or policy.

The Centers for Disease Control and Prevention (2011) identifies research on sexual orientation as one of the most pronounced gaps in health disparities research. A recent report by the Institute of Medicine (2011) ascertains that lesbian, gay, bisexual, and transgender older adults are one of the least understood groups in terms of their health and aging-related needs. In a 25-year review of the literature, Fredriksen-Goldsen and Muraco (2010) conclude that health research is glaringly absent in studies about lesbian, gay, bisexual, and transgender aging. It is important to recognize and understand the prevalence of health disparities by sexual orientation among older adults and the unique factors that characterize the experiences and needs of lesbian, gay, bisexual, and transgender adults as they age. In addition, there are implications of such disparities in aging-related public policy, services, and research. Understanding aging across these historically disadvantaged groups expands our knowledge of the diverse experiences and needs of the older adult population.

In the first study funded by the National Institutes of Health and the National Institute on Aging to address the aging and health of lesbian, gay, bisexual, and transgender adults 50 years of age and older, important new findings provide a portrait of the health disparities and strengths in these communities (Fredriksen-Goldsen et al., 2011). Collectively, data from a state-level population based study and data from a national survey of lesbian, gay, bisexual, and transgender older adults reveal essential knowledge about the prevalence of health disparities and resilience in these communities.

## Health Disparities: What Do We Know?

Utilizing state-level population based data, we found that contrary to the myth that older adults will not reveal their sexual orientation in public health surveys, approximately two percent of adults age 50 and older self-identify as lesbian, gay, or bisexual. Based on the number of adults age 50 and older currently living in the U.S., these findings indicate that more than two million older adults self-identify as lesbian, gay, or bisexual. Given the tremendous surge in the aging of the population in the next few decades, the number of older lesbians, gay men, bisexual women, and bisexual men will continue to rise exponentially. The population of lesbian, gay, bisexual, and transgender older adults is expected to double between 2000 and 2030.

Lesbian, gay, bisexual, and transgender older adults are a resilient yet at-risk population experiencing significant health disparities. The prevalence of many common health problems is elevated among these groups, even when taking into account differences in age distribution, income, and education. Compared to their heterosexual counterparts, lesbian, gay, and bisexual older adults are at an elevated risk of disability and mental distress. Forty-one percent of lesbian, gay, and bisexual adults age 50 and older have a disability; surprisingly, among sexual minority adults 18 years of age and older, women are more likely to have a disability than are men (Fredriksen-Goldsen, Kim, & Barkan, in press). Important differences in health behaviors are also evident, with lesbian, gay, and bisexual older adults more likely to smoke and engage in heavy drinking than their heterosexual counterparts.



Important differences between sexual minority women and heterosexual women are also evident. For example, older lesbians and bisexual women report heightened risks of cardiovascular disease and obesity and a lower likelihood of having a mammogram as compared to older heterosexual women. When comparing sexual minority men to heterosexual men, older gay and bisexual men are more likely to experience poor physical health compared to heterosexual men of similar age. While information on HIV status is not available in the population-based data, this disparity is likely related to the prevalence of HIV among gay and bisexual men. Given the effectiveness of anti-retroviral therapies, more adults are living into old age with HIV disease. It is also important to note that differences emerge between sexual minority groups. For example, older lesbians are significantly more likely to engage in heavy drinking as compared to older bisexual women. Furthermore, diabetes is significantly more common among older bisexual men than among older gay men, and older bisexual men are less likely to have obtained an HIV than gay men.

The study also illustrates important socio-demographic differences by sexual orientation and age. Despite higher levels of education for older lesbians, gay men, and bisexuals, and the higher likelihood of employment for older lesbians and bisexual women compared to older heterosexual women, this does not result in higher incomes. All of the older sexual minorities groups are less likely to be partnered or married, which likely reflects limited access to marriage and may result in less support as they age. Older gay and bisexual men, compared to older heterosexual men, have significantly fewer children in the household and are significantly more likely to live alone. In the general population, older women are more likely to live alone than older men, however in these populations, the trend is reversed and gay and bisexual older men are at an elevated risk for living alone. Older adults who live alone in the general population are at risk of social isolation, which is linked to poor mental and physical health, cognitive impairment, and premature morbidity and mortality.

Important health strengths are also evident among older lesbians, gay men, and bisexual women and men. For example, older gay and bisexual men show lower likelihood of obesity and a higher likelihood of receiving a flu shot and an HIV test as compared to older heterosexual men. In addition, older lesbians and bisexual women are more likely to receive an HIV test than their heterosexual counterparts. Furthermore, while much of the research on aging in these communities is

based on an assumption of differences by sexual orientation, there are some important similarities in health. For example, there are no differences found by sexual orientation in terms of having health insurance, engaging in physical exercise, or having high blood pressure or high cholesterol.

**“LGBT older adults are a resilient yet at-risk population experiencing significant health disparities.”**

### **Risk and Protective Factors Impacting the Health of LGBT Older Adults**

Since disparities in health exist among lesbian, gay, and bisexual older adults, we collaborated with 11 agencies across the nation that serve lesbian, gay, bisexual, and transgender older adults to conduct the first national study on lesbian, gay, bisexual, and transgender aging and health (Fredriksen-Goldsen et al., 2011). By conducting a census of socio-demographically diverse participants connected to these agencies, we assessed risk and protective factors associated with health among 2,560 lesbian, gay, bisexual, and transgender older adults. Although most previous studies of aging in these communities have relied on responses from adults in mid-life, this study represents a much broader age spectrum, ranging in age from 50 to 95, with 10 percent age 80 and older, 25 percent age 70-to-79, 41 percent age 60-to-69, and 24 percent age 50-to-59. This component of the study is also unique because it includes transgender older adults (seven percent).

The findings from this national study confirm the higher rates of disability found in the state-level population based study, with almost half of the lesbian, gay, bisexual, and transgender older adults having a disability. The elevated risk of mental distress found in the population based study is also substantiated; an alarming one-third (31 percent) of lesbian, gay, bisexual, and transgender older adults report depression. Transgender older adults are at heightened risk of both disability and depression. More than half (53 percent) of the lesbian, gay, bisexual, and transgender older adults experience

loneliness and more than one-quarter (27 percent) have experienced the death of a partner.

There are also positive signs of health and resilience in these communities. For example, most of the lesbian, gay, bisexual, and transgender older adults (91 percent) engage at least weekly in leisure and wellness activities and 82 percent engage in moderate physical activities. Eighty-nine percent feel good about belonging to their communities. More than one-third (38 percent) attend spiritual or religious services or activities at least once a month.

### Social and Historical Context of Aging

The social and historical context of aging influences disparities in health. The lived experiences of lesbian, gay, bisexual, and transgender older adults range from coming of age in the shadow of the Great Depression to being part of the baby boom generation. In order to understand the lives of these older adults, particularly the oldest, we must understand the historical context of their lives. Many of these older adults came of age during an era when homosexuality and gender variance were severely stigmatized and criminalized, and as a result, invisibility reigned. The impact of the civil rights movements in the 1960s and the Stonewall riots in 1969 sparked the gay liberation movement and younger lesbians, gay men, bisexual, and transgender adults began to emerge from the margins of society.

Many lesbian, gay, bisexual, and transgender older adults have spent the majority of their lives masking their sexual orientation and gender identity, with their life stories largely silenced.

Unlike some minority groups, most lesbian, gay, bisexual, and transgender older adults are not readily identifiable and they must constantly manage the disclosure of their sexual orientation or gender identity fearing discrimination and victimization.

### Discrimination and Victimization

Over their lifetime, most lesbian, gay, bisexual, and transgender older adults have faced serious adversity. Discrimination creates several significant risk factors for lesbian, gay, bisexual, and transgender older adults and their communities (Fredriksen-Goldsen, Kim, Muraco & Mincer, 2009). Both historical and contemporary experiences of victimization create obstacles to accessing and utilizing necessary health and social support services. Due to the perception of being lesbian, gay, bisexual, or transgender, 82 percent of these older adults have been victimized at least once in their lives, and nearly two-thirds (64 percent) at least three times. More than two-thirds (68 percent) have experienced verbal insults and 42

percent have been threatened with physical violence. Other types of victimization they have experienced include being hassled by police (27 percent), threatened to be outed as lesbian, gay, bisexual, or transgender (23 percent), not hired for a job (22 percent), or had property damaged (20 percent). Transgender older adults experience higher levels of victimization and discrimination than non-transgender older adults.

### Obstacles to Healthcare

Lesbian, gay, bisexual, and transgender older adults encounter obstacles in accessing quality healthcare services which can have extensive consequences. The American Medical Association (2009) states that if physicians do not recognize patients' sexual orientation and patients do not disclose, it can result in serious medical problems. However, 21 percent of lesbian, gay, bisexual, and transgender older adults have not revealed their sexual orientation to their primary physician, with bisexual women and men less likely to disclose than lesbians and gay men. This prevents discussions about sexual health, hormone therapy, risk of breast cancer, hepatitis and HIV risk, or other potential risk factors. Thirteen percent of lesbian, gay, bisexual, and transgender older adults have been denied or provided inferior healthcare and almost one-quarter (22 percent) of transgender older adults need to see a doctor but can't because of cost. In addition, 15 percent fear accessing healthcare outside the lesbian, gay, bisexual, and transgender community and eight percent fear accessing healthcare inside the community.

### Distinct Networks of Support

While biological family members play a primary role in the support of older adults in the general population, most lesbian, gay, bisexual, and transgender older adults care for one another. They rely most heavily on partners and friends, many of a similar age, to provide assistance and help as they age. More than one-quarter (27 percent) assist someone close to them who has a health issue or other needs. Of the caregivers, 35 percent provide care to a partner or spouse, 32 percent to a friend, and 16 percent to a parent or parent-in-law. Seventeen percent currently receive care: 54 percent from their partner or spouse and 24 percent from a friend. While in the general caregiving literature women provide the majority of care, in the lesbian, gay, bisexual, and transgender communities, men are as likely to provide care as women (Fredriksen-Goldsen, 2007; MetLife Mature Market Institute, 2010). The importance of friends in the lives of lesbian, gay, bisexual, and transgender older adults is well documented, yet

recent research has found that friends often recognize limits in their ability to provide care over the long-term, especially when decision making is required for the older adult receiving care (Muraco & Fredriksen-Goldsen, in press). Despite the fact that their support systems differ and they often lack legal protection for their loved ones, an alarming 30 percent do not have a will and 36 percent do not have a durable power of attorney for healthcare.

### Implications for Moving Forward

Addressing the unique circumstances of lesbian, gay, bisexual, and transgender older adults requires a comprehensive approach to transform existing public policies, aging services, and research. There are recent advances in policies addressing the needs of lesbian, gay, bisexual, and transgender older adults; for example, effective January 2011, new federal regulations were enacted to prohibit discrimination in visitation based on sexual orientation and gender identity by hospitals participating in Medicare and Medicaid programs. Yet many existing public policies that are intended to support older adults in times of need are often inaccessible to lesbian, gay, bisexual, and transgender older adults and their loved ones. For example, same-sex partners do not have access to federal family leave benefits, equivalent Medicaid spend-downs, Social Security benefits, bereavement leave, or automatic inheritance of jointly owned real estate and personal property.

The unique health risks faced by these older adults require changes in legislation that are often considered beyond the scope of aging-related policy. For example, policy and programmatic interventions are needed to combat existing discrimination, victimization, and stigma. Protection from discrimination based on sexual orientation and gender identity in employment as well as housing and public accommodations at federal, state, and local levels are needed to insure the economic security and safety of these older adults and their families. Given the high levels of victimization experienced by lesbian, gay, bisexual, and transgender older adults, it is imperative that hate crimes based on sexual orientation, gender identity, and age be fully prosecuted. As we move forward, it is essential that services and demonstration projects funded by the Older Americans Act (OAA) target social and health services and programs that address the needs of lesbian, gay, bisexual, and transgender older adults and their caregivers.

### Services and Intervention Developments

Many lesbian, gay, bisexual, and transgender older adults are living alone without adequate services or

supports. Creating comprehensive health and aging services for lesbian, gay, bisexual, and transgender older adults by fostering partnerships between aging and general services in the lesbian, gay, bisexual, and transgender community, as well as with federal, state, and local mainstream providers of health and aging services is desperately needed.

Cultural competency training is necessary for healthcare and human service professionals addressing lesbian, gay, bisexual, and transgender older adults and caregivers, incorporating diversity in age, gender, ethnicity, race, education, income, geographic location, and ability. It is important to define the competencies necessary for effective healthcare practice with lesbian, gay, bisexual, and transgender older adults and their families and advocate for the integration of these competencies as part of the degree requirements in educational programs including medicine, nursing, social work, and other educational programs.

To respond effectively to health disparities and consequent needs, interventions are needed that are tailored to meet the distinctive health and aging needs of lesbian, gay, bisexual, and transgender older adults, recognizing that bisexual and transgender older adults are critically underserved. The early detection and identification of such at-risk groups will enable public health initiatives to expand the reach of strategies and interventions to promote healthy communities, especially aimed at prevention and reduction of obesity, heavy drinking, and smoking. The expansion of HIV prevention, education, and treatment programs to include older adults will be an important step forward.

### Research

In order to address these critical health and aging needs, it is imperative that sexual orientation and gender identity measures be included in aging-related research, including in public health surveys. Better data collection documenting sexual orientation and gender identity is needed to determine the risk of health disparities, as well as elevated morbidity and mortality among older sexual minorities. While there are ambiguities in measurement, important advancements are being made in the development and utilization of measures of sexual orientation, sexual identity, gender identity, and sexual behavior.

While previous research has generally collapsed lesbian, gay, bisexual, and transgender older adults into a single sexual minority group, the findings reported here document important differences, and the heterogeneity of subgroups should not be overlooked (Fredriksen-Goldsen, Kim, Barkan, Balsam, & Mincer, 2010; Kim &

Fredriksen-Goldsen, in press). Research is desperately needed to better understand the impact of risk and protective factors on the health of lesbian, gay, bisexual, and transgender older adults, including the increased likelihood of living alone, not having children, and relying on peers to provide assistance.

We need to better understand the life course trajectories of those reaching old age in these communities. Given the existing peer-based support structures within these communities, those living to very old age may be at high risk for institutionalization. Future research is needed to explore the decision-making processes guiding lesbian, gay, bisexual, and transgender older adults and their caregivers and the relationships between health and key life events and the utilization of informal and formal supports.

### Conclusion

Given the increasing diversity in our aging society, it is imperative that we begin to address the health and aging needs of lesbian, gay, bisexual, and transgender older adults. Examining the health and well-being of older adults from historically disadvantaged populations sheds new light on diversity as well as cumulative risks in aging. Understanding aging across these communities requires a perspective cutting across the life course as it intersects with individual, cultural, and societal effects. The insights gleaned through this work exemplify aging as a multidimensional process embedded with inequalities and opportunities in an increasingly heterogeneous society.

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# The Diverse Elders Coalition and LGBT Aging: Connecting Communities, Issues, and Resources in a Historic Moment

Robert Espinoza

2011 represents a milestone for the aging sector. Referenced by many as the first year that baby boomers began turning 65 (based on a popular reference that places the origins of this generation at 1946), 2011 opened a massive demographic shift that will dramatically age the U.S. population over the next few decades. Yet for a coalition of seven national organizations representing millions of marginalized older adults nationwide, 2011 had a broader resonance. It was the year that the Diverse Elders Coalition entered the federal stage to highlight the policy needs of lesbian, gay, bisexual, and transgender (LGBT) older adults and elders of color.<sup>1</sup> It was the year that this visionary coalition achieved what rarely moves beyond theoretical circles; it seeded a multi-organization, advocacy apparatus that in less than a year has begun refocusing the mainstream policy conversation on our most disadvantaged communities.

This article begins with a brief literature review on the socioeconomic conditions facing LGBT elders and elders of color, noting significant disparities across multiple areas related to health and well-being in one's later years. It then describes the formation of the Diverse Elders Coalition, including an overview of the issues that emerged as its focus and its key achievements in both building an infrastructure for aging advocacy and achieving short-term advocacy wins. Finally, the article concludes with a discussion of the coalition's importance to policy makers concerned with enacting improvements for LGBT elders and elders of color (many of whom are LGBT elders of color), and the broader relationship to an LGBT aging political movement.

## Profound Disparities, Heightened Vulnerability

The available research shows that LGBT elders and elders of color experience profound disparities across similar areas with related consequences.<sup>2</sup>

**Discrimination across the lifespan and its economic effects.** The economic conditions of LGBT elders and elders of color have been shaped by discrimination they have encountered across the lifespan, which worsens as they enter old age. Historians note how an elder of color entering retirement age in 2011 likely first entered the workforce during a time of de jure and de facto discrimination shaped by racial segregation in schools, communities, and the workforce; had limited access to higher education; and was often concentrated in employment with low wages and no pensions or retirement benefits (Dumez & Derbew, 2011). Similarly, today's LGBT elders have lived through decades of discrimination, including years when homosexuality was criminalized and labeled a mental disorder, and overt

discrimination was encouraged. Even today, these realities describe the everyday experiences of many LGBT older adults, with notable hardship experienced by transgender and gender non-conforming older people.

**Economic vulnerability.** A lifetime of discrimination has destabilized the economic security of LGBT older adults and elders of color, as evidenced by higher poverty rates, diminished retirement supports, and the worsening wealth gap between elders of color and their non-white, non-LGBT counterparts—all of which continues into retirement age. As noted earlier, because many LGBT elders and elders of color have lived through decades where discrimination in the workplace was both legal and common practice, they are more likely to have experienced reduced lifelong earnings, earned less in Social Security benefits (exacerbated by regular employment interruptions), and are more likely to enter their older years with fewer financial options.

Many elders of color were (and still are) concentrated in jobs with low wages and few retirement options. For example, researchers have documented how hiring practices in the service and agricultural industries have disproportionately segmented Latinos into professions with low pay, limited benefits, and little access to health insurance; this has had serious consequences for the financial security and long-term health outcomes of Latino older adults (a percentage of whom are LGBT). Research shows that the median income for households headed by Latino individuals over age 65 is \$22,116 as compared to \$31,162 for households headed by non-Latino Whites in the same age range (Cummings, Hernandez, Rockey Moore, Shepard, Sager, & Brownstein-Santiago, 2011). Further, up to eight percent of elder Latinos in the United States are not able to receive Social



Security either because they have not paid into the system for a sufficient number of years or because they are immigrants who do not have the appropriate legal status to receive these earnings from their labor. Ineligibility for Social Security means that this portion of Latino elders is not eligible for Medicare benefits. These disadvantages are especially burdensome for Latino elders who have less access to federal benefit programs at a point in their lives when they are most likely to experience health complications associated with aging. And for those Latino elders who are also lesbian, gay, bisexual, and transgender, the LGBT-based discrimination they experience magnifies their economic vulnerability.

**Higher poverty rates.** Based on a revised federal formula that accounts for out-of-pocket medical and other living expenses, the U.S. Census Bureau estimates that 16.1 percent of elders in this country are in poverty, which includes hundreds of thousands of LGBT elders. Studies have found that 24 percent of lesbians and 15 percent of gay and bisexual men are poor, compared to 19 percent and 13 percent of heterosexual women and men, respectively—a disparity that persists as LGBT people age (Albelda, Badgett, Schneebaum, & Gates, 2009). In another study, same-sex elder couples face higher poverty rates than their heterosexual peers; 9.1 percent and 4.9 percent among elder lesbian and gay couples, respectively, in contrast to 4.6 percent among elder heterosexual couples (Movement Advancement Project & Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders, 2010). As the number of people age 65 and older surges over the next few decades, so will LGBT older adults who live in or fall into poverty. Poverty has always disproportionately affected people of color, including elders. Two current examples: while blacks comprise only nine percent of the U.S. population, they make up 21 percent of the elder population living in poverty, and the Office of Minority Health estimates that one in four American Indians/Alaska Natives lives in poverty (Cawthorne, 2008).

**Poor health care and health disparities.** Heightened stress, culturally and linguistically incompetent healthcare and aging care, and other socio-economic factors contribute to health disparities among LGBT elders and elders of color. For older people of color, the consequences of inadequate care include higher rates of numerous chronic diseases as well as higher mortality rates from HIV/AIDS, diabetes, and cardiovascular disease, as compared to their white peers. For example, a 2010 report by the Alzheimer's Association showed that Latinos are one and a half times more likely than whites to have Alzheimer's and other dementias due in part to

factors such as lower income and education levels, heightened stress, and high blood pressure. (The broader literature suggests that these aforementioned disparities extend across other communities of color.) Compounding this problem is that many LGBT elders and elders of color also lack the necessary insurance coverage—or the information about available benefits—to make health care an affordable reality.

**Social isolation.** LGBT older adults are twice as likely to live alone as heterosexual older adults and more than four times as likely to have no children, meaning that the informal caregiving support structure we assume is in place for older adults might not be there for LGBT older people. For LGBT elders, social isolation compounds the physical and mental health concerns that many elders experience as they age. Research suggests that social isolation can lead to a number of mental and physical ailments such as depression, delayed care-seeking, poor nutrition, and poverty—all factors that greatly lessen the quality of life for both LGBT older adults and elders of color. Living in isolation, and fearful of the discrimination they could encounter in mainstream aging settings, many marginalized elders are also at a higher risk for elder abuse, neglect, and various forms of exploitation. For LGBT elders of color, this social isolation might be intensified, since they might also be isolated from their racial and ethnic communities as LGBT older people and isolated from the mainstream LGBT community as people of color.

**Cultural and linguistic incompetence.** The aforementioned lack of cultural and linguistic competence in healthcare and aging settings presents additional obstacles to healthy aging for LGBT older people. LGBT people routinely experience culturally insensitive and discriminatory treatment in mainstream healthcare settings. A 2011 report on transgender discrimination by the National Center for Transgender Equality and the National Gay and Lesbian Task Force documented pervasive insensitivity and violent treatment of transgender patients in emergency rooms, mental health clinics, and drug treatment programs (Grant, Mottet, Tanis, Harrison, Herman, & Keisling, 2011). Notably, the report found that transgender Latino respondents reported the highest rate of unequal care of any ethnic category. This trend extends into other institutional environments. A 2010 nationwide survey of Area Agencies on Aging found that only one-third of these agencies offered LGBT aging training to staff and very few offered LGBT-specific programs or outreach (Knochel, Corghan, Moone, & Quam, 2010). Among the general Latino population, advocates who work with Latino elders have routinely

pointed out how most aging programs and resources are not offered in culturally and linguistically appropriate ways, which makes them inaccessible to a culturally diverse, Spanish-speaking elder population. And without the proper information or care, the health and well-being of these communities deteriorates.

### A Coalition Emerges in Response

In December 2010, the seven organizations that would comprise the Diverse Elders Coalition (DEC) met in Washington, DC, to discuss the political possibilities of working together. The seven organizations included la Asociación Nacional Pro Personas Mayores, the National Asian Pacific Center on Aging, the National Caucus and Center on Black Aged, the National Hispanic Council on Aging, the National Indian Council on Aging, Services and Advocacy for GLBT Elders (SAGE), and the Southeast Asia Resource Action Center.

The event was historic for three main reasons. First, it was the first time that these seven organizations had come together to discuss their commonalities, their unique organizational focuses, and how to align the two in order to advance the policies that could improve the lives of marginalized older people nationwide. Second, while each of these organizations had placed their own issues on the policy agenda of the broader aging field (with varying levels of success), never before had a collection of organizations representing marginalized elders focused its collective attention on the mainstream aging debate. Third, it was the first time that LGBT aging issues were being discussed in tandem with a racial and economic issues framework—and an LGBT organization (Services and Advocacy for GLBT Elders) was in the lead.

A vision would quickly emerge for the coalition. Within the first meeting, the DEC would identify as its core purpose: to win policy gains that improve the lives of low-income people of color, American Indians, Alaska Natives, and LGBT elders, and to educate our communities on policies that improve our lives. This purpose affirmed that the coalition was as concerned about policy improvements as it was about building the necessary infrastructure to move and sustain those changes. The purpose also contained an overarching theme of economic hardship among older adults—a thread that ran through the societal problems articulated by the seven groups. Finally, this purpose spelled out differences that would require specialized analysis, notably the unique relationship of American Indians and Alaska Natives to the federal government and the specific needs of LGBT older adults across the seven organizations.

In the months that followed, the coalition would tighten its focus on three policy goals, each of which contained a unifying theme and has since served to build its advocacy strength. The first DEC priority is ensuring that the upcoming reauthorization of the Older Americans Act specifies elders of color and LGBT older adults as populations of greatest social need while preserving key funding for programs such as the Senior Community Service Employment Program (SCSEP), which promotes critical employment opportunities for poor and low-income elders. In support of this priority, the DEC worked with the Leadership Council of Aging Organizations (LCAO) to include eight recommendations specific to LGBT elders and elders of color in LCAO's official consensus document on reauthorization of the Older Americans Act. The document serves as LCAO's official stance on reauthorization with members of Congress, and for the first time in its history, it includes recommendations that would broaden definitions of greatest social need, minority and family to specify LGBT elders and elders of color, promote cultural and linguistic competence through the Aging Network, improve data collection to understand the reach of aging services into our communities, and more.

The coalition is also working with other organizations to protect Social Security using a combination of earned media, electronic outreach and social media, and town halls to connect marginalized elders to the national debate on entitlement programs and increase awareness about the unique ways that marginalized elders are affected by Social Security. For example, three organizations in the coalition—the National Hispanic Council on Aging, Services and Advocacy for GLBT Elders, and the Southeast Asia Resource Action Center—are coordinating a national community engagement effort that has hosted town halls around the country, created original videos and issue briefs on Social Security and their communities, and placed stories in ethnic and LGBT media outlets to reach underserved older adults better. And as the debt deal intensifies, the coalition has broadened its advocacy to include preserving Medicare and Medicaid.

Finally, the coalition has been educating its communities about the improvements made possible through health care reform while remaining active on discrete aspects of health care reform that could better target LGBT older adults and elders of color. For example, in early April, the DEC submitted various recommendations to the National Prevention Council, delineating where the draft of the National Prevention Strategy could better improve the health and quality of life

of our country's diverse elders and achieve significant life expectancy at age 65. Many of these recommendations made their way into the final draft of the National Prevention Strategy, which was released in June 2011.

### Progress for LGBT older adult advocacy

The emergence of the Diverse Elders Coalition signals an important shift for the aging policy landscape and for marginalized elders nationwide. As described in this article, although LGBT elders and elders of color face significant disparities in health and well-being, the public policies that are meant to support them often ignore these realities, underfund the programs that are improving their lives, and are often embedded with inequities that reproduce long-held disadvantage. In the last year, seven organizations have proposed ways to begin correcting this disconnect—from writing LGBT elders and elders of color into the federal framework of the Older Americans Act and ensuring that health care reform targets and reaches marginalized older adults to creating a political infrastructure where underserved communities can shape the policy debate about Social Security, Medicare, and Medicaid.

And for advocates concerned with the future of LGBT older adults, the coalition offers additional insights and possibilities. The coalition has advanced policy recommendations that explicitly name both LGBT elders and elders of color by (1) identifying common policy vehicles (e.g., Older Americans Act, Social Security, health care reform) and (2) distilling the themes that create a common interest (e.g., heightened vulnerability, a lack of explicit recognition and related funding in federal aging policies and programs, and more). From the LCAO consensus document to the National Prevention Strategy, the DEC's achievements reinforce the importance of broadening both the policy framework and the breadth of institutional actors to effectively place important yet often hidden LGBT issues on the policy agenda. Additionally, as the organizations have worked closely together, they have developed a better understanding of how each other's issues affect their own communities. For example, a formal evaluation of the coalition found that it was able to deal with some initial struggles with LGBT issues, which can feel charged for groups less familiar with the dynamics of LGBT-explicit advocacy. As a member of the coalition, SAGE has noted how many of the members now discuss LGBT elders as members of their own racial and ethnic communities—and likewise, SAGE has placed an overt emphasis on understanding where racial equity fits into its broader policy and programmatic agenda.

It might also be that the subject of LGBT aging carries with it a number of subject matters that facilitate an intersectional lens that links sexual orientation, gender and gender identity, race, class, and more. Unlike the policy issue silos or narrow identity politics that have compartmentalized many in the LGBT field (and the broader policy field), a proper understanding of LGBT aging requires a deliberate examination of issues such as housing, health, poverty and class, stigma and discrimination, and more—all of which reveal racial, economic, and gender disparities and intersections. More importantly, they also reveal common entry points, as evidenced by the three policy areas that are in the forefront for the Diverse Elders Coalition.

2011 will be remembered as the year this country began seeing a growing and more diverse older adult population. But for the Diverse Elders Coalition, 2011 will be remembered as the year seven organizations began seeing each other—and the aging field began seeing them.

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### Endnotes

1. "Elders of color" is used in this article to describe the range of racial and ethnic elder communities living in the U.S. that are diverse across race, ethnicity, country of origin, immigration status, sexual orientation and gender identity, and other characteristics. It also acknowledges that different communities have unique policy considerations (e.g., the unique federal status of American Indians and Alaska Natives, among others).

2. The empirical research on LGBT older adults is limited for a variety of reasons, including the lack of large-scale data and research on LGBT people. Even the estimates on LGBT people vary based on differences in definitions, differences in survey methods (which can affect the willingness of people to respond), and a lack of consistent questions in surveys over a period of time.

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## Improving the Lives of Transgender Older Adults

Harper Jean Tobin

Like all older adults, older transgender people—those whose gender identity or expression differs from the gender they were assigned at birth—face myriad challenges as they age. Transgender people in general experience high levels of discrimination, poverty and victimization, but little is known about the growing population of older transgender people and their needs (Institute of Medicine, 2011). Some older transgender women and men transitioned from one gender to another at a time when trans people were invisible, legal rights were nonexistent, and doctors recommended starting a new life and avoiding other trans people. Others come out and transition later in life, and may face the loss of existing sources of social and financial support. Trans people are commonly challenged and mistreated in all kinds of settings over what name they go by, how they dress, which restroom they use, and whether their ID matches their gender identity.

Many trans older adults have experienced abuse in long-term care facilities, including the denial of medication or personal care services, physical abuse, and psychological abuse such as being isolated from other residents, involuntarily outed, and prevented from dressing consistently with their gender identity. Still other trans people are simply refused admission into long-term care facilities. California law mandates training on lesbian, gay, bisexual, and transgender (LGBT) issues for nursing home staff, but these trainings have not yet been implemented. 2010 guidance from the Department of Housing and Urban

Development (HUD) states that anti-transgender discrimination may violate the Fair Housing Act (Department of Housing and Urban Development, 2011). In addition, the Centers for Medicare and Medicaid Services (CMS) is working to develop LGBT training for facilities and state surveyors, and advocates are urging CMS to provide additional guidance on older LGBT people's rights under the federal Nursing Home Reform Act.

These challenges are not limited to long-term care. A recent survey of 320 area agencies and state units on aging found that more than one in four reported that

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transgender older adults would either not be welcomed by local service providers or the agency was unsure of how welcome they would be (Knochel, Croghan, Moone, & Quam, 2011). The fear and reality of discrimination lead to underutilization of services. Although trans older adults live in every state and region, fewer than one in five area agencies reported receiving a request for assistance from a trans older person in the last year.

Transgender older adults also face numerous obstacles to accessing adequate health care. Obtaining routine preventive screenings that involve body parts associated with one's birth gender (such as pelvic exams for transgender men) can be extremely intimidating, and insurance coverage can be denied when the procedures are coded for the "wrong" gender—though Medicare has recently instituted a technical change to fix this problem. Medicare does cover many of the medical needs associated with gender transition, however, it still excludes coverage for sex reassignment surgery based on a decades-old determination that such procedures are experimental even though they are now widely recognized as safe, effective, and medically necessary. The result is an arbitrary division where non-surgical transition-related care is covered, but those who need surgical care must pay out of pocket.

Existing research indicates transgender people are twice as likely as others to have served in the armed forces, thus many rely on the Veterans Administration (VA) for health care and other supports (Grant, Mottet, Tanis, Harrison, Herman & Keisling, 2011). Discrimination and refusal of care at VA hospitals has been a major challenge for transgender veterans. Problems have included staff refusing to use a veteran's preferred name or personal pronoun, refusing to provide evaluations or prescriptions for hormone therapy, asking invasive questions about anatomy when not relevant to providing care, and even refusing trans veterans any care whatsoever. In June 2011, the VA issued a groundbreaking directive to all facilities requiring that trans veterans be provided equal respect and adequate care, including most forms of transition-related care (Veterans Health Administration, 2011). While this directive represents a huge step forward, as in Medicare, decades-old VA regulations still prohibit coverage of sex reassignment surgery.

A recent Institute of Medicine (IOM) report on LGBT health identified transgender aging as a major research gap, naming topics such as elder abuse, substance

abuse, risks and best practices for long-term hormone therapy, sexual health, and cancer, as areas in which more transgender research is needed. The IOM also called for including questions about gender identity in federal surveys, including surveys of older adults by the Administration on Aging (AoA) and CMS. AoA has committed to collecting LGBT health data, but this may take years to be fully implemented.

We all worry about our security and independence as we age. Transgender people should have all the opportunities and supports in later life that any older person might need. Over the course of 2011, the Services and Advocacy for GLBT Elders (SAGE) and the National Center for Transgender Equality convened community leaders to develop a transgender aging policy agenda, including policy objectives in all the areas discussed here. The agenda will be released in late 2011. There is much to be done to improve the lives of trans older adults, and it will require action from advocates, providers, regulators, and community members at the federal, state, and local levels.

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# Reflections on Advancing an LGBT Aging Agenda

*Michael Adams*

In the five years since I assumed the role of executive director of SAGE (Services & Advocacy for GLBT Elders)—the country's oldest and largest organization focused on lesbian, gay, bisexual, and transgender (LGBT) aging issues—I have seen substantial growth in the LGBT aging field and a corollary deepening of interest across multiple sectors in the concerns of LGBT older people. Much of that progress was foreshadowed by the push for LGBT inclusion at the diennial White House Conference on Aging in 2005, and in the vision statement and strategic plan adopted by SAGE in 2007 and 2008, respectively. But progress does not occur simply because committed and passionate advocates put their mind to it. Indeed, many an organizing effort has remained an isolated shot in the dark, and many an inspiring strategic plan has gathered dust on a shelf and failed to seed the change it imagined. That is even more the case during very difficult economic times. Nonetheless, there has been notable forward movement in advancing the interests of LGBT older people in recent years.

This article offers reflections on how and why progress has been made, highlights some of the key obstacles to forging ahead on an LGBT aging agenda during such difficult times, and addresses some of the apparent limitations of the advances that have been secured. It posits that: 1) policy change is made much easier when it is undergirded by leadership with capacity; 2) such change necessarily requires a new allocation of resources (power, funds, seats at the table, etc.); 3) new resource allocation—always difficult—triggers especially tough resistance during lean times; 4) those challenges to some degree can be overcome by deft leadership and creative advocacy; but 5) there are significant limits to what can be accomplished under such circumstances, and those limits are evident in today's LGBT aging arena.

## **Building Leadership With Capacity**

The experience of the LGBT aging field suggests that good ideas and theory are not enough to induce policy change. For years, this field has been blessed with the brightest of minds that could incisively dissect how aging policy and practices poorly serve LGBT older people. Yet while the influence of those brilliant minds succeeded in creating a body of thought about what needed to change, their efficacy in moving the dial toward policy change was limited. Some of this resulted from intentional neglect by the federal government; the administration of George W. Bush systematically ignored the general interests and needs of the LGBT community as a seeming matter of dogma and policy, and LGBT elders fared no better. Progress was also limited by resistance to change among some who had a significant

stake in the status quo and feared a weakening of that stake if a new elder population were to be recognized as a legitimate focus of public policy. Another barrier to change was the fact that few LGBT or aging organizations were paying much attention to LGBT aging issues; the LGBT world has historically been marked by ageism, and the very notion of LGBT elders was foreign to an aging world that traditionally avoided elder sexuality of any type.

Part of the explanation for the limits on progress lies with the LGBT aging field's relative absence of strategic leadership backed by institutional capacity. Indeed, the lack of attention by LGBT and aging organizations to LGBT elder issues itself can be ascribed at least in part to the inability of the field's leaders to wield enough organizational heft to re-shape the discussion and get potential partners to take a closer look at LGBT aging issues. SAGE's trajectory was reflective of the historical problem. Founded in 1978, SAGE stood for years as the country's only LGBT aging organization. When other LGBT aging groups eventually emerged, they were invariably small and under-resourced. Because SAGE was always substantially larger, had more reach, and enjoyed a more significant historical pedigree than its sister organizations, it episodically assumed a national role through a series of national conferences on LGBT aging issues and other efforts. But, as a result of resource limitations and leadership challenges, the organization's national focus was not consistent and did not produce sustained results. Over time, SAGE was known most reliably as a local service provider in New York City. To address the field's lack of institutional leadership, SAGE decided to



lay claim to the mantle of national leadership by growing the organization to scale and by explicitly committing to building national advocacy and training programs to complement the agency's historic commitment to local service delivery.

By any objective measure, SAGE in recent years has met its goals of building its institutional capacity and scale in order to provide leadership. The organization's budget, while still relatively small, has quadrupled in the last four years and now stands at almost \$7 million annually. Staff and programming have grown in a commensurate fashion. SAGE's national affiliate network has more than tripled in size from six local affiliates to 21 across 15 states plus Washington, DC, while the organization has simultaneously built new strategic partnerships with key industry leaders. In turn, SAGE's influence and reach in the aging field has grown dramatically in recent years. Last year, we opened a federal policy office in Washington, DC. The organization's growing stream of policy reports and briefing papers—offering LGBT aging perspectives on issues ranging from reauthorization of the Older Americans Act to Social Security, Medicaid, and Medicare—has broken new ground and captured considerable attention. Moreover, the organization has helped catalyze a new interest in aging issues among LGBT thought leaders and funders, which in turn is translating into greater attention to aging issues by national and local LGBT organizations. For example, after the Department of Health & Human Services (HHS) announced the establishment of the country's first National Resource Center on LGBT Aging, prominent LGBT funders stepped forward with significant investments to ensure that the Resource Center had the wherewithal to fulfill its mission of providing training and education to community providers and LGBT older people across the country.

The Obama administration's decision to establish the National Resource Center is emblematic of the progress on LGBT aging issues in recent years. Other critically important breakthroughs include a recent decision by the federal Centers for Medicare & Medicaid Services that states have the legal authority to provide same-sex couples in need of Medicaid coverage for long-term care with spousal impoverishment protections similar to those that have been afforded to married heterosexual couples; the incorporation of LGBT and elder-inclusive language in the National Prevention Strategy mandated by the Affordable Care Act; and the Leadership Council of Aging Organizations' (LCAO) decision to include a

series of LGBT-inclusive provisions in its consensus document on reauthorization of the Older Americans Act. The ability of SAGE to exert effective leadership in cooperation with key partners has been critical to these advances. At the same time, the incremental nature of the advances highlights the great deal of work that remains to be done to ensure that public policy on aging adequately protects the financial and health security of LGBT older people.

### Change Requires New Resource Allocations

SAGE's emergence as a national leader able to affect policy change itself represents big change for the LGBT aging field. And this change has required a notable allocation of new resources. The primary engine has been institutional philanthropy. Nearly half of SAGE's annual budget comes from private foundations. Both LGBT and aging funders—neither of whom historically invested much in LGBT aging work—have stepped up to the plate and provide SAGE with meaningful funding to build the organization's capacity and support its leadership. Government too has played a role, perhaps most notably with the Administration on Aging's 2010 decision to award SAGE the multi-year grant to establish the National Resource Center on LGBT Aging. Thankfully, this support for SAGE has not been accomplished via reallocation of resources away from other LGBT aging organizations and programs. Unfortunately, however, the scale of those efforts always has been small and the resources allocated to support them have been extremely limited.

The shift in resource allocation that has built SAGE as a national leader is reflective of what also must happen in the public policy arena in order to advance the interests of LGBT older people through systems change. To paraphrase an adage, the line between policy and budget is a thin one. Much of aging policy comes down to how resources are allocated across different program interventions and populations. The current raging debate about government spending and deficits is itself framed by many as a struggle over what level of resources to allocate to entitlement programs that provide the safety net, such as it is, for older Americans. Even policy reforms that on their face are not linked to resource questions (e.g., state legislation requiring aging providers to be trained and report on LGBT cultural competency) often end up rising or falling based on whether there are resources for implementation. This reality creates especially difficult challenges in a time of shrinking resources in the public sector.

Indeed, in today's lean times, public policy shifts often require creative thinking and leadership if they are to be resourced for success. When establishment of the National Resource Center on LGBT Aging was announced by HHS, it reflected the Obama administration's policy that LGBT elders had unique needs and the federal government had a role to play in helping to meet those needs. However, the federal funds allocated for the new initiative were not of a sufficient scale to achieve the National Resource Center's policy goals. In response, SAGE, as the National Resource Center sponsor, reached out to private funders to match the federal government's resource allocation and effectively leverage the policy shift during the first three years of the Center's existence. While likely time-bound, this coupling of public and private resources nonetheless helps to explain the marked impact the National Resource Center has had in its first 18 months.

### **Achieving New Resource Allocation is Hard Work**

SAGE's experiences advocating on behalf of LGBT older people have taught us just how difficult it is to achieve new resource allocations. Our efforts to create an LGBT senior center within New York City's vaunted senior center system illustrate the point powerfully. For many years, a mainstay of SAGE's LGBT aging advocacy agenda has been the argument that aging policies and programs have systematically ignored the needs of LGBT elders, and that this problem must be rectified by, among other things, allocating government funding to support targeted LGBT aging programs. In New York City, this has translated into SAGE's long-standing call for the city to fund an LGBT senior center among its network of more than 250 senior centers. Historically, that plea has faltered on the city's requirement that senior centers must seek to serve every senior in a given neighborhood as opposed to a specific sub-population of seniors across the city.

In 2008, SAGE saw an opportunity for progress when New York City's Department for the Aging (DFTA) announced plans to reshape the city's senior center system. The DFTA initiative envisioned the creation of a number of larger hub senior centers, with the possibility that one or more of those hubs might be for special populations like LGBT elders. Although the initiative envisioned the creation of new centers, there was no indication of new funding. In fact, new funding seemed unlikely since by this time the economy was already tightening. Thus, while never formally acknowledged, DFTA's unspoken premise seemed to be that existing

centers would be closed to make way for the new centers.

SAGE and several other special-population aging organizations advocated in favor of the DFTA initiative to the extent that it offered the opportunity to redress an historically inequitable distribution of resources that effectively sidelined providers for marginalized elder communities. But the DFTA plan predictably set off a firestorm of protests among existing centers, which feared that they would face closure if the initiative moved forward. As a result, SAGE and a handful of other special-population aging organizations found themselves pitted against the city's powerful senior center network in a battle over reallocation of finite resources. Not surprisingly, the senior center network was extremely effective at exerting political pressure to kill DFTA's initiative, thus preserving the status quo resource allocation and leaving SAGE and its allies arguably even more marginalized than they had been at the start.

Three years later, New York City is finally making good on its effort to strengthen its aging services network with an Innovative Senior Center Initiative. The Initiative will be implemented in January 2012, and will include city funding for two special-population senior centers—one for LGBT older people and another for blind and vision impaired elders. The contrasting results can be explained by at least two important factors that distinguish the 2008 and 2011 drives. The first is leadership: SAGE and its partners were able to provide much more capable leadership in 2011 compared to 2008 by refusing to be pitted against the larger aging network and instead working cooperatively with the network. We were aided by the arrival of a new city Aging Commissioner, whose deft hand furnished the second distinguishing factor: in 2011 the city offered to put more resources on the table for its initiative rather than implicitly threatening to remove resources from the existing network. While some advocates for the current network still argued that the new resources should go to existing programs (which have been subjected to numerous cost-cutting measures in recent years), the specter of an inexorably shrinking pie was somewhat alleviated. The bottom line: new resource allocation is hard work, but when strong leadership and deft strategy are pined, progress can be achieved. To be sure, the New York City breakthrough does not resolve funding challenges for LGBT elder services there; critically important programs of SAGE and our partners remain unfunded. But there is no question that real progress has been made.

## The Limits to Progress

While there have been notable policy advances on behalf of LGBT older people in recent years, there are limits to that progress. Some of those limits relate to which players are positioned to have a real federal policy impact. Especially in lean times, it will likely be primarily the larger and stronger institutions that are able to deploy enough scale and heft to secure new resource allocations to advance their agendas. This is true whether the resource shift is funding, seats at key policy tables, or pure policy change. The point should not be overstated. Small organizations with deep policy expertise and a well-honed sense of strategy can have important policy impacts at the federal level. This is even more so the case at the state and local levels, where policy change efforts are often more effectively led by local advocates. Moreover, it is critically important that larger institutions work strategically and effectively with smaller organizations for any number of reasons, including the need to harness particularized expertise and the importance of reach into and credibility with diverse communities. But scale matters when it comes to having an impact on federal policy. This creates challenges in the LGBT aging field, where only a handful of small organizations work specifically and exclusively with and/or on behalf of LGBT elders of color, transgender elders, and elder lesbians. These small organizations out of necessity tend to have outsized missions. Limited scale and resources mean that their particularized voices and policy perspectives frequently are not brought to the fore in an impactful manner. A relatively larger organization can lack reliable partners to complement its work strategically. In the LGBT aging context, the problem is further exacerbated by the fact that SAGE, while much larger than its sister LGBT aging organizations, remains small relative to the broader national aging field and is itself spread thin.

The still limited scale of the LGBT aging field's lead organization produces yet another challenge. Policy change is often facilitated by shaping the environment in which policy is made—the way media, intelligentsia, and other thought leaders perceive and think about a given issue. Unfortunately, the capacity of SAGE and the broader LGBT aging field to re-shape the policy environment is quite limited. High-impact campaigns deploying social media strategies and other large-scale education efforts are typically beyond the reach of SAGE and the LGBT aging field as a whole. This tends to steer LGBT aging policy advocacy in the direction of extremely

important but nonetheless “surgical” approaches at the federal-agency level rather than more broad-reaching efforts that might require Congressional action and would undoubtedly require a much greater level of capacity. Some important policy problems (e.g., certain inequities in Medicaid) are susceptible to fixing via this route, while others (e.g., the exclusion of LGBT older people as a listed minority elder population in the Older Americans Act) most likely require legislative fixes that are harder to achieve without environmental reform that strengthens the attraction to LGBT-friendly aging policies by increasing awareness and understanding of LGBT aging issues.

The breadth of LGBT elder interests, especially when juxtaposed to the resources available to the LGBT aging field, poses still another challenge. For example, LGBT older people have a particularly strong stake in the debate currently raging about government spending and entitlement programs given their higher rates of poverty and presumed heavy reliance on Social Security, Medicaid, and Medicare in their later years. But SAGE's ability to impact the entitlements debate directly is extremely limited. To date, organizations like AARP that have real heft in those meta-debates have yet to prioritize the stakes of LGBT older people in their work on entitlement programs. The drive for expanded community-based care is another good example. Since the general lack of cultural competency on the part of institutional care providers means that LGBT elders face special challenges in assisted living and nursing settings, they have a particularly strong interest in the expansion of community-based care options. Unfortunately, SAGE has not had the resources to play an instrumental role on that issue.

SAGE has compensated for the limits on its own influence by playing a lead role in the creation of the national Diverse Elder Coalition (DEC), a path-breaking collaborative that brings together SAGE and six national people-of-color organizations that focus exclusively or heavily on aging issues. There are early indications that DEC, which is weighing in on the entitlements debate, is gaining traction and that this type of collaboration can make a significant difference. But the DEC itself is limited by the capacity of its members and the Coalition's scant resources.

## Conclusion

This article has argued that policy change is much more likely to occur when it is pushed by leadership backed by institutional capacity, that the resource



allocation necessary for such change is especially difficult during lean times, and that policy progress during such times nonetheless can be achieved through a mix of deft leadership and creative advocacy. Advances by LGBT aging advocates in recent years illustrate these points. At the same time, the experience of LGBT aging advocates also highlights some of the likely limits to progress during difficult times, as forward movement is shaped and restricted by *who* has the capacity to engage in the advocacy process, *what issues* stronger and larger institutions are effective at advancing, and in a still underdeveloped space like the LGBT aging field, *what remains* beyond the reach of even the field's strongest leaders.

Given that LGBT aging advocacy sits at the intersection of two of the country's most profound trends—the rapid aging and diversifying of the nation's populace—continued policy progress on the issues of concern to LGBT older people is critically important. The aspirations of LGBT older people for

financial and health security are closely linked to similar claims for equity and support among other diverse elder populations. Together, these diverse elder communities comprise the future majority of this graying nation's population. The most rancorous policy debates of the moment—which include aggressive efforts to restructure the historic safety net constructed by entitlements like Social Security, Medicaid, and Medicare—may have a potentially profound impact on our society's commitment to provide long-term care and support for our older generations just as they are increasingly comprised of diverse elder communities. Strong leadership, new resource allocations, and creative advocacy and policymaking to safeguard the interests of LGBT older people and all diverse elder communities have never been more important.

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# How Health Care Reform Will Help LGBT Elders

Kellan Baker • Jeff Krehely

## Introduction

Older lesbian, gay, bisexual, and transgender (LGBT) Americans make up a significant and growing share of the LGBT and over 65 populations. Today LGBT elders are gaining visibility with the aging of LGBT baby boomers, who are the first generation of LGBT people to have lived openly gay<sup>1</sup> or transgender lives in large numbers.

These individuals confront the same challenges as all people who age. But they also face at least three unique barriers and inequalities that impact their financial security, good health and access to health care, and positive engagement with their communities (Movement Advancement Project & Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders, 2010).

The first barrier is the effects of social stigma and prejudice, past and present. Historical prejudice against many LGBT elders negatively impacts their connections to their families of origin, their chances of having and raising their own children, and their opportunities to earn a living and save for retirement. This prejudice impedes equal access to health and community services, programs, and opportunities that are critical for their well-being.

The second barrier is reliance on informal “families of choice” for social connections, care, and support. Family members provide about 80 percent of long-term care in the United States, and more than two-thirds of adults who receive long-term care at home depend on family members as their only source of help (Family Caregiver Alliance, 2001). Because LGBT elders are more likely than their non-LGBT counterparts to be single, childless, and estranged from biological family members, they must often rely on friends and other community members as their chosen family (de Vries, 2008). However, government policies, laws, and institutional policies generally prioritize legal and biological family members, and often deny other caregivers the support afforded to opposite-sex spouses and biological family members.

The third barrier is that many laws and programs fail to address—or create extra barriers to—social acceptance, financial security, and better health and well-being for LGBT elders. Safety-net programs and laws intended to support and protect older Americans often fail to provide equal protection for gay and transgender elders. This is largely because these laws and programs

either do not acknowledge or do not provide protections for LGBT elders’ partners and families of choice. They also often fail to address the ongoing stigma and discrimination that result in substandard treatment of LGBT elders.

This article explains how the Affordable Care Act (ACA), which is the health care reform law that Congress passed and President Obama signed into law in March 2010, can help mitigate the health-related problems that the three barriers create. Before the analysis of the ACA, we first present a brief discussion of the health-specific challenges that gay and transgender elders face.

## Health Challenges for LGBT Elders (Krehely & Adams, 2010)

**Inability to access affordable and comprehensive insurance coverage.** LGBT people have lower rates of health insurance coverage than the general population, which is a result of higher costs and outright exclusions from insurance plans. Looking at costs, for example, when employers offer health insurance to the same-sex partner of an employee or retired employee, federal law treats the value of the partner’s insurance as taxable income, and the LGBT retiree must pay income taxes on this benefit. Employers must also pay payroll taxes on the cash value of employee domestic partner benefits. By contrast, married heterosexual couples can receive these benefits tax-free (and employers do not have to pay payroll taxes on them). Taxation of health benefits costs the average employee with same-sex domestic partner benefits \$1,069 more per year in taxes than a married heterosexual employee with the same coverage, while employers pay \$57 million in additional payroll taxes (Badgett, 2007).

Because of this inequity—and the fact that LGBT people are generally less financially secure than others—many LGBT older adults simply are not offered, or cannot afford to receive, these benefits.

In terms of exclusion from plans, transgender elders are particularly disadvantaged in access to both public (i.e., Medicare) and private health insurance coverage. Medicare and most private policies carry specific exclusions for transition-related care, which are sometimes interpreted in practice to deny coverage to transgender people for even basic medical care. In the case of Medicare, the federal Centers for Medicare and Medicaid Services (CMS) have clarified that Medicare covers hormone replacement therapy and routine preventive care such as prostate screenings, mammograms, and pelvic exams, regardless of the gender marker in the individual's Social Security record. However, few providers and transgender patients are aware of these rules or of the existence of a special billing code (condition code 45) developed by CMS to avoid automatic denials of coverage in cases involving apparent gender discrepancies.

Moreover, Medicare specifically excludes coverage for sex reassignment surgery. This exclusion, which is based on a decades-old policy that inaccurately categorizes such services as experimental and cosmetic, certainly hinders access to medically necessary care for transgender elders. But it also encourages private insurers, state Medicaid plans, and the veterans' health care system to continue to allow similar exclusions that target care for transgender people (National Center for Transgender Equality, 2011).

### **Lack of culturally competent health care services.**

Lack of LGBT cultural competency in the health care system means that gay and transgender elders are more likely to delay getting necessary care and prescriptions than their heterosexual and non-transgender peers. They are also more likely to resort to visiting emergency rooms for care, often due to fear of discrimination by doctors and facilities that provide preventive and non-emergency care. Further, transgender people who are visibly gender non-conforming face particular barriers in access to health services, since they cannot choose to disclose their transgender status selectively depending on the attitude of their health care providers.

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 and pharmacists to hospital and nursing home staff—might be openly hostile towards LGBT elders, untrained to work with them, or unaware that gay and transgender older adults even exist.

Transgender people in particular have grounds to 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 prospect of needing intimate personal assistance from paid aides or, even worse, needing to reside in a nursing home." (Cook-Daniels, 2007, p.13)

Prejudice and hostile treatment from staff, fellow patients, and other patients' families can create extremely unwelcoming environments for LGBT elders. In response, they might withdraw or be excluded from social activities, compounding 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 elders, staff members might refuse to place them in a gender-segregated ward that matches their gender identity, refuse to use appropriate names and pronouns or to provide appropriate clothing, or even perpetrate harassment or violence against the transgender patients in their care. These issues become even more severe when patients are mentally or physically incapacitated and unable to advocate for themselves.

**Health disparities.** Governments and service providers rarely track and, as a result, are largely unaware of the health disparities that many LGBT older adults experience. However, the limited available data suggest that later life carries unique health challenges for LGBT persons in areas that include HIV/AIDS, mental health, and chronic health conditions.

**HIV/AIDS.** HIV diagnoses among those over age 50 are on the rise, and the proportion of people living with AIDS in that age group is now more than double that of people under age 24. Yet there are almost no HIV prevention programs targeted at older adults, and health care providers do not generally talk to their older patients about HIV/AIDS risks. Additionally, older adults might suffer from the long-term effects of drug treatment for HIV/AIDS, such as increased and earlier chances of cognitive decline and increased risk of developing chronic conditions such as kidney failure, severe depression, cancer, and osteoporosis.

**Mental health.** Research shows that gay and transgender people experience high rates of stress, much of which is related to coping with a lifetime of stigma and systematic discrimination. Numerous studies have shown

that the LGBT population experiences higher rates of smoking, alcohol use, drug use, suicide, and depression, and these disparities are exacerbated for LGBT older adults (Cochran & Mays, 2007).

**Chronic health conditions.** Studies indicate higher levels of chronic health problems among LGBT older adults, including asthma, diabetes, HIV/AIDS, obesity, rheumatoid arthritis, and various forms of cancer (Adelman, Gurevitch, de Vries, & Blando, 2006; Barker, 2004; Barker, Herdt, & de Vries, 2006). Gay and transgender people are also less likely than their heterosexual and non-transgender counterparts to receive appropriate screening and preventive care for conditions such as heart disease, cancer, HIV, and depression. Often left undiagnosed and untreated until too late, these chronic conditions cause significant excess morbidity and mortality among LGBT elders.

Another area of concern for transgender elders is the lack of research on the long-term effects of hormone use, as well as on the effects of potential interactions between exogenous hormones and other medications, including HIV medications.

### Health Care Reform's Impact on LGBT Elders

The Affordable Care Act is the most significant and far-reaching reform of America's health system since the creation of Medicare and Medicaid in the 1960s. In particular, the law envisions a much-needed overhaul of the health insurance system through the introduction of new protections and options for consumers in the private health insurance market. The law also expands access to more comprehensive benefits and services that focus on improving our nation's health and lowering health care costs by investing in keeping people healthy in the first place.

The vast range of the ACA's reforms brings much promise for LGBT Americans. Thanks to the ACA, many gay and transgender Americans who were never able to afford health insurance or health care soon will be able to apply for Medicaid or affordable private coverage in every state. They will not be subject to denials of insurance coverage on the basis of pre-existing conditions or to arbitrary rescission of vital coverage when they become ill. The ACA is also key to efforts such as expanding cultural competency in the health care workforce to include LGBT issues, improving data collection to better identify and address health disparities, and recognizing the increasing diversity of America's families. The law also includes numerous other provisions that will specifically help seniors, including LGBT elders (Baker & Krehely, 2011).

### ACA's Impact on Elders

#### **Reduce prescription drug costs in Medicare Part D.**

In 2010, more than 3.5 million seniors who fell into the Medicare donut hole (the gap in coverage for those whose annual drug costs are between \$2,800 and \$4,550) received one-time \$250 rebates. As of January 1, 2011, they are receiving a 50 percent discount on brand-name medications and increased savings on generic drugs, and the law eliminates the donut hole by 2020. Under the ACA, the average senior who hits the donut hole will save an estimated \$700 per year. These provisions provide significant financial relief for LGBT seniors with chronic conditions that require expensive medications, including HIV and AIDS. In addition, costs for medication purchased through the state-based AIDS Drug Assistance Programs (ADAPs) now help low-income elders reach the other side of the donut hole.

**Provide a free annual wellness visit for all Medicare beneficiaries.** As of January 1, 2011, all Medicare beneficiaries are eligible for a free annual check-up with the provider of their choice.

**Provide free Medicare coverage of vital preventive services.** Starting on January 1, 2011, Medicare covers a wide range of preventive screenings and services at no cost. Depending on age and sex, these benefits may include various vaccinations and screenings for conditions such as type 2 diabetes, colorectal cancer, depression, HIV, breast cancer, and osteoporosis.

**Encourage better care coordination.** More than 60 percent of older Americans have at least one chronic condition and are likely to see multiple doctors in order to receive the care that they need. The ACA provides incentives to providers to develop new models of coordinated care to facilitate communication regarding patient history and follow-up, eliminate duplicate tests, reduce hospital readmissions, and improve overall quality of care and patient outcomes.

**Expand coverage for seniors under age 65.** Almost nine million adults ages 50-to-64 currently do not have health insurance coverage. The ACA expands Medicaid eligibility to all adults with incomes under 133 percent of the federal poverty line (FPL; 133 percent of FPL is approximately \$14,000 per year for an individual and \$29,000 for a family of four). For uninsured Americans with incomes between 133 and 400 percent of FPL (up to \$43,000 for an individual and \$88,000 for a family of four), the ACA provides premium subsidies to purchase coverage through the new state-based Health Insurance Exchanges, which will become operational in 2014. Plans offered through the Exchanges will have to provide coverage for a set of essential benefits, and they will not



be allowed to impose any lifetime spending caps for these services. These benefits include ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

**Protect patient rights and lower costs in the private health insurance market.** Under the ACA, insurers may not deny coverage to anyone on the basis of pre-existing conditions (starting in 2014). Insurers also may not terminate coverage unless in case of fraud, and annual and lifetime caps are prohibited. The ACA introduces restrictions on insurance rating on the basis of health or age; starting in 2014, insurers may not vary premiums by any more than 3:1 on the basis of age.

**Provide new options for long-term care.** Long-term care is paid for by Medicaid rather than Medicare, and most of these resources are focused on nursing homes and other long-term care facilities. This makes it difficult for seniors requiring daily assistance to afford to stay in their homes. The ACA makes it easier for lower-income dual eligibles (people who are eligible for both Medicare and Medicaid) to receive services at home by providing extra funds to states that provide in-home services through Medicaid. The law also increases protections through 2015 for spouses of people receiving Medicaid home care services so that they do not have to spend down their assets in order for an ill spouse to qualify for Medicaid home care. The Obama administration recently issued guidance to state Medicaid directors notifying them that they may treat same-sex partners the same as heterosexual spouses for purposes of Medicaid spousal impoverishment protections.

**Implement the Elder Justice Act.** Millions of elders are emotionally or physically abused or financially exploited by caregivers every year, and the vast majority of cases go unreported. The ACA incorporates the Elder Justice Act, which creates two new national councils on preventing elder abuse, supports the development of long-term care ombudsman programs, provides new financing for state-based Adult Protective Services programs, and dedicates new resources for combating criminal abuse in long-term care facilities.

### Conclusion

Issues affecting LGBT elders are receiving increased attention in numerous public policy forums in addition to the ACA. *Healthy People 2020*, the federal blueprint for a healthier nation between 2010 and 2020, emphasizes the

importance of specific health services and programs for gay and transgender seniors (U.S. Department of Health and Human Services, 2011). The March 2011 report from the Institute of Medicine, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, calls for new research into LGBT health needs across the life course, with a particular focus on the dearth of studies of the specific issues facing LGBT elders (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2011).

Our country is on the cusp of a boom in the number of gay and transgender older adults. These elders live in all corners of the U.S. and many of their needs are the same as those of any other group of seniors: the ability to age with dignity in their communities, access to coverage and services responsive to their particular health needs, financial security, and protection from abuse and neglect. The ACA provides an important framework to help our nation begin to better serve and care for our elder gay and transgender parents, friends, and neighbors.

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### Endnote

1. For variety and simplicity, we sometimes use the word “gay” as an umbrella term for gay, lesbian, and bisexual.

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# Safe Spaces? The Need for LGBT Cultural Competency in Aging Services

*Hilary Meyer*

"AoA frequently turns to national organizations to support the Aging Network in their efforts to work with specific minority populations that are traditionally underserved....We now recognize that [lesbian, gay, bisexual and transgender] LGBT older adults also represent a community with unique needs that must be addressed." Assistant Secretary of the U.S. Department of Health and Human Services Kathy Greenlee, February 10, 2010

It is no secret that even under the best conditions, the aging process can be challenging. Those challenges become exponentially more difficult as other inequities are piled on. Lesbian, gay, bisexual, and transgender (LGBT) older adults have faced years of such inequities, leaving them with significantly more to overcome than their heterosexual peers. At the baseline, LGBT older adults have lived through decades of their lives when they faced being arrested and/or institutionalized just for being a known homosexual. Staying in the closet was rarely a choice—it was a necessity for survival.

Sexual orientation and gender identity are also only two pieces of any given person's identity. Many LGBT people are also coping with inequities related to race, ethnicity, and socio-economic status and the lack of supports that are available that account for these cross-identities.

Enduring so much social stigma, bias, prejudice, and legally-condoned discrimination for so many years has affected the LGBT older adult populations in numerous and documented ways. For example, lesbian, gay, and bisexual older adults are more likely than their heterosexual peers to have experienced psychological distress in the past year, more likely to need medication for mental health issues, and more likely to have problems with alcohol abuse. A National Institutes of Health (NIH)-funded study released this year reported that nearly half of LGBT older adults have a disability (Fredericksen-Goldsen, Kim, & Goldsen, 2011).

Beyond the health disparities themselves, LGBT older adults are more likely than their heterosexual peers to delay or not seek medical care until they are forced to go to an emergency room. The fear and mistrust of health care providers that keeps LGBT people from seeking care until it is of dire necessity is for good reason; several recent studies evidence that LGBT individuals are victims

of harassment, hostility, and neglect by caregivers and health care facilities in startling numbers. As researchers began publishing information highlighting these unique needs and issues, it became clear that a national intervention was necessary.

## **The National Resource Center on LGBT Aging's Inception**

For years, the Older Americans Act has directed the aging network to pay particular attention to serving populations with greatest social need. With that, the U.S. Administration on Aging (AoA) has a history of funding national organizations to serve as technical assistance resource centers for specific minority populations including Hispanic Americans, African Americans, Asian Americans, and Native Americans. By and large, these resource centers were created to address the health disparities of marginalized groups by using innovative approaches designed to increase access to health care and improve self-care management techniques.

Guided by that directive and with the disconcerting evidence that has surfaced in recent years evidencing LGBT older adults' health disparities, AoA took action. In 2010—for the first time in United States history—AoA publicly recognized that older LGBT individuals have unique needs that must be addressed. This recognition came in the form of a three-year grant to SAGE (Services and Advocacy for GLBT Elders) to create the National Resource Center for LGBT Aging. As HHS Secretary Kathleen Sebelius stated, "The Resource Center will provide information, assistance and resources for both mainstream aging organizations and LGBT organizations and will provide assistance to LGBT individuals as they plan for future long-term care needs" (Services and Advocacy for GLBT Elders, 2010). With the federal government's imprimatur, the vision statement was

developed: older lesbian, gay, bisexual, and transgender individuals in the United States feel welcome and supported in their communities, urban and rural, by both mainstream and LGBT organizations and have access to culturally appropriate supports and services to assist them in their efforts to live as independently as possible in the setting of their choice.

The three objectives of the National Resource Center are as simple in design as they are complex in practice. The objectives are to:

1. Educate aging network services organizations about the existence and special needs of LGBT older adults.
2. Sensitize LGBT organizations to the existence and special needs of older adults.
3. Educate LGBT individuals about the importance of planning ahead for future long-term care needs.

In order to accomplish these objectives, a partner-based model was implemented such that under SAGE's lead, 10 national partners contribute in various ways to the Center's work. These partners are the American Society on Aging, Hunter College, CenterLink, FORGE Transgender Aging Network, GRIOT Circle, The LGBT Aging Project, National Association of Area Agencies on Aging, National Council on Aging's National Institute of Senior Centers, Openhouse, and PHI. The cumulative effect of having 10 partner organizations on board is information dissemination to thousands of professionals and LGBT older adults themselves across the country. In fact, statistics show that the National Resource Center's website ([lgbtagingcenter.org](http://lgbtagingcenter.org)), which hosts hundreds of articles, publications, and videos addressing LGBT aging issues, is being accessed by people in over 150 countries across the world. To that end, having the government's backing and partnering with well-established organizations has moved LGBT aging issues into the public discourse where it never was before.

### Moving From Dialogue to Action: Cultural Competency

While promoting visibility and general awareness to the issues is a key component, enhancing the quality of service provisions so that LGBT older adults can safely access and receive culturally competent care is, in some cases, a matter of life or death. With that, the National Resource Center is tasked with training aging services providers across the country. A recent nationwide study of area agencies on aging found that agencies whose staff had received some form of LGBT training were twice as likely to receive a request to help an LGB individual and

three times as likely to be requested to help a transgender older adult (Knochel, Croghan, Moone, & Quam, 2010).

These statistics provide further evidence that the National Resource Center's mission to create a national cultural competency training initiative could substantially improve the lives of many LGBT older adults.

To do so, there first needed to be a working definition of cultural competency. In a provider setting, the National Resource Center considers an organization to be culturally competent when the staff, using the systems within the organization, are able to identify and address the needs of a particular group within the larger pool of all constituents. In this case, the cultural group is LGBT older adults. Recognizing that there is an ongoing dialectic debate about proper terminology, the National Resource Center sees competency as having three dimensions. These include: cultural awareness (being knowledgeable about what LGBT older adults typically experience when accessing—or thinking about accessing—services), cultural humility (no matter how much we learn about or become aware of a culture, each individual is the expert on their own experience), and cultural responsiveness (learning new patterns of behavior and effectively applying them individually and within the organization's setting). With those definitions in mind, there are some important areas in which service providers can make concrete changes to contribute to LGBT older adults' safety and feelings of inclusion.

To that end, the National Resource Center brought together six of the partner organizations whose expertise includes training providers on LGBT aging: SAGE, CenterLink, Openhouse, LGBT Aging Project, Transgender Aging Network, and GRIOT Circle. Over the course of a year, the lead curriculum development organization, PHI, wrote, edited and tested the most comprehensive and collaboratively created curricula on LGBT aging cultural competency to date. To continuously evaluate the efficacy of the training's ability to shift knowledge, skills, and attitude, Hunter College joined the effort as the evaluation partner. With these curricula in hand (one set to train aging services providers and the other to train LGBT organizations), the National Resource Center's trainers are available across the country to bring the trainings to any organization that requests them.

The key learning objectives in the curricula include:

1. Learning about the culture, needs, and concerns of LGBT older adults.
2. Considering why LGBT older adults are least likely to access health care, social services, and LGBT organization services.



3. Identifying best practices for helping LGBT older adults to feel more included within aging network and LGBT organizations.

After an organization's staff has completed a National Resource Center training, they are then equipped with the knowledge of how to begin to create (or enhance) an LGBT-inclusive environment. An organization aspiring to cultural competency would be one where, amongst other signs of inclusivity:

- the staff are knowledgeable and sensitive to the reasons why LGBT older adults are far less likely than their non-LGBT counterparts to access health and human services—and the subsequent health disparities that causes;
- intake forms, intake interview guidelines, and marketing materials create a culture of respect for diversity, including acknowledging the spectra of race, ethnicity, sexual orientation, and gender identity;
- policies and procedures related to addressing biased behavior and language are posted in a publicly accessible place and staff are trained and comfortable in implementing them;
- programming and services offered not only include LGBT perspectives but also honor LGBT people's lives and contributions; and
- board and executive leadership reflect the diversity and inclusion of LGBT older people by race, sex/gender, and socio-economic status.

Of course cultural competency training in general, even one as comprehensive as the National Resource Center's, has limitations. For example, even with a completely trained staff, the other residents or peers that access the organization's services could well present significant challenges. That is why a key to the trainings is a module dedicated entirely to giving feedback and addressing bias. When providers are trained in what to say, how to say it, and are prepared with the understanding of the need to address these situations, resident-to-resident bias can be curbed dramatically.

Additionally, with staff turnover, there is no way for every person on staff to be trained at any given time. To address this, the National Resource Center trainers emphasize that these competency shifts must permeate throughout the organizational culture such that respecting and including LGBT people is not seen as "another thing that we have to do" but rather it is "just the way things are done around here." That said, due to a trickle-down effect, the more trainings that are scheduled and executed each year, the higher the number of

providers who are trained on how to implement systems of culturally competent service there are within aging services organizations. With this shift, the goal is that the health disparities identified in the beginning of this article should begin to narrow.

### State Policy Answers

Taking into account these evidenced health disparities and the knowledge that legislative efforts can be an important first step at addressing them, some state legislatures have already passed key bills to affect change. California led the charge in 2006 when they introduced the Older Californians Equality and Protection Act, which required the state's department of aging to include LGBT older adults' needs in technical assistance, programs and services, and any needs assessment measurements. New York State followed suit with a near identical bill that was signed into law on September 23, 2011.

California pushed the legislative effort even further in 2008 with SB 1729—a law that requires that health care staff in senior care settings be trained on preventing and eliminating discrimination based on sexual orientation and gender identity.

These laws are a vital step in beginning the process of ensuring that LGBT older adults find safe and welcoming environments within the aging care networks. The hurdle, though, is that these measures did not come with any funding attached, and without that funding, state agencies already strapped for cash are struggling to find ways to implement these laudable requirements.

If each and every state across the country passed such legislation as SB1729 and were able to find resources to make the implementation feasible, not only would LGBT older adults receive better care, but the country could end up saving money. Consider the evidence that LGBT older adults are less likely than their non-LGBT peers to access preventive health services and therefore end up relying more heavily on emergency room care—a system that is more costly and less effective than if the proper preventive measures were taken.

Certainly this cost-benefit analysis of preventive versus crisis care is not new. The relevance of that debate in this context, though, is that if service providers were able to provide culturally competent care to LGBT people, those older adults would be more likely to access providers before a crisis arose. With funding resources stretched as thinly as they are, there is no denying that providing a cost-effective solution to helping a large, and growing, segment of the older adult population makes good business sense.

### Finding Permanent Solutions

Establishing the National Resource Center on LGBT Aging was an integral first step in this process and has shown initial signs of success. There must be continued investment in this work, however, to be able to continue to implement the necessary systemic changes. As the Older Americans Act is up for reauthorization, the Leadership Council of Aging Organizations recently released a consensus document that integrated eight recommendations specific to LGBT elders and elders of color—including the need to promote cultural competence among service providers. Diverse coalitions of organizations have come together to recognize needs and make policy recommendations on how to promote change. We must continue to support these necessary actions; the lives of our elders depend on it.

*Hilary Meyer, JD, is the director of the National Resource Center on LGBT Aging, a project of SAGE (Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders).*

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# Bridging the Service Gap: LGBT Older Adults, Public-Private Partnerships and Program Innovation

*Lilliam Barrios-Paoli • Catherine Thurston*

In today's tough economic climate, city agencies are increasingly subject to challenging cuts meant to close gaps in city budgets. In New York City, as in elsewhere, these cost-cutting measures have eroded vital safety net programs, such as services and supports for older adults. Yet, in keeping with the graying of America, the population of New Yorkers age 60 and over is growing, and their needs are increasingly diverse.

## **A Demographic Snapshot**

Today, more than 1.3 million New Yorkers, or 16 percent of the city's residents, are age 60 or over. By 2030, this age group is projected to increase to 1.8 million, outnumbering school-age children for the first time in the city's history (U.S. Census Bureau, 2008). These older adults speak 170 different languages, and 44 percent were born in another country. A conservative estimate concludes that 32 percent of older adults in New York City are of low income and many deal with chronic health conditions (New York City Center for Economic Opportunity, 2008).

Lesbian, gay, bisexual, and transgender (LGBT) older adults reflect the diversity of the general population, yet also have unique needs that are not often met by traditional aging services. Compared to their heterosexual peers, LGBT older adults in New York City are: twice as likely to live alone, half as likely to have significant others, half as likely to have close relatives to call for help, and more than four times more likely to have no children (Cantor, Brennan, & Shippy, 2004).

In addition to such social isolation, LGBT older adults face a host of other challenges such as lack of culturally competent healthcare, heightened vulnerability to poverty, and unequal treatment under laws designed to protect older adults (Movement Advancement Project & Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders, 2010). This can lead to depression, delayed care-seeking, poor nutrition, and premature mortality. However, despite a greater need for supportive social services, LGBT elders often do not access such services out of fear of harassment or hostility.

## **A New Model for Older Adult Services**

Since the founding of the nation's first senior center in 1943 in the Bronx, senior centers in New York have evolved into a network that includes more than 250 centers offering a range of programs. However, this network is used by only two percent of the city's older adult population (Barbaro, 2008). Today's older adults may be unaware of what the centers offer, or may have different needs and expectations than those that shaped the current system.

With the city facing budget cuts and an underutilized network, the Council of Senior Centers and Services (CSCS) approached the New York City Department for the Aging (DFTA) with the idea to develop, in partnership with community organizations, new ways to meet the needs of the city's diverse population. DFTA engaged in an extensive consultative process throughout 2009 and 2010 with advocacy groups, service providers, city agencies, philanthropists, researchers, and older adults. DFTA was interested in designing a program and social service model that would be constituent driven. Together with Bobbie Sackman, director of public policy at CSCS, it looked to organizations such as Services & Advocacy for GLBT Elders (SAGE) that had already developed this model. Based on these consultations, DFTA worked with CSCS to create a model for senior centers to serve older New Yorkers more efficiently and effectively: the Innovative Senior Center (ISC; New York City Department for the Aging, 2010).

DFTA announced plans to fund eight ISCs in geographic areas found to have a high ratio of need to the availability of senior center resources, and up to two centers for special populations, including the

Continued ►

LGBT community. A streamlined procurement process—the first of its kind in city government—was used to select the organizations to provide the ISCs. This process included prequalification to identify suitable candidates and a narrative proposal from the prequalified organizations.

Each proposer for an ISC was required to offer certain core services, including nutritional support, help accessing public services and benefits, links to community resources, comprehensive and preventive health promotions, and opportunities for social engagement. Proposers were also encouraged to be creative in thinking about program delivery—through web-based services, for example, or collaborating with community partners to reach greater numbers of older adults.

### An Historic Center

In October 2011, DFTA announced that SAGE would provide the ISC for the LGBT community. The SAGE Center, slated to open in January 2012, will be the city's—and the country's—first LGBT senior center. Drawing on its 32 years of experience in constituent-driven program design, SAGE will create a safe and vibrant space for LGBT older adults that can also serve as a model of innovation across the nation. The SAGE Center will: extend LGBT-affirming services throughout New York City's five boroughs, reaching LGBT older adults who do not use their local centers for fear of discrimination and who may not know of or be able to access SAGE's current services; address research showing that LGBT older adults identify primarily not as older but as LGBT, and so want their social interaction to center on this identity; allow for the program flexibility necessary to address the next wave of older adults—aging baby boomers—who have different needs and expectations than their predecessors; and provide information and resources specific to LGBT older adults to guide them in decision making in the areas of finance, housing, or health care.

DFTA's commitment to innovative programming for older adults, and to partnering with community

organizations, represents a key step in making New York City even more age-friendly than it is now. DFTA and SAGE hope that this new model of service delivery will translate into centers with dynamic programming, high participation rates, and better health outcomes for all older New Yorkers, including LGBT older adults.

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# The Policy Issues and Social Concerns Facing Older Adults with HIV

*Daniel Tietz • Nathan Schaefer*

Given what many Americans think they know about HIV, you might be wondering why an organization devoted to understanding and addressing the needs of aging Americans has turned its attention to HIV. Here's why: the nation's first ever National HIV/AIDS Strategy reported that by 2015, 1.2 million Americans will be living with HIV, and the Centers for Disease Control and Prevention estimates that fully half of them will be age 50 or older by 2015 (see Figure 1; Centers for Disease Control and Prevention, 2008).

Almost one-third of people with HIV in the U.S. are women and 80 percent are people of color. And just over half are men who have sex with men. Not long ago, few would have expected to see large numbers of older adults living with HIV. But in the major U.S. cities where most people with HIV live, 40 percent of them are over age 50. This graying of the AIDS epidemic is primarily the result of new classes of HIV medications, first introduced in the mid-1990s, that effectively suppress HIV and prevent the collapse of the immune system. Before 1995, a person diagnosed with HIV often had a life expectancy of a few years. Today that same person can expect to live an almost typical life span if diagnosed and treated early.

However, this burgeoning population is also the result of older people becoming infected with HIV. Just a decade ago only 10 percent of new HIV infections occurred in those over age 50. Today they account for 17 percent of new diagnoses and are increasing (see Figure 2).

Targeted prevention interventions and appropriate care are two key challenges in addressing the aging of the HIV epidemic. Due to the persistent myth that HIV only affects the young, a growing number of older adults are getting HIV because they don't believe that they are at risk. In fact, older adults are more vulnerable to HIV infection than younger people due to certain biological changes associated with aging, such as thinner mucosal membranes in the anus and vagina that tear more easily during sexual intercourse, thus creating easy access for the virus. More significantly, there have been virtually no widespread, federally funded HIV prevention efforts targeted to older adults. Research finds high rates of unprotected sex among all older adults and reports that as many as 18 percent of older adults with HIV engage in unsafe sex (Golub, Tomassilli, Pantalone, Brennan, Karpiak, & Parsons, 2010).

Just as with others, HIV treatment for older adults is quite effective as long as they adhere to their medication

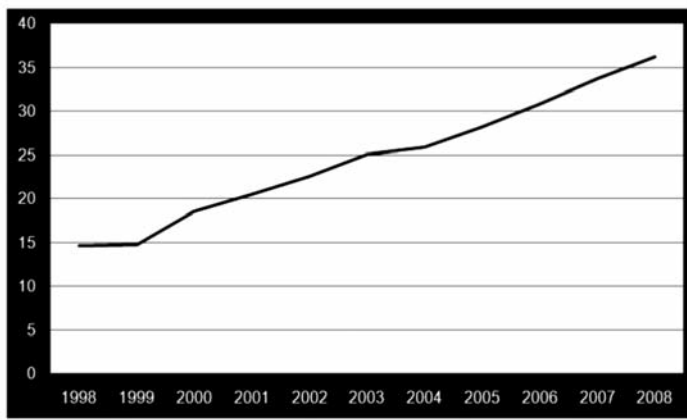
regimens. But for reasons not yet well understood, older adults with HIV are exhibiting increased rates of age-related illnesses 20-to-30 years earlier than is typical among their peers without HIV. Some describe this as accelerated aging. Research by AIDS Community Research Initiative of America (ACRIA) and others has shown that there are increased rates of cardiovascular disease, hypertension, diabetes, and osteoporosis among older adults with HIV, as well as cancer. In fact, several studies indicate that adults with HIV age 50 and older report three comorbid conditions on average, as opposed to just one such condition among HIV-negative adults over age 70 (Brennan, Karpiak, Shippy & Cantor, 2009; Havlik, Brennan & Karpiak, 2011; Vance, Mugavero, Willig, Raper & Saag, 2011). This creates significant challenges for this population and their providers.

Moreover, older adults with HIV suffer from high rates of depression. Approximately 40 percent of the participants in ACRIA's Research on Older Adults with HIV (ROAH) study had high depression scores using a standard measure, which is exacerbated by persistent HIV stigma. Depression not only has a negative impact on quality of life, but may be the single best predictor of treatment non-adherence and poor outcomes. Furthermore, there is a consistent link between depression and physical comorbidities.

Finally, adherence to a complex regimen of pills is facilitated by having a spouse, partner, or nearby friend or neighbor who can provide the emotional support and instrumental assistance that is essential for successful aging. But ROAH found that older adults with HIV are more socially isolated from family and friends than are those without HIV. More than 70 percent of the older adults in ROAH lived alone, fewer than 15 percent had a spouse or partner, and they had little support from family or friends (see Figure 3; Brennan et al., 2009). Moreover, ROAH found fragile social networks that are

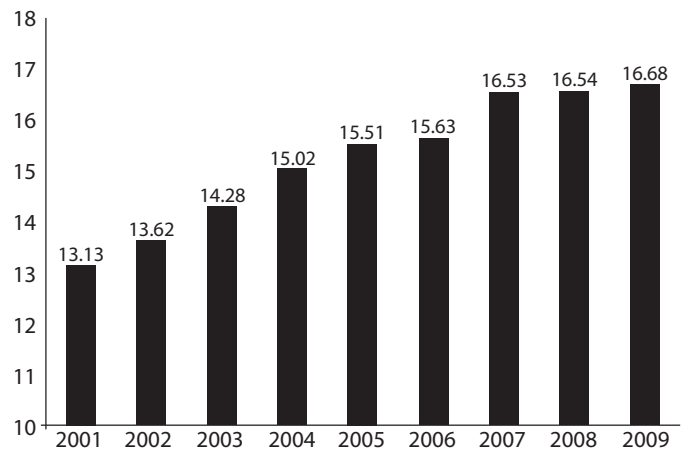
**Figure 1**

% of People Living with AIDS Diagnosis Over Age 50 in US – CDC Surveillance Data



**Figure 2**

% of New HIV Infections in those 50 and Older



inadequate to deliver the caregiving and support these older adults with HIV need to age successfully. Without such support, they will not be able to manage their health effectively and will more likely be relegated to costly long-term care facilities.

Increasingly, HIV is taking its place as one of many treatable chronic conditions affecting older adults. But the evolution of people aging with HIV into long-term survivors demands a parallel evolution in HIV care and services. The challenges of managing the care of those with HIV into their 50s and beyond are often substantial and the present medical model is unlikely to be sufficient. In an effort to address this gap, ACRIA recently joined with the American Academy of HIV Medicine and the American Geriatrics Society to develop clinical guidelines for the management of the health of older adults with HIV, which are expected to be issued in October 2011.

For a host of reasons, AIDS service organizations (ASOs) and other community-based organizations (CBOs) serving people with HIV are not prepared alone to meet the needs of those aging with HIV. Likewise, the existing senior services network across the country is ill-prepared to address the needs of older adults with HIV, and those most at risk, not least because of a lack of HIV knowledge and continuing myths, stigma, and discrimination.

Given existing resource limitations and the likelihood of future funding reductions how can we best address the health, psychosocial, and other needs of aging adults with HIV and help to reduce the number of new infections among older adults? How do we draw on the strengths that already exist among these older adults and their communities?

Below are several policy recommendations that we believe could improve our understanding of older adults

with and at risk of HIV and make a genuine difference in how we deliver care and services.

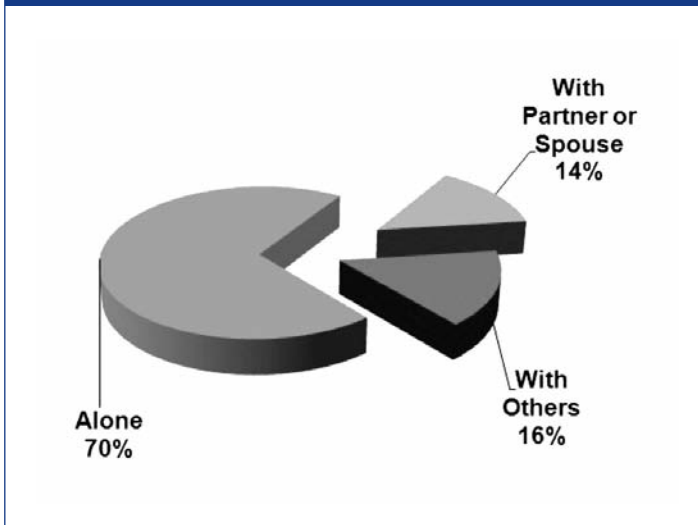
### Department of Health and Human Services

There is very little research on older adults with HIV. They are often exempted from clinical studies and drug trials, leaving a dearth of information about the effects of HIV and its treatment on the aging body. As noted earlier, we must recognize the high incidence of multiple morbidities and the long-term effects of highly active antiretroviral treatment (HAART) and other drug therapies. The social context in which older adults with HIV live, including the damaging effects of stigma on their physical and emotional well-being, must also be considered in efforts to improve care. Greater understanding of the unique health circumstances that people with HIV experience as they age is necessary, and will require a coordinated and targeted response from federal agencies, most notably those within the Department of Health and Human Services (HHS).

HHS supports demonstration projects, such as Special Projects of National Significance (SPNS) grants through the Ryan White Treatment Modernization Act, and other resources that could specifically target this population. Research could help identify the unique treatment needs of older adults with HIV, particularly in the management of multiple morbidities. Structural interventions aimed at delivering targeted training and capacity building are needed if ASOs and CBOs are to improve program services and access for these older adults.

HHS could also support demonstration projects that address mental health interventions for the persistent problems of depression and other mental illness among older adults with HIV. Appropriate community-based care

Figure 3



can reduce costs associated with institutionalization and could greatly improve the quality of life for many older adults with HIV. Finally, HHS and the Office of AIDS Research at the National Institutes of Health (NIH) could support research to better understand the development, causes, and course of comorbid conditions and how they affect the management of HIV, as well as the effect HIV and its treatment have on comorbidities.

### Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) can greatly improve its epidemiological surveillance systems and data collection to track and understand older adults with HIV better. For example, it is currently difficult to glean from CDC data who is being diagnosed late in the course of HIV disease (those found to have AIDS upon an initial HIV diagnosis) or the demographic characteristics and number of older adults newly infected. Specifically, the CDC could provide data by age (in five-year increments) and risk category for adults over age 50 in the same manner in which trends are monitored for those under age 50. The availability of such data would inform HIV prevention programs, and educate public health and medical professionals on the specific routes of HIV transmission among older adults, thus improving tailored prevention interventions.

At present the CDC recommends an annual HIV test for all Americans aged between 16 and 64—an age cap which should be extended, since many adults over age 64 are sexually active. Improved HIV incidence data and screening recommendations would help ensure early HIV diagnoses. Early diagnosis is incredibly important, as delays compromise an individual's prognosis. Also, those

who are unaware of their HIV infection are more likely to transmit the virus to others.

Another area needing significant improvement is prevention programming. At present there are no CDC-approved HIV prevention models aimed specifically at older adults. The distinct experiences and risk behaviors of older adults warrant a new prevention model. The CDC has historically designed and targeted such programs to populations deemed at high risk. With approximately one in six new HIV diagnoses among those over age 50, the trend clearly indicates an urgent need. Any CDC prevention model should also include a social messaging component in order to end the rampant HIV and anti-gay stigma often seen in nursing homes, senior centers, and other senior programs.

### Older Americans Act

The Older Americans Act (OAA) funds Area Agencies on Aging (AAAs) nationwide that support programming for older adults in senior centers, home delivered meals and other nutrition programs, long-term care and caregiver support, the prevention of abuse and neglect, and other social services. The legislation is due for a reauthorization this year, and clear opportunities for making the legislation more responsive to older adults living with and at risk for HIV are rising to the forefront.

Earlier this year, for the first time, a large coalition of aging organizations included specific recommendations that would better address older adults with HIV in the OAA. The Leadership Council of Aging Organizations, a coalition of 65 national aging organizations, recommended the inclusion of older adults with HIV as a population with greatest social need, recognizing their growing number and the related health disparities, discrimination, and stigma.

Defining older adults with HIV as a population of greatest social need within the OAA will allow the U.S. Administration on Aging (AoA) to dedicate critical resources to states for community planning and social services, research and development projects, and personnel training in the field of aging. This is a key step in helping senior centers, nursing homes, and other senior programs address the unique HIV prevention and treatment needs of older adults.

The authors have made additional recommendations to improve the OAA's response to the HIV epidemic. Included in these recommendations is an amendment to improve training of health care workers to help them provide culturally competent care for older people with HIV. This amendment would require state area plans, submitted to the AoA, to provide specific

assurances with respect to services and support for older adults with HIV.

A final recommendation for the OAA addresses HIV prevention programs across the broad range of aging services provider settings. An amendment could include HIV within the definition of disease prevention and health promotion. This amendment would specifically identify HIV as within the scope of the OAA's activities on health promotion and disease prevention.

Since it is expected that half of all Americans with HIV will be over age 50 by 2015, it is critical that we consider how all programs and policies that affect older Americans will respond to the epidemic (Centers for Disease Control and Prevention, 2008; Effros et al., 2008). Reauthorization of the OAA is a significant and precedent-setting opportunity to do just that.

In sum, existing resources and service networks must be integrated to ensure more seamless and comprehensive care and services for older adults with HIV. Working to create effective referral and services relationships among the existing array of aging support services and the ASO/CBO networks will do much to improve provider knowledge and reduce barriers. Until we address these barriers, older adults with HIV are unlikely to have equal access to the health and social support systems available to other aging adults in the U.S. In addition, we must work to empower and educate older adults with and at risk of HIV to engage their health and services providers with their unique and specific needs.

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# LGBT Aging: Research and Policy Directions

*Brian de Vries*

A significant impediment to our understanding of aging within and about LGBT communities is the absence of data; sexual orientation and gender identity have not been included in federal surveys and health records. This dearth is associated with inexact estimates of the size of the LGBT population and, with some exceptions included below, a body of research mostly based on small non-probability samples that are often collected within select geographic areas. Certainly significant data collection challenges exist. For example, the operational definition of sexual orientation and gender identity is complex and lacks consensus; LGBT persons—and older LGBT persons in particular—may be reluctant to publicly disclose or “out” themselves for research and other purposes (Institute on Medicine, 2011). Still, much has been learned through these studies; much remains to be understood.

Older LGBT persons, much like LGBT persons in general, frequently have been considered a homogeneous group, as supported by the acronym under which they are identified. Although they share several features, LGBT persons are probably most bound by their otherness (Institute of Medicine, 2011)—their non-heterosexual and/or non-gender-conforming identities and the associated stigma and discrimination they have encountered over their lifetimes. These experiences factor into findings such as lower rates of health insurance (e.g., through unequal access/lack of partner recognition), delays in seeking health care (from a system that had previously labeled them as sick) (Movement Advancement Project, 2010), and higher rates of disabilities noted in these populations, including HIV/AIDS, asthma, diabetes, and other chronic conditions (Fredriksen-Goldsen, Kim, & Goldsen, 2011). The LGBT label, however, encompasses a broad array of persons of differing genders, gender identities, and sexual orientations, as well as race, ethnicity, socio-economic status, and a host of other attributes and characteristics, including and/or interacting with age.

Research into the experiences of older gay—and, to a smaller degree, bisexual—men, for example, reveals higher rates of depression (Mills et al., 2004) and anal cancer risks (Chin-Hong et al., 2004) in comparison with comparably aged heterosexual men. Research with older lesbians—and, to a smaller degree, bisexual women—as compared with heterosexual women suggests higher rates of reproductive cancers and higher rates of heart disease risks (Valanis, Bowen, Bassford, Whitlock, Charney, & Carter, 2000). Research with older transgender persons is rare but reports many similar (and often exacerbated) findings and references to the long-term unknown consequences of extended hormone use. These group findings are in addition to the physiological changes that are noted among aging individuals such as the increasing needs for support in activities of daily living.

The source of this support is an issue that dramatically differentiates LGBT and heterosexual persons. Gerontologists have commented on the hierarchical patterns engaged by older persons as they seek and receive assistance (Cantor & Mayer, 1978); spouses are first sought as supporters and caregivers, followed by adult children and then other relatives, if the former two are unavailable, and finally neighbors, friends, and formal services in roughly that order. The heteronormativity of this pattern is made clear in charting the experiences of older LGBT persons; most lesbians and the majority of gay men are without partners and most are without children in later life (de Vries, 2006). Friends are thus often the first line of caregiving defense for LGBT persons. Recent attention has been directed toward the families of choice created by LGBT persons largely comprising these friends; almost two-thirds of a national sample of LGBT baby boomers noted that they had a family of choice (MetLife Mature Market Institute, 2010). Such relations, however, fall outside of typical policy and program parameters that focus on family ties and obligations for care provision; friends are not expected to be, and often not respected as, caregivers. Moreover, friends (mostly of comparable age) may not be able or available to provide the care that is needed by an LGBT elder.

In the absence of more formal support systems and in the face of stigma and discrimination, older LGBT persons have struggled to create communities and receive services to meet their needs. These efforts have garnered some national attention and highlight alternative ways to think about aging, caregiving, and community. A better understanding of the LGBT aging community is not only the basis for effective and competent service provision to meet their needs, but it mandates reflection on the assumptions underlying policies and services and provides an opportunity to reconsider how best to engage and work with an

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increasingly diverse older population (de Vries & Blando, 2004). Policies and programs that address the effects of stigma, include non-traditional family forms, and honor diverse life trajectories have benefits for all.

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# Services & Advocacy for GLBT Elders (SAGE)

[www.sageusa.org](http://www.sageusa.org)

SAGE is the country's largest and oldest organization dedicated to improving the lives of lesbian, gay, bisexual and transgender (LGBT) older adults. The mission of SAGE is to lead in addressing issues related to LGBT aging. In partnership with constituents and allies, SAGE works to achieve a high quality of life for LGBT older adults, supports and advocates for their rights, fosters a greater understanding of aging in all communities, and promotes positive images of LGBT life in later years.