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Abstract

This chapter provides an overview of the current public policy dilemmas faced by lesbian, gay, bisexual, and transgender (LGBT) older people in areas such as economic security and employment, health equity and healthcare access, housing, HIV and aging, data collection and research, and major federal legislation meant to protect older people in this country. It summarizes the current research and literature on LGBT aging and offers an assessment of the national advocacy capacity of national, state, and local nonprofit organizations working to support LGBT elders. The chapter closes with future considerations for strengthening policy supports for a growing, vulnerable, and neglected demographic of LGBT older adults.

Keywords

Policy • Aging • Advocacy • Legislation • LGBT

Overview

The purpose of this chapter is to provide an overview of the most pressing public policy issues currently faced by LGBT older people. Attention is given to the historical context behind these issues, key research and policy recommendations, recent policy advancements, an assessment of the infrastructure of LGBT aging organizations and programs, and future consid-

erations for strengthening the policy apparatus that can spur political change for LGBT older people. The intent is to spur the reader to understand advocacy, as well as identify ways in which he or she might be able to become an advocate on behalf of LGBT elders.

Learning Objectives

By the end of this chapter, the reader should be able to:

1. Understand recent, current, and pressing policy issues faced by LGBT older persons.

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2. Identify relevant policy that affects LGBT older persons.
3. Understand the multidisciplinary infrastructure of national, state, and local organizations working to advance policy change for LGBT elders.

Introduction

In the last decade, the visibility of lesbian, gay, bisexual, and transgender (LGBT) older adults has grown considerably, gaining significant traction in federal public policy discussions on aging, long-term care, and LGBT rights. The broader societal awareness about aging and long-term care can be partially attributed to a demographic shift that has rapidly changed the age composition of the US population; estimates forecast that the percentage of people aged 65 and older will grow from 13.7 % of the US population in 2012 (or 43.1 million people) to 21 % in 2040 (or nearly 80 million people) (Administration on Aging, Administration for Community Living 2013). This aging shift has captured the attention of policy government officials, nonprofit leaders, health and aging professionals, and mainstream media. Additionally, the increased visibility and acceptance of LGBT people have enabled a concurrent growth in organizations and programs focused on LGBT older people, many of which produce landmark policy analysis and spearhead advocacy to remove the policy barriers faced by LGBT people as they age. Conservative estimates suggest that there are at least 1.5 million LGBT people aged 65 and older in this country and that this number will double in the next two decades (Movement Advancement Project and SAGE 2010). Yet despite the policy progress made over the last five years in regard to LGBT elders (Espinoza 2013b), policy leaders often omit LGBT elders from major discussions and proposals focused on improving the health and wellness of US seniors. Concurrently, the LGBT aging sector that is positioned to steer a policy

agenda for LGBT elders remains marginal, especially when compared to the magnitude of the population and its large-scale concerns, or when contrasted with the much larger national aging and long-term care field.

This chapter begins by reviewing the policy research and literature on LGBT older people, notably the research that was produced from 2010 to the present. The chapter then examines various policy issues in depth, including the Older Americans Act; economic security, employment, and poverty; affordable housing and safe, long-term care; health equity and healthcare access; HIV and aging; and data collection and research. The chapter proceeds to describe the multidisciplinary infrastructure of national, state, and local organizations working to advance policy change for LGBT elders and proposes a variety of issues that should be resolved through future scholarship, such as developing best practices for integrating LGBT issues into national surveys and clinical settings so that LGBT elder advocates can draw from data for future policies and programmatic interventions.

Policy Research and Literature on LGBT Older People

The policy research and literature on lesbian, gay, bisexual, and transgender (LGBT) aging dates back to 2000, though most policy reports on this subject were produced from 2010 to the present. In *Outing Age: Public Policy Issues Affecting Gay, Lesbian, Bisexual, and Transgender Elders*, the first in-depth policy report on LGBT elders, Cahill et al. (2000) outline a variety of political, social, and cultural challenges faced by LGBT older people, including the lack of LGBT-friendly social services, unequal treatment in safety net programs such as Medicaid and Medicare (among others), ongoing discrimination in housing and nursing homes, and a general lack of policies that protect LGBT people. They note that ageism in the LGBT community coupled with heterosexism in the

aging field has colluded to exclude the realities of LGBT older people from policy conversations on aging, long-term care, health, and LGBT rights.

This landmark policy report both lays the groundwork and anticipates the policy advocacy movement that will emerge on LGBT elders in the ensuing two decades: Today we stand at the edge of two tidal waves: a growing wave of GLBT people aging and entering the social service and community institutions which care for and advocate for the elderly; and a tidal wave of reaction against government, and against government funding for social service needs. How will GLBT people fare as these waves wash over our communities? To date, aging service providers are not ready for the new wave of GLBT elders, policy makers are running away from it, and until very recently, frankly, the GLBT community has not faced this wave either (p. iv).

In 2010, the Movement Advancement Project and SAGE (Services and Advocacy for GLBT Elders) revive this LGBT aging policy agenda by positing that LGBT older adults deal with three overarching challenges: the long-term consequences of stigma and discrimination; the over-reliance of LGBT older people on “families of choice” that are not legally protected and are often rendered secondary to spouses and biological next of kin in public policies, legal protections, and within most mainstream aging service provision; and the general unequal treatment of LGBT people in aging services and under the law. The authors surmise that these challenges compound to impair LGBT elders’ financial security, proper health and healthcare access, and their level of social support. In response, the authors enumerate more than 50 policy recommendations in areas such as Social Security, Medicaid, Veteran’s Benefits, visitation and medical-decision-making, housing and more (pp. 65–68). The report also elicits the support of a few national aging organizations, including AARP (formerly the American Association of Retired Persons), the American Society on Aging, and the National Senior Citizens Law Center, which forecasts how mainstream national aging organizations will become more supportive of an LGBT elder policy agenda in the years that follow.

Subsequent policy reports focus on discrete policy areas or subpopulations of LGBT older

people who face additional barriers and considerations. SAGE (2011b) describes the opportunities offered by the [Older Americans Act](#) to support LGBT elders, citing recommendations for this signature legislation to amend its definitions to specify LGBT older adults; require data collection and reporting on the extent to which local services and programs serve LGBT older people; broaden definitions of “family” to include families of choice; and support LGBT cultural competence training nationwide. The National Senior Citizens Law Center (2011) profiles the stories of more than 700 LGBT older people and their loved ones in long-term care settings, describing harrowing incidents throughout the country of verbal and physical harassment from staff and other residents, as well as stories of staff members refusing to use a resident’s preferred (gendered) name or to provide basic care or services, among other stories of hardship. In its recommendations, the report calls for additional research on the experiences of LGBT elders in long-term care facilities and more LGBT cultural competence training for nursing home and other aging professionals, as two notable examples. The National Academy on an Aging Society (2011) examines a variety of current policy topics related to LGBT elders, including the policy barriers faced by older adults with HIV, the role of public policy in creating culturally competent aging services for LGBT elders, and how the Affordable Care Act explicitly supports both older people and LGBT people, among other issue areas. This report represents the first multi-issue policy report on LGBT aging published by a national organization focused on aging: the Gerontological Society of America. SAGE and the National Center for Transgender Equality (2012) offer more than 60 recommendations for policy and practice in regard to supporting transgender older people, including recommendations related to privacy and documentation, violence, aging service and healthcare barriers, employment and housing discrimination, and more. The reader is referred to Chap. 14 in this book for further discussion on transgender elders. SAGE (2013a) identifies 10 policy areas that can promote health equity

among LGBT older people of color, including data collection, strengthening Social Security, increasing funding for culturally and linguistically competent aging supports, and more. The author notes that though LGBT elders of color represent an important segment of the demographic shift that is rapidly diversifying and aging the US population, “the available research shows that they often face heightened health disparities and are largely rendered invisible in public policy discussions on aging” (p. 1). The reader is referred to Chaps. 6–8 in this book for further discussion on LGBT elders of color. The National Hispanic Council on Aging (2014) focuses on the importance of funding and delivering LGBT-friendly culturally and linguistically appropriate services to LGBT Latino older people. The needs assessment finds that LGBT Latino people deal with multiple barriers to accessing supportive communities when they age, including the biases of more conservative people of faith, the lack of environments that embrace LGBT Latino elders as people with multiple identities, and the compounding challenges of having survived discrimination rooted in one’s sexual and gender identity, as well as one’s racial and ethnic realities. The Equal Rights Center (2014) argues for stronger LGBT-friendly non-discrimination protections in housing based on a 10-city investigation among older same-sex couples. The investigation finds that in 48 percent of the tests, older same-sex couples experienced at least one form of differential treatment when seeking housing in senior-living facilities, such as being provided less information about additional units, or being required to pay additional fees or costs, and undergo a more extensive application process, among other hurdles. The Diverse Elders Coalition (2014) argues for policy improvements in eight areas related to HIV and aging, including funding HIV prevention programs aimed at older people, increasing Medicaid expansion across states, developing and propagating clinical care guidelines for treating older people with HIV, and more. The report also calls for the inclusion and funding of HIV and aging as a significant need in the upcoming 2015 White House

Conference on Aging, the existing Ryan White Care Program, and the current reauthorization of the Older Americans Act.

Policy Issues Faced by LGBT Older Adults

LGBT older people face an array of policy barriers in areas related to the Older Americans Act, economic security and employment, health equity, HIV and aging, affordable housing and long-term care, and data collection and research. LGBT elders are not explicitly accounted for in most public policies that are meant to support older people, and many LGBT elders face unequal treatment under the law as LGBT people and as same-sex couples. LGBT elders concurrently experience differential treatment in accessing aging and health services, housing, and long-term care—with marginal legal protections or policy-funded interventions. The data and research on LGBT older people remain thin and underfunded. Nevertheless, policy advocates have advanced a variety of protections in recent years, widening opportunities to protect LGBT elders in safety net programs, aging services, and federal and state public policy.

Older Americans Act

The Older Americans Act (OAA) serves as the country’s largest vehicle for funding and delivering services to older people in the USA; estimates suggest that its funding scope is more than \$2.3 billion annually (National Health Policy Forum 2012). The OAA also emphasizes reaching older people with the “greatest social need,” which includes economically vulnerable people and racial and ethnic minorities. However, the OAA does not include LGBT-specific provisions that would increase funding for programs, services, and research related to LGBT older people. Without these provisions, the national array of service providers and local and state government agencies that comprise the country’s “aging

network” are not compelled, encouraged, or mandated to consider LGBT people as a population worthy of targeted supports (SAGE, n.d.b).

The reauthorization of the OAA, which takes place every five years, provides an opportunity to amend this legislation in ways that address these concerns. In response, national LGBT and aging advocates have proposed that the OAA be amended to specify LGBT older adults as a population of “greatest social need.” Additionally, advocates propose that OAA require that state and area agencies on aging report the extent to which they serve LGBT older people; that OAA increase funding for both research and programs focused on LGBT elders; and that the National Resource Center on LGBT Aging, a technical assistance and training center seeded by the US Department of Health and Human Services (HHS) in 2010 and led by SAGE, be permanently established in the OAA (SAGE, n.d.b).

These recommendations have garnered widespread support from leading national nonprofits in the aging field such as the Leadership Council of Aging Organizations, as well as from members of Congress and federal agencies (SAGE 2011a). A proposed 2012 Senate bill and a proposed 2014 House bill on OAA reauthorization included these LGBT-friendly recommendations (Tax 2014). In July 2012, the Administration for Community Living (ACL) at HHS issued guidance recommending that LGBT older people be considered by ACL’s grantees as a population of greatest social need in local planning efforts (SAGE 2014a). In addition to the legislative remedies outlined above, federal agencies can exercise their authorities to issue regulatory and administrative changes that move forward many aspects of these recommendations.

Economic Security, Employment, and Poverty

A lifetime of discrimination in the workforce and in public benefit programs has diminished retirement savings, exacerbated economic

security, and spurred higher poverty rates for many LGBT older people, notably LGBT people of color who deal with the added burdens of multiple forms of discrimination (MAP and SAGE 2010). These economic conditions are worsened by the current recession, the general increase in healthcare costs over the years, the pervasiveness of age-related bias (as early as age 40), and LGBT-specific discrimination in the employment process and the workplace (Cray 2013). The federal government does not prohibit workplace discrimination based on sexual orientation and gender identity, while 29 states lack protections for both sexual orientation and gender identity in the workplace (Human Rights Campaign 2014a, b). Additionally, many LGBT older people and their families do not have other assurances such as adequate paid leave protections that would allow them or their primary caregivers to take time off from work to care of their loved ones when they are ill; paid leave protections nationwide are sparse; and typically “families of choice” who are friends and caregivers of many single LGBT older people, are not protected by leave protections (Make 2013a). The reader is referred to Chap. 29 in this book for further discussion on LGBT issues in the workplace.

Finally, unequal treatment for same-sex couples in federal programs such as Medicaid and Social Security has left many LGBT older couples without the financial resources they need to live financially secure in old age (MAP and SAGE 2010). The June 2013 Supreme Court decision that effectively struck down the federal Defense of Marriage Act has spurred numerous improvements for same-sex couples in accessing important federal benefits, though the breadth of these benefits continues to evolve as the federal administration implements this decision across programs (Tax 2014). Two notable policy tensions are whether federal benefits should be available to all legally married same-sex couples regardless of whether they reside in a state that does not sanction same-sex marriage and whether these benefits should extend beyond marriage and

support couples or dyads in civil unions, domestic partnerships, and/or mutually dependent caregiver relationships (Freedom to Marry 2013; Movement Advancement Project and SAGE 2010). The reader is referred to Chap. 36 in this book for further discussion on the implications of the Supreme Court ruling on same-sex marriage.

To improve the economic security of LGBT older people, policy leaders propose an array of policy remedies. Congress could pass the Employment Non-Discrimination Act, which would provide critical workplace protections related to sexual orientation and gender identity to millions of LGBT workers (Cray 2013). Additionally, the President could issue an executive order that prohibits federal contractors from discriminating on the basis of sexual orientation and gender identity (Ford 2014). Federal, state, and city governments could enact paid leave laws that expand legal recognition to same-sex couples and broader “families of choice,” allowing LGBT older workers and their caregivers to support one another in times of illness (Make 2013b). The federal government could ensure that LGBT people, same-sex couples, and their families of choice in all states have access to federal benefits across areas such as Medicare, Social Security, Veteran’s Benefits, the Family and Medical Leave Act, and more (Lambda Legal 2013). The Social Security Administration could exercise its authority to ensure that same-sex couples in marriages, civil unions, and domestic partnerships have equal access to Social Security spousal, survival, and death benefits, regardless of the state in which they reside (Novak 2014).

The federal administration has made significant progress following the June 2013 Supreme Court decision that invalidated the Defense of Marriage Act. In June 2013, the Social Security Administration (SSA) announced that transgender people could update their Social Security records to reflect their proper gender identities, and in April 2014, SSA issued updated guidance that a gender transition does not affect the validity of transgender people and their spouses (with additional review required in some states) (National Center for Transgender Equality 2013; 2014a).

In April 2014, the US Department of Health and Human Services released guidance that legally married same-sex couples are eligible for Medicare benefits, regardless of where the couple lives (2014). In May 2014, the Administration for Community Living issued guidance to its grantees that they could include same-sex married couples in their definitions of “spouse,” “family,” and “relative” and that grantees should follow the “place of celebration” rule, meaning that same-sex marriages will be affirmed for ACL programs, regardless of the state in which they reside (SAGE 2014a). Finally, a bill has been introduced in the US Senate—the Social Security and Marriage Equality (SAME) Act of 2014—that would extend spousal, survival, and death benefits under Social Security to married same-sex couples in all states (Goodwin and Knox 2014).

Affordable Housing and Safe Long-Term Care

Many LGBT older people struggle with securing safe and affordable housing. Research shows that LGBT older people encounter various forms of differential treatment when attempting to buy or rent homes and apartments, as well as access senior housing (Movement Advancement Project and SAGE 2010; Equal Rights Center 2014). Additionally, many LGBT elders encounter bias and discrimination from staff members and fellow residents in independent living and assisted-living facilities, nursing homes, and home care (National Senior Citizens Law Center 2011). Espinoza (2014) notes that while a crop of affordable LGBT senior housing complexes have been developed around the country, generating significant media attention and widespread interest from LGBT older people and their advocates, the availability of these complexes and the limited stock of units cannot meet the demand of millions of LGBT older people who might want to reside in these residences; advocates posit that housing solutions for LGBT elders must be more innovative and expansive.

The author also argues that a lifetime of discrimination has hampered the economic security and limited the housing options of many LGBT older people, notably people of color, transgender people, and women. The broader housing crisis, recession, and foreclosure crisis has only worsened these housing realities for LGBT elders.

Policy advocates argue for the importance of federal and state-level non-discrimination protections that include sexual orientation and gender identity and which cover public accommodations to account for nursing homes and other long-term settings (Human Rights Campaign 2014a). To support LGBT senior housing complexes as well as a range of housing supports geared at LGBT older adults (i.e., LGBT sensitivity training for housing providers, know-your-rights resources for LGBT elders who are seeking housing, and more), federal and state governments could increase funding for these types of housing developments and supports (U. S. Department of Housing and Urban Development, n.d.). The Older Americans Act, the US Department of Housing and Urban Development, and the Centers for Disease Control and Prevention could play critical roles in funding and promoting senior housing communities that offer more skilled long-term services to LGBT older people, as well as promote independent living communities that allow for aging in place. Finally, increased funding for LGBT cultural competence training that reaches long-term care staff and housing providers around the country could help ensure that LGBT elders live in homes and long-term care facilities that feel more welcoming and safe (SAGE 2013b).

A February 2014 report on housing discrimination among same-sex older adults garnered widespread media attention and visibility on LGBT elders and housing (Equal Rights Center 2014). Around the country, housing developers and community advocates have increasingly spearheaded the creation of LGBT senior housing complexes, including Los Angeles, Minneapolis, Philadelphia, and more (SAGE 2013a). The National Resource Center on LGBT Aging

continues to train hundreds of aging providers nationwide on the issues faced by LGBT elders, increasing knowledge and supportiveness for LGBT elders among aging professionals (National Resource Center on LGBT Aging 2014). State advocates have also led LGBT sensitivity trainings for housing providers to reduce bias and discrimination aimed at LGBT older people (Wayland 2014).

Health Equity and Healthcare Access

Fredriksen-Goldsen et al. (2011) conducted a national study of LGBT older adults that found significant disparities in areas related to physical and mental health, including obesity, high blood pressure, cholesterol, arthritis, cataracts, asthma, cardiovascular disease, diabetes, and other areas. In regard to mental health, the authors found that more than half of the study's respondents had been told by a doctor that they had depression and 39 % had seriously thought about suicide. And in many of the health areas examined in the study, LGBT older people of color and transgender people faced higher health disparities. The research shows that many LGBT older people report avoiding or delaying care for fear of discrimination; as one example, older people with HIV are often more likely to be dually diagnosed with HIV and AIDS than their younger counterparts, a medical designation that suggests that older people are not seeking proper care to detect HIV, older people are not speaking candidly about their sexual health with their providers, and/or older people are not being screened properly by medical professionals, many of whom might mistakenly assume that sexual activity diminishes or goes away in old age (National Resource Center on LGBT Aging 2011). One systematic barrier to LGBT-friendly patient-centered health care is that questions about sexual orientation and gender identity, which would identify LGBT patients to doctors, nurses, and other medical professionals, are rarely asked in the patient intake process. Conversely, evidence suggests that these questions improve candor and can lead to important interventions related to

common LGBT health concerns (The Fenway Institute and The Center for American Progress, 2013).

To address national health disparities, the Affordable Care Act (ACA) put into place a number of enhancements for LGBT people and seniors, including new provisions that prevent health insurers from denying coverage based on preexisting conditions such as a person's sexual orientation, gender identity or HIV status, and various supports for people aged 65 and older, including assistance with prescription drug costs and increased access to more prevention services (SAGE 2013d). The extent to which ACA has improved healthcare access for LGBT older people remains unknown, though the need for improved health coverage is more substantiated. The Center for American Progress (2013a) has found that 34 % of LGBT people were uninsured at the beginning of the open enrollment period (October 2013) for the ACA's marketplaces. Twenty-eight percent of LGBT people aged 50–64 were uninsured in this research (K. Baker, personal communication, May 28, 2014). Additionally, 82 % of uninsured LGBT people reported discrimination when trying to access their partners' plans; 67 % had been without health insurance for more than two years, and 60 % reported delaying medical care for the past 12 months because they could not afford the costs of health care (Center for American Progress 2013b). The reader is referred to Chap. 19 in this book for further discussion on the impact of health reform on LGBT elders. Finally, transgender older people in particular struggle with accessing health care; lifelong discrimination has limited their job security, their incomes, and their access to private employer insurance. In turn, many transgender older people rely largely on federal programs such as Medicare and Medicaid, which have historically contained arbitrary exclusions for transition-related health care, placing the financial burden for these procedures entirely on the transgender patient (SAGE and NCTE 2012, pp. 15–16).

A 2013 report on health equity (SAGE) outlined various policy proposals to improve the health of LGBT older people, in particular people of color who face multiple health and aging-related challenges. The report recommends passage of two legislative bills related to the Older Americans Act, which would facilitate support programs geared at LGBT older people, as well as culturally and linguistically appropriate supports for people of color and limited-English-proficient people, a percentage of whom are LGBT. The US Department of Health and Human Services (HHS) and its relevant agencies could exercise their authorities to fund programs that target LGBT older people, while encouraging other grantees and community-based partners to work closely with LGBT nonprofits when implementing their health initiatives. Because the federal and state marketplaces did not collect data on the sexual orientations and gender identities of new enrollees, it remains unclear how many LGBT people are included in the roughly 8 million people who enrolled in the ACA marketplace (K. Baker, personal communication, May 28, 2014). Thus, SAGE (2013b) recommends that the federal regulations on state exchanges explicitly account for LGBT older people, which could include LGBT data collection on enrollees. Additionally, in May 2014, HHS declared that Medicare could no longer arbitrarily exclude transition-related surgery, regardless of a person's medical condition. This decision means that transgender people can obtain this surgery if it is approved by a medical provider that accepts Medicare and if they are able to cover the remaining medical costs such as deductibles and co-pays (National Center for Transgender Equality 2014b).

HIV and Aging

Since its onset in the early 1980s, the HIV/AIDS epidemic has disproportionately affected LGBT people, notably men who have sex with men, transgender people, and people of color. As HIV

treatment drastically improved in the mid-1990s, HIV/AIDS became less of a death sentence and more of a chronic and manageable illness, profoundly altering the age composition of the epidemic into the present (SAGE, n.d.a). By 2015, one in two people with HIV in the USA will be aged 50 and older—and by 2020, this proportion will increase to nearly three in four people (or 70 %). Research also shows that new infections are on the rise among older people, many of whom report not being screened or tested by healthcare providers who mistakenly assume that sexual activity ends in older age. Additionally, older people are often dually diagnosed with both HIV and AIDS, a clinical designation that means the virus has worsened to a state of medical and financial crisis (Cahil et al. 2010). A growing body of medical research indicates that people with HIV in their early 50s exhibit the same number of comorbidities as people without HIV in their early 70s; the virus, the anti-retroviral treatment, and a range of socioeconomic factors compound to spur aging and disability faster and sooner among people with HIV (American Academy of HIV, Medicine, American Geriatrics Society and AIDS Community Research Initiative of America 2011). More broadly, few organizations, government agencies, or health and aging service providers account for the existence or the growing needs of older adults with HIV, many of whom are LGBT and/or people of color (Diverse Elders Coalition 2014).

Advocates propose a range of policy interventions to support this demographic, as recently described in a policy report authored by the Diverse Elders Coalition (2014). The Ryan White Care Program, which provides essential services to people with HIV throughout the country, must be sufficiently funded to support the growing population of older people with HIV. The Centers for Disease Control and Prevention (CDC) could dedicate funding for HIV prevention campaigns aimed at older people, as well as better promote its testing guidelines to reach older populations. HHS could implement and promote guidelines for the clinical care of older people with HIV, given the number of

earlier age-related comorbidities; these guidelines were recently created by a national team of HIV experts from different fields and disciplines (American Academy of HIV, Medicine, American Geriatrics Society and AIDS Community Research Initiative of America 2011). The reauthorization of the Older Americans Act and the 2015 White House Conference on Aging provide critical opportunities to integrate policy changes and recommendations for older people with HIV. Finally, if every state opted to expand Medicaid coverage through the Affordable Care Act (ACA), and every person with HIV was in care, this change would provide coverage to more than 200,000 people with HIV who otherwise might not receive appropriate health care.

The visibility of HIV and aging has grown in the last few years. In fall 2013, a Congressional hearing and briefing examined the policy barriers faced by older adults with HIV, gathering experts from around the country (ACRIA 2013). In 2013, the CDC issued a landmark surveillance report tracking HIV among people aged 50 and older in five-year increments; this report allows researchers to better track the course of the epidemic as older people age (Centers for Disease Control and Prevention 2013). In May 2014, national advocates representing older people, people with HIV, LGBT people, and communities of color held a historic national teleconference and released an updated policy report on HIV and aging, calling for action on eight policy recommendations that would dramatically improve the health and wellness of older adults with HIV (Diverse Elders Coalition 2014).

Data Collection and Research

Espinoza (2013a) describes the various challenges faced by the systematic data collection and research on LGBT older adults. The large-scale quantitative data and research on LGBT older people remain thin and sparse, which prevents the knowledge that would substantiate and inform properly designed programs, policies, and interventions that target LGBT elders.

Questions that capture a person's sexual orientation and transgender status are not included in most federal surveys, from the US Census to the broad array of federal surveys on health, retirement, long-term care, and other matters relevant to LGBT elders. This means that statistics on the total number of LGBT older people in this country are conservative estimates at best. Further, where questions are asked, the related sample sizes for people aged 50 and older are often too small to form representative findings; few, if any, questions related to sexual orientation and gender identity are assessed for their clarity and accuracy among older populations, many of whom might have generational traits that shape their understanding of these research questions as well as their willingness to respond. Moreover, the challenges with securing older adult samples in representative surveys intensify when researching LGBT elder subgroups. For example, researchers struggle with reaching low-income, racially, and ethnically diverse transgender older people; most studies on transgender people have older adult samples that are more likely to be white and have higher income than their younger counterparts (SAGE and NCTE 2012, p. 4).

Along the same lines, questions on sexual orientation and gender identity are rarely captured in the patient intake process by most public and private health and aging entities, despite evidence that these questions can improve patient candor and patient care; further, when properly aggregated and reported, the responses to these questions could help illuminate health disparities (The Fenway Institute and The Center for American Progress 2013). Finally, state and area agencies on aging are not encouraged or required to measure the extent to which they outreach and serve LGBT older people in their areas, which limits the public understanding on the types of services and supports that LGBT elders receive in different parts of the country (SAGE, n.d.b). Research shows that too few state and area agencies on aging provide outreach to LGBT communities or LGBT-friendly services through their agencies (Knochel et al. 2011).

To broaden the data and knowledge on LGBT older adults, advocates and researchers propose various policy solutions (SAGE 2013b). The US Department of Health and Human Services (HHS) and agencies within HHS such as the Administration for Community Living (ACL) and the Centers for Disease Control and Prevention could develop, include, and test elder-sensitive questions on sexual orientation and gender identity in their national survey instruments. The Office of the National Coordinator for Health Information Technology could include data collection on sexual orientation and gender identity within its meaningful use standards for electronic health records. State health departments could integrate questions on sexual orientation and gender identity into their patient intake processes for people entering the Medicaid-funded system, similar to recent efforts in New York State (Espinoza 2013a, b). HHS could track data on discrimination and mistreatment of LGBT older people through the National Ombudsman Reporting System, and ACL could require that state and area units on aging to collect data that measure the extent to which LGBT older people are being served by the national aging network, especially in more conservative, less LGBT-friendly areas (SAGE 2013b).

In 2013, the CDC began testing a question on sexual orientation in its National Health Interview Survey and encouraged states to use questions on both sexual orientation and gender identity in the CDC's Behavioral Risk Factor Surveillance System (U.S. Department for Health and Human Service 2013). In 2013, the New York State Department of Health integrated questions on sexual orientation and gender identity into its statewide patient intake process for specific Medicaid-funded facilities, and the New York State Office for the Aging also revised its intake forms to include these questions (Espinoza 2013a, b). Both developments signal opportunities for other federal and state agencies to modify their surveys and patient intake processes to include LGBT-specific questions, ideally with elder-appropriate methodologies that collect robust samples of LGBT older people.

To protect LGBT elder clients and patients, these questions should be accompanied with protocols for collecting data, LGBT cultural competence training for professionals, and resources that educate LGBT patients on their legal rights in aging and long-term care settings (National Resource Center on LGBT Aging 2013). The reader is referred to Chaps. 22 and 34 in this book for further discussion on healthcare practices with LGBT elders, and the ethical standards and practices in human services and health care.

Related Disciplines

To better understand the political progress that has been achieved for LGBT elders, as well as what can be accomplished in the future, it is important to map the sector of organizations, programs, and coalitions working on federal, state, and local advocacy for LGBT older people. These organizations work across disciplines and sectors, yet their policy endeavors are generally focused on policy analysis and joint advocacy activities such as holding briefings for lawmakers, offering legal guidance to federal and state agencies, and building public awareness and support for LGBT elder policy concerns. While extremely successful in the last 10 years, advocates argue that the LGBT aging sector must significantly expand in order to continue achieving large-scale change for future generations of LGBT older adults.

LGBT Aging Organizations, Programs, and Coalitions

While the visibility of LGBT aging has increased dramatically since 2007, as well as the number of nonprofit actors working to address the lives of LGBT older people, this sector continues to be comparatively small when compared to the broader aging and LGBT rights fields and to the national nonprofit sector. Only a few national organizations and less than 50 state and local

organizations are primarily focused on LGBT aging in their missions and programs, a percentage of which are leading policy analysis and advocacy. As evidence of the national underfunding and marginalization of LGBT aging, Funders for LGBTQ Issues has reported that US foundation giving to organizations and programs serving LGBT older people grew marginally from \$1.9 million to \$3.5 million between 2007 and 2012 (Funders for LGBTQ Issues 2009; Funders for LGBTQ Issues 2013). More broadly, US foundations awarded more than \$49 billion to nonprofits in 2012 (Foundation Center 2013), meaning that foundation giving to LGBT aging is a minute fraction of total foundation giving in the USA. A sufficiently funded LGBT aging sector of national and state organizations—working in coalition with their partner organizations in the aging and long-term care field—will be vital to support the growing millions of LGBT older people over the next few decades.

National Organizations

While the sector of organizations working to support LGBT older people has expanded in the last decade, it remains a small field led by a few national organizations and a few dozen organizations working largely at the local level. SAGE (Services and Advocacy for GLBT Elders), which was founded in 1978, remains the largest and oldest national organization focused primarily on LGBT older people, coordinating direct services for LGBT elders, providing training to aging providers on LGBT cultural competence (through its National Resource Center on LGBT Aging, seeded in 2010 by the US Department of Health and Human Services), spearheading federal and state policy improvements with national and state partner organizations, and producing online consumer resources for LGBT elders related to health, legal, and financial planning, caregiving, and more (SAGE, n.d.f). Old Lesbians Organizing for Change (OLOC) is a national network for lesbians aged 60 and older; its signature programming includes

regional and national gatherings, as well as trainings and resources focused on the manifestations of ageism, a system of attitudes, behaviors, and institutional practices that devalue older people based on faulty or overstated presumptions about old age (Old Lesbians Organizing for Change, n.d.). Additionally, a small group of national organizations have focused programs and initiatives on LGBT older people over the last five years, including among others, the Center for American Progress, the Equal Rights Center, FORGE, the Human Rights Campaign, the National Center for Lesbian Rights, and the National Gay and Lesbian Task Force (SAGE, n.d.). Notably, the American Society on Aging coordinates a national network focused on LGBT aging issues that convenes key experts and produces research, news, analysis, and scholarship on matters relevant to LGBT older adults (American Society on Aging, n.d.).

State Organizations

SAGE affiliates exist in 26 cities and towns around the country (across 19 states and Washington, DC) providing aging services to LGBT elders and engaging in local and state advocacy (SAGE, n.d. e). These affiliates tend to be small in budget size and programmatic scope, and they exist as programs within broader-themes nonprofits or as autonomous organizations (S. Worthington, personal communication, 2014). Additionally, local organizations focused on LGBT elders exist in other parts of the country; notable examples include GLBT Generations (Minneapolis, MN); the LA Gay and Lesbian Center of LA (Los Angeles); Lavender Seniors of the East Bay (Oakland, CA); Openhouse (San Francisco); Sun-Serve (Wilton Manors, FL); and Training to Serve (St. Paul, MN). Three organizations focus on LGBT older people of color: the Azteca Project (Chula Vista, CA); the Detroit Elder Project at KICK (Detroit, MI); and GRIOT Circle (Brooklyn, NY) (SAGE, n.d.d).

Partnerships and Coalitions

To address the policy barriers faced by LGBT older people, nonprofits have formed partnerships and coalitions on a range of issues. SAGE has partnered with the Movement Advancement Project and the National Center for Transgender Equality to author policy reports on LGBT aging and transgender elders, respectively, and it has partnered with groups such as the Equal Rights Center and the National Hispanic Council on Aging to support the research methodologies and report releases of policy studies on housing discrimination and LGBT Latino older people, respectively (Equal Rights Center 2014; Movement Advancement Project and SAGE 2010; National Hispanic Council on Aging 2014; SAGE and National Center for Transgender Equality 2012). In 2010, seven organizations formed the Diverse Elders Coalition, a coalition focused on federal policy improvements for elder of color and LGBT elders; since 2010, the coalition has increased policy awareness and led advances in areas such as the Older Americans Act, the Affordable Care Act, and HIV and aging, among others. This coalition has highlighted how organizations with different marginalized populations can find common areas of interest and leverage their institutional power to affect large-scale change (Espinoza 2011, pp. 8–12). The National Gay and Lesbian Task Force coordinates a “New Beginning Initiative” focused on administrative and regulatory policy opportunities for LGBT people, including a working group of 10–12 national organizations focused on LGBT aging (National Gay and Lesbian Task Force, n.d.). Organizations such as ACRIA (AIDS Community Research Initiative of America), the Gay Men’s Health Crisis, and SAGE have coled national policy research and advocacy related to HIV and aging (SAGE, n.d.). Around the country, nonprofits and individual advocates have formed coalitions and task forces to support policy change for LGBT elders. Three noteworthy examples are the LGBT Aging

Policy Task Force in San Francisco; the LGBT Older Adult Coalition in Detroit, MI; and the LGBT Elder Initiative in Philadelphia, PA. These networks have overseen LGBT elder needs assessments, brought together advocates to produce policy reports and recommendations, and organized meetings and educational seminars on issues affecting LGBT older adults in their communities (Bajko 2013; LGBT Elder Initiative, n.d.; The LGBT Older Adult Coalition, n.d.).

How did this LGBT aging sector come to be, and what can it accomplish in the future, as the needs of LGBT elders grow larger? Adams (2011) describes the historical context, possibilities, and limitations behind the relative growth of the LGBT aging sector since 2005, when the White House Conference on Aging first included LGBT delegates in its decennial gathering. Between 2007 and 2011, Adams notes that SAGE, the largest organization in this field, grew from a \$1.5 million annual budget to nearly \$7 million, and its local affiliates grew from six to 21. Adams argues that early leaders in the LGBT aging field succeeded in developing necessary local services for LGBT older people in different parts of the country, as well as in identifying the various policy barriers affecting LGBT elders, but they struggled with developing the type of institutional capacity (e.g., organizations, networks, coalitions) that could move political and cultural change at the federal and national levels and that could connect the dots among local groups to form a national grassroots movement. The author acknowledges that the election of an LGBT-friendly Presidential administration in 2008, the increased awareness of elders brought on by the aging of the Baby Boom generation, and the pivotal support of a handful of private foundations all contributed to a climate in which organizations such as SAGE could build its infrastructure and policy apparatus. It also created a climate where more organizations could prioritize LGBT older people, at least through discrete programs and initiatives. Nevertheless, the author emphasizes the urgency of policy change that can open up many more government funding streams to LGBT elder programs and

warns that the underfunded LGBT aging field is limited in its ability to focus on large-scale legislative reforms and culture change.

Adams (2011) writes: 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 (p. 18).

Issues to Be Resolved Through Research and Other Scholarship

A 2011 report on LGBT health from the Institute of Medicine calls for additional research on various issues related to later adulthood, including broader demographic and descriptive research (i.e., the number and percentage of elders who are LGBT, across their full diversity); family and interpersonal relations, including the role of families of choice; experiences with health services, including barriers to access and quality of care; physical and mental health; and sexual and reproductive health, including HIV and aging. The report also calls for more research on transgender and bisexual elders (Institute of Medicine 2011, pp. 283–284). More research in these areas could inform the types of programmatic interventions needed to support the full breadth of LGBT older adults. Additionally, the research could yield insight into the specific policy barriers faced by LGBT older people across the spectrum; for example, further research on bisexual older people would identify a host of policy opportunities to support aging among this population.

Further research should also assess the proper implementation of various policy proposals, including how to properly ask elder-appropriate questions related to sexual orientation and gender identity in both surveys and clinical settings—in ways that preserve confidentiality, yield accurate information, and shield LGBT respondents from

prejudice, stereotypes, and discrimination from health providers and social service staff collecting these data (Espinoza 2013a, b). Elder-friendly questions in surveys and clinical questions should be routinely tested and validated, and best practices on these questions should be widely shared across sectors that interact with LGBT older people. Policy proposals also request that agencies within the national aging network, such as state and area units on aging, report the extent to which they conduct outreach to LGBT communities, as well as track the number of LGBT older people they serve (SAGE, n.d.b). Recognizing the possible biases of staff members within the aging network, and the limited resources afforded to aging services in many areas of the country, further research should understand the feasibility of revising local intake forms to better capture these data, as well as how to provide data on LGBT people in cost-effective ways. Around the country, aging providers and LGBT community organizations are developing and implementing programs and services that are meant to support the health, community, and financial security of LGBT older people (Barrios-Paoli and Thurston 2011). Research should assess the impact and effectiveness of these programs, with advice on which programs could yield the best outcomes with the most efficient resources and which programs can be properly replicated throughout the country. The LGBT aging field could benefit from a slate of evidence-based practices that address the various subpopulations that comprise LGBT elders, as well as the range of later adulthood issues outlined in the 2011 IOM report on LGBT health.

Summary

LGBT older people are at the center of a demographic shift that is rapidly changing the US population. As the Baby Boom generation continues turning age 65, millions of LGBT people will become more visible in the aging and long-term care field. This increase in elder

numbers and LGBT visibility has sparked the imagination of policy advocates who have produced a vast literature documenting the many policy barriers faced by LGBT older people. In general, LGBT elders lack the community support, economic security, and proper health and healthcare access to age successfully. They face an array of concerns, from health and economic security, to data collection and housing, to reforming major legislation such as the Older American Act and much more. Recent advances in regard to marriage equality for same-sex couples have shifted the economic supports for legally married LGBT older adult couples, but these federal benefits related to marriage constitute only a small fraction of the inequalities and hardships faced by the broader LGBT older adult population, in particular transgender people, poor and low-income people, and people of color.

Is the current LGBT aging sector sufficiently resourced to meet this demand? Many advocates fear that it is not. The LGBT aging sector needs to grow in its scope and strength, and the broader aging and long-term care must become increasingly responsive to LGBT issues in order to address the profound aging of America. Recently, progress has been made as mainstream aging organizations have begun to lend their support and resources to partnerships and coalitions that are focused on repairing the policy inequities of LGBT older people.

Yet any forward movement in public progress also raises more questions. If the LGBT aging field is able to convince the aging network to track the extent to which they serve LGBT older people, what's the best and most inexpensive way to accomplish this goal, given that we live in an economic era of restrained financial resources? If health and aging providers become increasingly aware about the existence of LGBT people in their clientele, how should we equip these thousands of practitioners with the tools and training to work with this growing demographic? Policy implementation and enforcement is as important as policy advancement, especially when dealing with vulnerable populations.

The LGBT aging field has made significant strides in moving the aging field to the point

where it can ask these more difficult questions—now it needs the large-scale private and public support to move the national dial in support of LGBT elders nationwide.

Learning Activities

Self-check Questions

1. What role do LGBT elders play in self-advocacy?
2. What are the barriers to inclusion of LGBT elders in discussion on aging policy?
3. What are the challenges faced by systemic data collection of LGBT elders in research?

Experiential Exercises

1. Conceptualize ways in which you can advocate on behalf of LGBT elders.
2. Develop an interdisciplinary approach in which LGBT elder can plan and implement self-advocacy strategies.
3. Start a letter writing campaign to state legislators and policy makers to promote fairness and equity for LGBT elders.

Multiple-Choice Questions

1. Which of the following contributed to a climate in which organizations such as SAGE could build its infrastructure and policy apparatus?
 - (a) Election of an LGBT-friendly Presidential administration in 2008
 - (b) Increased awareness of elders brought on by the aging Baby Boom generation
 - (c) Support of a handful of private foundations
 - (d) All of the above
 - (e) None of the above
2. Which of the following is the largest organization in the LGBT aging sector?
 - (a) PFLAG
 - (b) SAGE
 - (c) AARP
 - (d) EEOC
3. Which of the following is a barrier to accessing supportive communities for LGBT Latino people as they age?
 - (a) Biases of more conservative people of faith
 - (b) Lack of environments that embrace LGBT elders as people with multiple identities
 - (c) Compounding challenges of having survived discrimination rooted in their sexual and gender identity
 - (d) All of the above
 - (e) None of the above
4. Which of the following legislation contains an array of barriers in affordable housing, HIV and aging, economic security, and employment?
 - (a) Older Americans Act
 - (b) Senior Citizen Protection Act
 - (c) Elders Anti-Victimization Act
 - (d) LGBT Aging Act
5. When seeking housing in senior-living facilities, LGBT people often experience which of the following treatment?
 - (a) Subsidized funding
 - (b) More information about additional units
 - (c) Required to pay additional fees or cost
 - (d) Undergo an abridged application process
6. Which of the following usually impair LGBT elders' financial security, healthcare access, and level of social support?
 - (a) Broad definition of family
 - (b) Affordable Care Act requirement of routine medical tests
 - (c) Reliance of families of choice that are not legally protected

- (d) Extensive reporting protocols 4-a
7. Which of the following is considered a landmark policy report for laying the groundwork and anticipates the policy advocacy movement on LGBT elders? 5-c
6-c
7-b
8-a
9-c
10-d
- (a) The Aging and Health Report
(b) Outing Age
(c) Expanded and Improved Medicare for All Act
(d) Older Workers; Employment Preferences
8. Which of the following legislation put into place a number of enhancements for LGBT people and seniors to prevent health insurers from denying coverage based on preexisting conditions such as a person's gender identity or HIV status?
(a) Affordable Care Act
(b) Anti-Transgender Discrimination Act
(c) Senior Health Care Equity Law
(d) Medicare
9. Which of the following is a systematic barrier to LGBT-friendly patient-centered health care?
(a) Questions about sexual orientation and gender identity are stated negatively
(b) Questions about sexual orientation and gender identity are too intrusive
(c) Questions about sexual orientation and gender identity are rarely asked
(d) Questions about sexual orientation and gender identity are only intervention-focused
10. Which of the following is the primary reason for LGBT older people avoiding or delaying services?
(a) Fear of diagnosis
(b) Fear of not being screened properly by medical professionals
(c) Fear of being identified by the wrong gender pronoun
(d) Fear of discrimination

Key

- 1-d
2-b
3-d

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