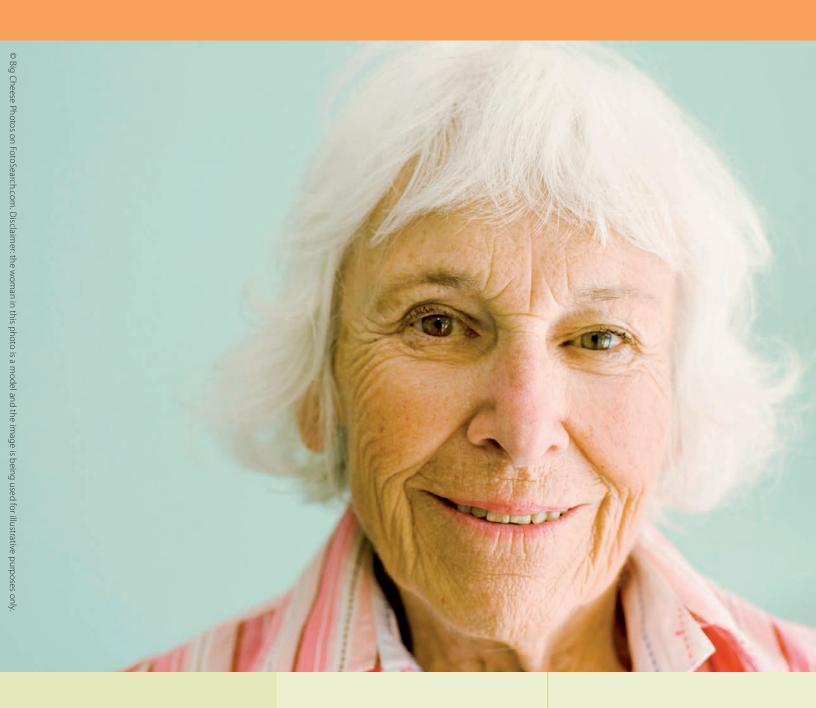
IMPROVING THE LIVES OF LGBT OLDER ADULTS

March 2010









With a foreword by



Authors Partners

This report was authored by:

LGBT Movement Advancement Project (MAP)

The LGBT Movement Advancement Project is an independent intellectual resource for the LGBT movement. MAP's mission is to speed achievement of full social and political equality for LGBT people by providing strategic information, insights, and analyses that help increase and align resources for highest impact. For more information, go to www.lgbtmap.org.

Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (SAGE)

SAGE is the world's oldest and largest nonprofit agency dedicated to serving LGBT older people. Since its inception, SAGE has pioneered programs and services for the aging LGBT community, provided technical assistance and training to expand opportunities for LGBT older people across the country, and provided a national voice on LGBT aging issues. In 2005, SAGE became the first official LGBT delegate at a White House Conference on Aging. In 2010, SAGE was awarded a 3-year, \$900,000 grant from the U.S. Department of Health and Human Services and the Administration on Aging to create the nation's only national resource center on LGBT aging. For more information go to www.sageusa.org.

This report was developed in partnership with:

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The American Society on Aging is an association of diverse individuals bound by a common goal: to support the commitment and enhance the knowledge and skills of those who seek to improve the quality of life of older adults and their families. The membership of ASA is a multidisciplinary array of professionals who are concerned with the physical, emotional, social, economic and spiritual aspects of aging. ASA's 6000 members are researchers, practitioners, educators, business people and policymakers concerned with the physical, emotional, social, economic and spiritual aspects of aging. For more information go to www.asaging.org.

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FOREWORD

As America's 65+ population continues to grow in ways challenging our social and economic fabric as never before, this insightful report reveals the conditions facing America's LGBT seniors. The clear understanding of these challenges provided in *Improving the Lives of LGBT Older Adults* will aid policy makers striving to make sure all Americans can age successfully.

Even as our country moves closer to insisting on fair treatment and full opportunity for all of our people, the effects of long-standing discrimination against the LGBT community remind us of how far we still have to go.

Myths about LGBT persons have long been an obstacle to justice. Even as our society has overcome some damaging stereotypes, other myths linger and hold back progress. Importantly, the report notes the mistaken belief that "LGBT people are more affluent than other Americans."

In fact, a lack of financial security is the fearful reality for a large percentage of LGBT older adults. This report makes a thoughtful and nuanced contribution to the public policy dialogue through its depiction of issues involving financial security, health and health care, and social and community support. The report provides depth to a steadily growing pool of information.

The special challenges facing many LGBT older adults must be kept in mind. Whether it's the problem of aging in isolation or the treatment of residents in institutionalized settings or other issues, many LGBT older adults often face special challenges. This report can help government and nonprofit organizations address some of those challenges.

From a holistic perspective, the report makes it clear that LGBT individuals and the LGBT community at-large have a major role to play in determining the degree to which policy and advocacy issues that affect LGBT older adults are given appropriate consideration. Advocacy with and on behalf of LGBT older people will make a significant difference.

While many members of AARP are members of the LGBT community, the issues raised in this report extend beyond our membership and our organization. It is not only a question of LGBT fairness—the issues raised involve the fair treatment of all Americans, and how our society will promote a secure retirement.

This report will help to inform our country as we move forward to fulfill our highest ideals, appreciate our diversity, take care of each other, and ensure that all our citizens can age with dignity and purpose.

Tom Nelson Chief Operating Officer



EXECUTIVE SUMMARY

Although largely invisible until very recently, lesbian, gay, bisexual and transgender (LGBT) older adults make up a significant (and growing) share of both the overall LGBT population and the larger 65+ population. While confronted with the same challenges that face all people as they age, LGBT elders also face an array of unique barriers and inequalities that can stand in the way of a healthy and rewarding later life. The additional challenges to successful aging faced by 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 or transgender lives in large numbers.

This report examines these additional challenges and how they make it harder for LGBT elders to achieve three key elements of successful aging: financial security, good health and health care, and social support and community engagement. The report also offers detailed recommendations for eliminating—or at least reducing—inequities and improving the lives, and life chances, of LGBT older Americans.

Overview: Key Challenges Facing LGBT Elders

As members of a legally and socially disfavored minority, LGBT elders face three unique circumstances that make successful aging more difficult for them than for their heterosexual counterparts:

- The effects of social stigma and prejudice, past and present. Historical prejudice against today's LGBT elders has disrupted their lives, their connections to their families of origin, their chance to have and raise their own children, and their opportunities to earn a living and save for retirement. The stigma associated with being lesbian, gay, bisexual or transgender continues to stand in the way of full participation in community and society for many LGBT elders. It impedes full and equal access to important health and community services, programs and opportunities.
- Reliance on informal "families of choice" for social connections, care and support. Today, about 80% of long-term care in the U.S. is provided by family members, and more than two-thirds of adults who receive long-term care at home depend on family members as their only source of help. By contrast, LGBT elders are more likely to be single, childless, and estranged from biological family—relying on friends and community members as their chosen family. Official policies, laws and institutional regulations generally prioritize only legal and biological family, and in many instances deny samesex partners, families of choice and other caregivers who do not fall into traditional categories many of the resources afforded to spouses and biological family members.

• Unequal treatment under laws, programs and services. Many laws, program and services 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 fail to provide equal protections for LGBT elders. In large part, this is because they either do not acknowledge or provide protections for LGBT elders' partners and families of choice, or because they fail to recognize and address ongoing stigma and discrimination that result in substandard treatment of LGBT elders.

The challenges identified above diminish LGBT elders' prospects for successful aging by making it harder for LGBT elders to achieve financial security; good health and health care; and social and community support.

At Issue: Financial Security for LGBT Elders

When many people think of LGBT elders, they mistakenly picture affluent individuals or couples living comfortable, urban lives. Contrary to the common stereotype, however, LGBT older adults as a group are poorer and less financially secure than American elders as a whole.

The lifetime of discrimination faced by LGBT elders—combined with the resulting effects on financial security—is compounded by major laws and safety net programs that fail to protect and support LGBT elders equally with their heterosexual peers. Key programs and their impacts are:

- **Social Security.** Despite paying into Social Security in the same manner as their heterosexual peers, LGBT elders are not equally eligible for Social Security benefits. The biggest difference in treatment: committed same-sex couples are denied the substantial spousal and survivor benefits provided to married couples.
- Medicaid and Long-Term Care. For married heterosexual couples, Medicaid has exemptions to avoid requiring a healthy partner to live in poverty to qualify a spouse for long-term care. Unfortunately, these spousal impoverishment protections do not apply to same-sex couples and families of choice.
- Tax-Qualified Retirement Plans. Despite positive changes in the law in recent years, LGBT elders still lack the same benefits as their heterosexual peers when it comes to the treatment of IRAs and similar plans.
- Employee Pensions/Defined-Benefit Plans. Employer policies regarding the Qualified Joint and Survivor Annuity (QJSA) or Qualified Pre-retirement Survivor Annuity (QPSA) deprive same-sex couples of needed financial protections for a surviving partner or chosen family member, though

these protections are available for heterosexual spouses.

- Retiree Health Insurance Benefits. Federal tax law currently allows an employer to provide health insurance to
 the heterosexual spouse of an employee or retired employee as a tax-free benefit; for same-sex couples, a partner's insurance benefits are treated as taxable income.
- **Estate Taxes.** The federal government allows a surviving heterosexual spouse to inherit all of the couple's assets without incurring any tax penalty. By contrast, federal and state laws require same-sex partners to pay inheritance taxes on some estates.
- **Veterans' Benefits.** The U.S. Department of Veterans Affairs provides a variety of benefits to veterans' heterosexual spouses, including pensions paid to the spouse of a service member killed in combat, medical care, and home loan guarantees. These benefits are not available to a same-sex partner.
- Inheritance Laws. In most cases, LGBT elders must put in place a series of specific and often expensive legal arrangements to try to ensure that financial decision making and inheritance will pass to a partner or family-ofchoice member.

Action is needed at both the federal and state levels to improve financial security for LGBT elders. Legal recognition of same-sex relationships at both the state and federal levels would address many of the inequities in government safety net programs. However, the uncertain timeline associated with this approach, coupled with the fact that it still would not help many single elders (both LGBT and heterosexual) who rely on families of choice, means we must also examine broader solutions.

At the federal level, many inequities could be addressed by adding and defining a category of person who is not a spouse (such as a permanent partner), but who would receive equal treatment to a spouse under various federal laws and safety net programs. While a specific state-by-state policy agenda is beyond the scope of this report, the report does outline broad state-level recommendations to advance equality on Medicaid rules, pension and domestic partnership benefits, estate and inheritance taxes, and more.

At Issue: Health and Health Care

Health and health care become increasingly important issues for people as they age. But LGBT elders often find it more difficult than others to receive the health care they need for five major reasons:

- 1.LGBT elders' health disparities are overlooked and ignored. Governments and service providers rarely track, and are largely unaware of, the health disparities of LGBT elders. For example, LGBT elders are more likely to delay getting needed care, and they have higher rates of HIV/ AIDS and chronic mental and physical conditions.
- 2.There is limited government and social support for families of choice. LGBT elders rely on family-of-choice caregivers, who often do not receive the same legal or social recognition as biological family caregivers.
- 3. Health care environments often are inhospitable to LGBT elders. Many professional caregivers are not accepting of, or trained to work with, LGBT elders. These providers may be hostile, discriminatory, or simply unaware that LGBT elders exist.
- 4. Nursing homes often fail to protect LGBT elders. Nursing home rules, together with prejudice and hostile treatment on the part of staff and fellow patients, can create unwelcoming environments for elders who are unable to advocate for themselves.
- 5. Visitation policies and medical decision-making laws often exclude families of choice. Without complex and often expensive legal arrangements in place, LGBT elders' partners or other loved ones may be shut out of medical decision making or denied visitation.

Given the sheer size of the U.S. health care system and the complex network of state and federal laws that regulate it (which are notoriously difficult to reform), multiple approaches to improving health care for LGBT elders are needed. The recommendations to help LGBT and other elders achieve good health and health care center on state and local advocacy (e.g., passing non-discrimination laws, including protections for LGBT elders in state health laws, changing state laws to more clearly recognize partners and families of choice for caregiving and medical decision-making) and provider education and training.

At Issue: Social Support and Community Engagement

Despite a high level of resilience and strong connections to families of choice, social isolation has still been found to be higher among LGBT older adults than in the wider population of elders. In addition to being more likely to live alone, LGBT elders also are more likely to feel unwelcome in, or be unwelcome in, health care and community settings. Research shows the harmful effects of this type of social isolation, including higher depression, poverty, re-hospitalization, delayed careseeking, poor nutrition and premature mortality.

Successful aging for LGBT elders depends on reducing their social isolation. This, in turn, requires addressing four major obstacles to social support and community engagement for LGBT elders, as follows:

- LGBT elders lack support from, and feel unwelcome in, mainstream aging programs. Despite their need for strong social networks, LGBT people often feel unwelcome at senior centers, volunteer centers, or places of worship. Few such agencies engage in outreach to LGBT elders, nor are they prepared to address incidents of discrimination toward LGBT elders by workers and other clients.
- LGBT elders lack support from, and feel unwelcome in, the broader LGBT community. Several authors have commented that ageism is particularly strong within gay male communities. Researchers have also found that many older LGBT people feel disconnected from or unwelcomed by younger generations of LGBT people. While LGBT advocates and organizations are becoming more intentional about reaching out to, involving, and harnessing the talents of LGBT elders, there is still a great deal of work to be done to build bridges within the LGBT community.
- LGBT elders lack sufficient opportunities to contribute and volunteer. Many LGBT older people are, or have the potential to be, powerful advocates for change. Not only can becoming active in this way reduce social isolation and provide a sense of purpose, adults who volunteer regularly have better physical and mental health and a lower risk of mortality. However, older adults as a whole lack sufficient opportunities for community engagement—and LGBT elders often feel unwelcome in, or are overlooked as potential volunteers for, existing volunteer programs.
- Housing discrimination adds to the challenges LGBT elders face in connecting to their communities. LGBT elders may be denied housing, including residency in mainstream retirement communities, based on their sexual orientation and gender identity and expression. This discrimination may separate LGBT elders from loved friends or partners, or push them into homelessness. LGBT elders may also feel the need to re-enter or stay in the closet in order to obtain or maintain housing.

Helping LGBT elders secure social support and community engagement requires action on many fronts. Mainstream aging services providers, for example, need to provide training to staff in cultural competency, while LGBT advocates should offer more programming directed at LGBT elders, plus more opportunities for them to become involved in advocacy and service provision. In addition, state and federal laws should be strengthened to prevent discrimination in housing based on sexual orientation.

Broad-Based Recommendations: Building the Foundation for Change

Much needs to change if we are to address the extra obstacles LGBT elders face to achieving financial security, good health and health care, and social support and community engagement. While the bulk of the report examines needed changes at an issue-by-issue level, the final section of the report examines the larger foundational changes that need to happen in order to support this work, and offers cross-cutting recommendations for improving conditions for LGBT elders. These broad-based recommendations include:

- Provide immediate relief to LGBT elders. Improving conditions for LGBT elders will take time—time that some LGBT elders simply do not have. We must find a way to meet critical needs now, and we can do so by: 1) focusing on increasing funding for (and provision of) LGBT elder programs; 2) helping to meet immediate care needs by providing access to volunteer caregivers; and 3) providing education, tools, and legal services to LGBT elders.
- Build an advocacy infrastructure and a strong coalition of allies. The recommendations outlined in this report represent a major undertaking. Progress will not happen without investment in two key precursors to change: infrastructure to support the movement's goals and sustain an effective advocacy effort; and new relationships and partnerships that can ensure broad-based support.
- Increase understanding of LGBT elder issues through research and public education. There is very little data available about LGBT older people. Advocates should encourage governments and agencies to collect LGBT data in appropriate federal, state and local studies and surveys. In addition, the use of real and personal stories can educate Americans and their elected officials about how current inequities affect the lives of LGBT older adults. Education on these issues also may help heterosexual elders become more accepting of LGBT older adults overall.

This report was intended to provide LGBT and mainstream aging organizations, Americans and their elected leaders with information, inspiration and ideas for improving the lives of LGBT older adults. As such, this report outlines why and how LGBT elders face additional obstacles to successful aging, and lays the groundwork for solutions that will benefit all Americans, whether young, old, heterosexual, or LGBT.

INTRODUCTION

Lesbian, gay, bisexual and transgender (LGBT) older adults are a largely invisible population. While there have always been LGBT elders, relatively few have been open about their sexual orientation until recent years.¹

Despite their relative invisibility, however, LGBT older adults make up a significant (and growing) share of the overall LGBT population and a significant share of the larger 65+ population as well. And, while confronted with the same challenges that face all people as they age, LGBT elders also face an array of unique obstacles that can stand in the way of a healthy and rewarding later life.

Most Americans and their elected leaders are unaware of the many ways in which unequal treatment and ongoing social stigma can hurt and impoverish LGBT elders. Consider the older gay man who loses the family home when his partner requires long-term institutional care; a heterosexual spouse would be protected from the same fate under Medicaid rules. Or consider the lesbian elder who is forced to spend her last days alone in the hospital because the federal government will not grant family medical leave to a close friend who would otherwise take care of her at home.

Heterosexual older adults take for granted the acceptance and support of their family and peers, as well as the benefits, services and protections they receive under the law and through government, community and health services. LGBT elders, however, are not afforded the same acceptance, benefits, protections and services – and the lack of a level playing field can have real and lasting effects.

Unequal treatment of LGBT elders can make it harder for them to achieve "successful aging" (a term used by gerontologists to describe life satisfaction and a sense of well-being in the face of growing older). This report examines the major challenges LGBT elders face in aging successfully. It then looks at how these challenges make it harder for LGBT elders to achieve three key elements of successful aging: financial security, good health and health care, and social support and community engagement. Finally, the report offers detailed recommendations for eliminating, or at least reducing, inequities and improving the lives, and life chances, of LGBT older Americans.

While the focus of this report is on individuals who are both older and LGBT, many of the recommended advocacy solutions would also help single elders, widows, widowers, and older heterosexual domestic partners. The report notes where these solutions could have broader impact.

This report does not address issues that more or less uniformly affect all LGBT people (such as hate crimes), nor does it attempt to analyze broader aging issues such as how to best finance Social Security.

Key Terms

- Lesbian, Gay, Bisexual and Transgender (LGBT). The terms lesbian, gay, and bisexual describe a person's sexual orientation and collectively include women and men who are predominantly or sometimes attracted to individuals of the same sex. The term transgender is independent of sexual orientation and describes those whose gender identity (their inner sense of being male or female) and/or gender expression (their behavior, clothing, haircut, voice and body characteristics) do not match the stereotypes associated with the gender assigned to them at birth—and who often live as members of the "opposite sex."
- Elders/Older Adults. This report interchangeably uses both "elders" and "older adults" to refer to Americans age 65 and older. This terminology has the most widespread acceptance in the aging community. We note, however, that some aging advocates such as Old Lesbians Organizing for Change (OLOC) prefer to simply use the term "old."
- Same-Sex Partner(s). Since most same-sex couples cannot legally marry, we use the term "same-sex partners" to refer to same-sex couples in committed relationships including marriage, domestic partnerships, civil unions, or similar relationships that are not recognized under law.
- **Spouse.** Because the federal government does not recognize the marriages of same-sex couples, this report uses the term "spouse" to refer to the husband or wife in a legally married heterosexual couple.
- Families of Choice. Many LGBT elders rely on life partners, close friends, and other loved ones for caregiving and social support. Because these loved ones are not related by blood or recognized as family under the law, we refer to them as "families of choice."
- Families of Origin/Legal Families. These terms refer to family members recognized under federal law, generally persons related in some manner by blood, marriage or adoption.

¹ To avoid hostility and stigma, many LGBT elders are careful to hide their sexual orientation from others (or may disclose their sexual orientation only to a few trusted individuals). This lack of disclosure is commonly referred to as being "in the closet," whereas LGBT people who are open with others about their sexual orientation are often referred to as "living openly," being "out of the closet," or simply being "out." An LGBT person who is closeted might refer to his or her "roommate," might not bring his or her partner to social events, and might avoid displaying family photos, whereas an openly LGBT person would reference and include the partner.

LGBT Older Adults in Profile

The challenges and inequities facing LGBT older adults are coming into sharper focus at a time when America's overall older population is experiencing unprecedented growth. The 65+ population in the United States, already 20% larger than the entire population of Canada, is expected to double in the next 30 years from 40.2 million to 80.0 million, as shown in *Figure 1*. This rate of growth is four times that of the population as a whole. Moreover, the "oldest old," those age 85 or older, will experience a two-and-a-half-fold increase from 6.1 million today to a projected 15.4 million in 2040, putting increasing pressure on health and long-term care services.³

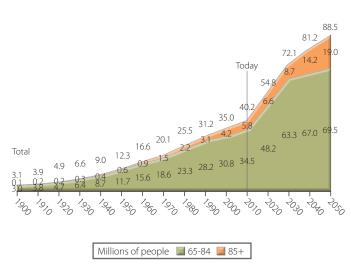
Figure 2 illustrates the dramatic change in the distribution of American society by age and sex—from the "pyramid" shape prevalent until the mid-20th century (many young and few old people), to a "bottle" shape by 2030 (nearly equal cohorts by age). The brown/gold strip follows the "bulge" of 76 million Baby Boomers⁴ who are just beginning to turn 65 in 2010. Older adults are disproportionately women, with almost three women for every two men age 65+, and two women for every one man age 85+. The older population is also becoming increasingly diverse. Today, one in five older adults is Hispanic or non-Caucasian, a number projected to rise to almost one in three older adults by 2030.6

Within this rapidly aging and increasingly diverse older America emerges a distinct population of LGBT older adults. There is no government data on LGBT elders, but UCLA's Williams Institute on Sexual Orientation and the Law estimates that 4.1% of American adults identify themselves as lesbian, gay or bisexual (whether they are open or closeted in larger society). Thus we estimate that LGB people age 65 or older number 1.5 million today and will grow to nearly 3 million by 2030.7 Lesbians will likely be over-represented in these numbers, reflecting both general population trends and the decimation wrought by HIV/AIDS, which disproportionately affected gay men.8

Aging poses unique challenges for LGBT older adults. These challenges are gaining visibility with the aging of LGBT Baby Boomers, who came of age at a time of rising social acceptance of LGBT people and who are the first generation to have lived openly gay or transgender lives in large numbers. With the first LGBT Baby Boomers now reaching age 65 as "out" individuals, new questions are being raised about inequities that can threaten LGBT elders' financial security, health and overall well-being. These inequities create extra barriers that do not exist for heterosexual older adults.

Figure 1: U.S. Population Age 65 and Over

From 1900 to 2050



Source: Through 2000: U.S. Census Bureau, *Demographic Trends in the 20th Century*, Census 2000 Special Reports, CENSR-4, Table 5, November 2002; 2010 to 2050: Population Division, U.S. Census Bureau, Table 12. *Projections of the Population by Age and Sex for the United States: 2010 to 2050 (NP2008-T12)*, August 14, 2008

² Because people are living much longer, distinctions are now sometimes made among the "youngold" (65-74), "old-old" (75-84) and "oldest-old" (age 85+).

³ U.S. Census Bureau, *U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin*, November 18, 2004.

⁴The generation born in the 19 years following World War II (1946 to 1964).

⁵ There are 17.3 million men age 65+, compared to 22.9 million women age 65+; and 1.9 million men age 85+, compared to 3.9 million women age 85+. U.S. Census Bureau 2010 projections.

⁶ Administration on Aging's webpage on diversity, http://www.aoa.gov/AoARoot/AoAPrograms/Tools_Resources/diversity.aspx, accessed December 22, 2009.

⁷ It is difficult to estimate the number of LGBT people age 65 and over, given a lack of data, differing estimates by experts in related fields, and stigma that causes under-identification and under-counting of older LGBT people. Many other sources use "the widespread assumption that between 3% and 8% of the overall population is lesbian, gay, bisexual or transgender," for an estimated 1 million to 2.8 million LGBT elders. See, for example, the Technical Assistance Resource Center: Promoting Appropriate Long-Term Care Supports for LGBT Elders—Program Announcement and Grant Application Instructions, U.S. Administration on Aging, November 2009.

⁸ Judith C. Barker, Gilbert Herdt, Brian de Vries, "Social Support in the Lives of Lesbians and Gay Men at Midlife and Later," Sexuality Research & Social Policy: Journal of NSRC, June 2006 Vol. 3, No 2.
9 Ibid

¹⁰ See footnote 1.

Figure 2 (part 1 of 2): U.S. Population by Sex

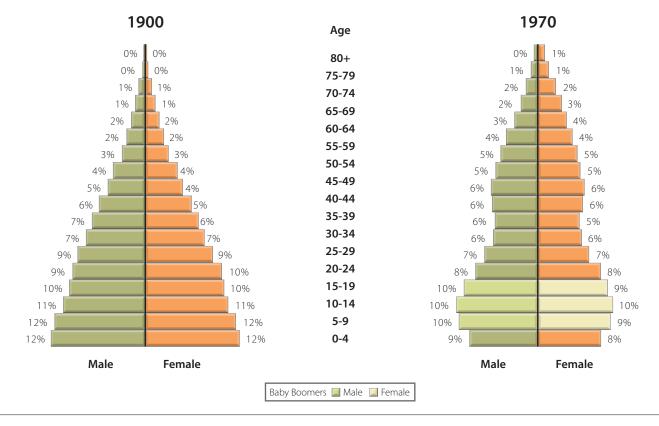
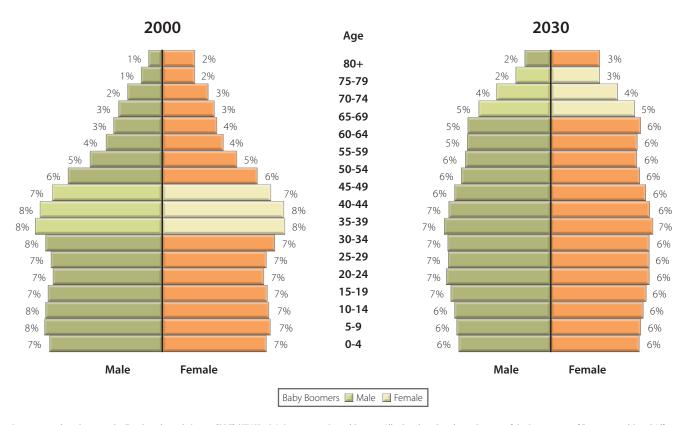


Figure 2 (part 2 of 2): U.S. Population by Sex



Source: 1900 data: Demographic Trends in the 20th Century [PDF] (CENSR-4) A Census 2000 Special Report; All other data: Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat, World Population Prospects: The 2008 Revision, http://esa.un.org/unpp 2

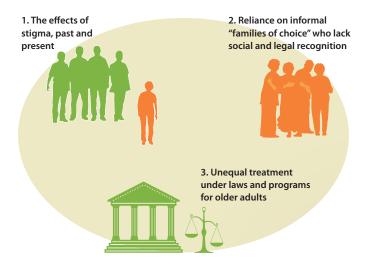
OVERVIEW: KEY CHALLENGES FACING LGBT ELDERS

All older people face considerable challenges as they age, including the frustrations of coping with an aging body and, often, a prolonged period of frailty and dependency at the end of life. Older people also face the challenge of maintaining a valued place in society while aging. There may be gains, such as retirement leisure, but also losses, such as the increasing threat of chronic illness. Leaving a valued position in the workforce, losing parental authority as children leave home, and/or experiencing bereavement with the death of family or friends can create problems for those who are unable to establish new sources of meaning and satisfaction. Adding to these challenges, it is difficult to create new social networks if one is no longer engaged in work or wider community life.

As members of a legally and socially disfavored minority, LGBT elders face significant additional obstacles to successful aging that heterosexual older adults do not. Broadly speaking, three unique circumstances make successful aging more difficult for LGBT people (see *Figure 3*):

- The effects of social stigma and prejudice, past and present.
- Reliance on informal families of choice for social connections, care and support – at a time when government and other institutions largely define family based on marriage and biological kin.
- Inequitable laws and programs that fail to address, or create extra barriers to, social acceptance, financial security, and better health and well-being for LGBT elders.

Figure 3: LGBT Elders Face Unique Challenges to Successful Aging



Challenge 1 — Effects of Social Stigma and Prejudice

An individual's quality of life in old age is influenced to a large extent by prior life experience, including the person's formal education, occupational experience and social



class. This "life course perspective on aging," embraced by most gerontologists, asserts that the last stage of life reflects the conditions of living in all of the stages that came before it. Earlier life events can have long-lasting effects. For example, poverty differences among elders more often than not are the result of differences in life opportunities that took shape decades earlier.

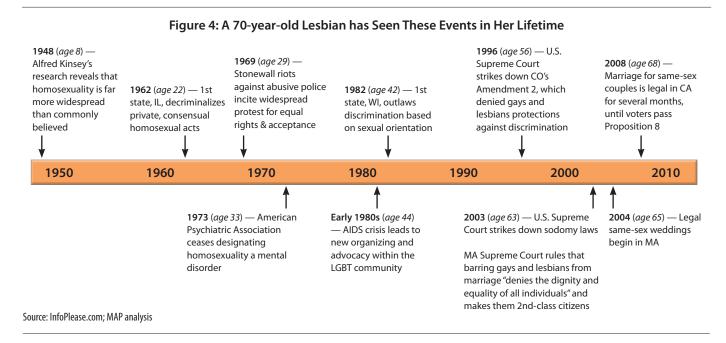
Historical prejudice against today's LGBT elders has disrupted their lives, their connections to their families of origin, their propensity to have and raise their own children, and their opportunities to earn a living and save for retirement. As illustrated in *Figure 4*, the current cohort of LGBT elders age 65+ consists of individuals whose expressions of love have been labeled a psychiatric disorder (until the Diagnostic and Statistical Manual was changed in 1973), a criminal activity (until the last sodomy laws were struck down in 2003), antifamily and immoral (still by many religious groups), and a security risk or morale threat (still by the U.S. military). These individuals have seen AIDS decimate their social networks and destroy their communities. They have felt increasingly unwelcome or invisible in LGBT communities as their bodies showed the effects of aging.

Furthermore, today's LGBT elders came of age at a time when being LGBT and old was viewed in an especially negative light. Douglas Kimmel, Tara Rose, Nancy Orel and Beverly Greene illustrate the historic prejudice and stigma experienced by LGBT elders:

"In the 1970s, often considered the early days of the modern gay movement in the U.S., there was little awareness of aging lesbians, gay men, bisexuals, and transgender people. ... Most of the images of older gay people were not very positive at the time. ... Gay and lesbian bars yielded negative images of old alcoholics mourning their lost youth. Perhaps most insidious was the belief that the gay life was for young people, who should enjoy it while they were still attractive. The stereotype used to disparage homosexuality was, "It may be fun when you're young, but wait until you are old,

¹¹ Barker, Herdt, and de Vries. (2006).

¹² Brian de Vries, "Lesbian, Gay, Bisexual and Transgender Persons in Later Life," in D. Carr (Ed.), Encyclopedia of the Life Course and Human Development (pp. 161-165), Farmington Hills, MI: Gale Publishing (2008).



unwanted, and alone.' Naturally, it was assumed that old lesbians and gays would have no spouses or children to care for them in their old age." ¹³

Researchers have pointed out that LGBT people are subjected to chronic stress related to their stigmatization and experiences of discrimination and violence.¹⁴ This "minority stress" has increased social isolation in LGBT older adults.15 Many of today's LGBT elders, particularly those who faced severe prejudice in their lives, have chosen to remain deeply closeted, but doing so can have devastating effects of its own. For example, according to a 2001 study by the U.S. Administration on Aging, LGBT older adults are only 20% as likely as their heterosexual peers to access needed services such as senior centers, housing assistance, meal programs, food stamps, and other entitlements. The tendency among many LGBT elders to avoid mainstream service providers stems at least in part from a fear of these institutions—and a legacy of harsh discrimination that branded LGBT persons in earlier decades as criminals, sinners, and physically or mentally ill.¹⁶

Judith C. Barker, Gilbert Herdt and Brian de Vries note

"Hiding from wider society the actual nature of one's sexual identity and sexual relationships, concealing the depth of one's emotional partnerships to particular people or gender groups, masking one's participation in the activities associated with a sexual minority community, and obscuring the true nature of one's identity and feelings in the mainstream world of family, school, and work, all have lifelong and serious consequences." 17

Of course, it is not just past discrimination and prejudice that influence quality of life for LGBT elders. The social stigma associated with being lesbian, gay, bisexual or transgender continues to stand in the way of full participation in community and society for many LGBT elders, and full and equal access to important services and opportunities. For example, as openly LGBT elders seek services and care from aging and health services providers, they interact with staff and clients who may harbor longstanding prejudices or simply be unused to working with LGBT elders. Not surprisingly, about one-third of lesbian and gay male Baby Boomers (26% of lesbians and 32% of gay men) identify discrimination due to sexual orientation as their greatest concern about aging.¹⁸

¹⁴ Ilan H. Meyer, "Minority Stress and Mental Health in Gay Men," Columbia University and The City University of New York, *Journal of Health and Social Behavior*, 1995, Vol. 36 (March): pp. 38-56.

¹⁶ Douglas Kimmel, Tara Rose, and Steven David (Eds.), Lesbian, Gay, Bisexual and Transgender Aging: Research and Clinical Perspectives, 6th Edition, New York, Columbia University Press, 2006.

^{13 &}quot;Historical Context for Research on Lesbian, Gay, Bisexual and Transgender Aging," in Douglas Kimmel, Tara Rose, and Steven David (Eds.), Lesbian, Gay, Bisexual and Transgender Aging: Research and Clinical Perspectives, 6th Edition, New York, Columbia University Press, 2006.

L. Kuyper and T. Fokkema, "Loneliness Among Older Lesbian, Gay and Bisexual Adults: The Role of Minority Stress," Archives of Sexual Behavior (epub ahead of print), 2009. While this study did not examine transgender adults, the experiences of LGBT service providers and anecdotal data from transgender adults support similar conclusions.

¹⁷ Barker, Herdt, and de Vries (2006).

MetLife Mature Market Institute, "Out and Aging The MetLife Study of Lesbian and Gay Baby Boomers," November 2006.

Challenge 2 — Reliance on Informal Families of Choice

It is difficult to age well without social support. Some developmental psychologists use the metaphor of a convoy to describe the protective layer of



family and friends who surround an individual and help him or her negotiate life challenges. In this metaphor, individuals are like ships traveling together through life's sometimes turbulent waters, guiding and aiding each other along the way.

When an individual is socially isolated,²⁰ he or she is living without a robust convoy. For older adults, the health risks of this type of isolation can be profound.²¹ Individuals who are frequently lonely suffer higher rates of morbidity, mortality, infection, depression and cognitive decline. Older adults who feel most isolated report 65% more depressive symptoms than those who feel least isolated. The most isolated also are three times less likely than their least-isolated peers to report very good or excellent health.²²

When older Americans begin to need some level of care, the hierarchy of people they can call on before turning completely to the professional, institutional system of long-term care services has been established by tradition. First, they are expected to turn to their spouse and own children; second, to parents and siblings; and third, to in-laws and the spouse's family. Fourth and *last* come friends and other informal caregivers.

This informal hierarchy is seen in practice. Today, about 80% of long-term care in the U.S. is provided by family members, ²³ and more than two-thirds of adults who receive long-term care at home depend on family members as their *only* source of help. ²⁴ This "family-first" hierarchy is codified and supported by official policies, laws and institutional regulations, which in many instances deny caregivers who do not fall into traditional categories many of the resources afforded to spouses and biological family members. ²⁵

Compared to other older people, LGBT elders rely far more heavily on non-traditional (and usually legally and socially unrecognized) caregivers. For example:

• LGBT elders rely less on spouses. Denied legal marriage except in a handful of states that acted only very recently on the issue, most LGB adults over age 60 are single, compared to only a third of heterosexual elders nationwide. A 2005-2007 New York study found that gay and bisexual men over age 50 were twice as likely to live alone as heterosexual men of the same age, while

older lesbian and bisexual women were about a third more likely to live alone.²⁷ In a 2006 study among those age 65 and older in the San Francisco Bay Area, almost three-quarters of gay men and almost half of lesbians reported their relationship status as single,²⁸ while a Los Angeles study found that 75% of gay and lesbian elders lived alone.²⁹ In the case of transgender people, medical providers for many years required candidates for sex reassignment surgery to divorce their spouses, move to a new place and construct a false personal history consistent with their new gender expression. These practices resulted in transgender people losing even more of their social and personal support systems than might otherwise have been the case.³⁰

- LGBT elders rely less on children. Social and legal impediments to family formation have left LGBT older adults significantly less likely to have children. In one San Francisco study, 90% of heterosexual seniors have children, but just 29% of LGBT seniors do.³¹ Similarly, a large New York study found that LGBT elders were four times less likely to have children to assist them.³²
- LGBT elders rely less on parents, siblings and inlaws. Lack of acceptance by their biological families has estranged many LGBT elders from their surviving parents, siblings, aunts, uncles, nieces, nephews and cousins. Other LGBT individuals have attempted to maintain these relationships by staying deeply closeted. While perhaps preventing estrangement, this strategy has shut valued relatives out of an important aspect of the LGBT elder's identity and could have practical effects (e.g., when an

²⁰ As indicated by living alone, having a small social network, low participation in social activities, a perceived lack of social support, and feelings of loneliness.

²¹ Erin York Cornwell and Linda J. Waite, "Social Disconnectedness, Perceived Isolation, and Health among Older Adults," Journal of Health and Social Behavior, Vol. 50, March 2009.

22"Few Friends Combined With Loneliness Linked To Poor Mental And Physical Health For Elderly," Science Daily, March 19, 2009.

²³ B. Coleman, S.M. Pandya, "Family Caregiving and Long-Term Care," AARP Public Policy Institute, 2002. Retrieved from http://assets.aarp.org/rgcenter/il/fs91_ltc.pdf.

²⁴ Fact Sheet: Selected Caregiver Statistics, Family Caregiver Alliance, 2001. Retrieved from http://www.caregiver.org/caregiver/isp/print friendly,isp?nodeid=439

²⁵ Barker, Herdt, anf de Vries (2006).

²⁶ According to the U.S. Department of Health and Human Services, Administration on Aging (2008), 30% of heterosexual elders nationwide are single.

27 Community Health Survey, Bureau of Epidemiology Services, New York City Department of Health and Mental Hygiene, July 2008.

²⁸ M. Adelman, J. Gurevitch, B. de Vries, and J. Blando, "Openhouse: Community Building and Research in the LGBT Aging Population," in Kimmel, Rose and David (2006). Large community survey including 700 participants of at least 50 years of age.

²⁹ D. Rosenfield, D., "Identity Work Among Lesbian and Gay Elderly," *Journal of Aging Studies* Vol. 13, 1999.

30 Kimmel, Rose and David (2006).

³¹ Brian de Vries, "Aspects of Life and Death, Grief and Loss in Lesbian, Gay, Bisexual and Transgender Communities." In Kenneth J. Doka and Amy S. Tucci (Ed.), Living with Grief: Diversity in End-of-Life Care, 2009.

³² SAGE and Hunter College Brookdale Center, "Assistive Housing for Elderly Gays and Lesbians in New York City," October 1999.

¹⁹ Kimmel, Rose and David (2006).

LGBT elder cohabitating with a same-sex partner forgoes care offered by a sibling in order to remain closeted).

• LGBT elders rely more on friends and other informal caregivers. Because of the lack of kin-based social support, friendships become crucial social connections for many LGBT elders. By creating "families of choice," these individuals form strong bonds with an inner circle of friends and others whom they can call in a time of need, often in response to alienation from biological kin.³³

While LGBT elders are only half as likely as heterosexuals to have close relatives to call for help,³⁴ they are more likely than the larger population to rely on families of choice. In a 1999 study, about two-thirds of midlife and older gay men and lesbians identified a family of choice.³⁵ About a third described their friends as equivalent to family; some felt that their friends were like family yet different; and others viewed their friends as family by default ("They're all I have left"). Implicit to many was a sense of mutual dependence with families of choice. For example, one man said, "Gay people have to make their friends their family. If my brother and sister-in-law's friends fell away, they'd still have their family. If my friends fell away, I would have nothing." One woman said, "We need each other in a way that heterosexuals don't. We've led a life of nobody being there."³⁶

While non-traditional caregivers are an important asset, relying exclusively on such caregivers presents tremendous challenges. Families of choice provide a partial, but not complete, solution to the social support needs of LGBT elders because they are not recognized as legitimate (and/ or preferred) providers of care by civil and social institutions and the law. For example, the Federal Family Medical Leave Act does not provide medical leave for a person who wishes to take care of a close friend or unmarried life partner, while caregiver support programs often do not recognize the families of LGBT elders

Another limitation of the family of choice when it comes to caregiving is that it is less likely to be intergenerational. Elderly people who rely on their families of origin as caregivers have the potential for support from children, grandchildren, nieces and nephews. By contrast, friends of LGBT older people are more likely to be roughly the same age – and, as a result, they may not necessarily be capable of providing long-term, extended care because they are facing health challenges of their own.

Finally, it may be more difficult to rely on friends for longer-term or more intense forms of care, in comparison to relying on one's family of origin. According to Barker, Herdt and de Vries:

"Close kin, spouses, or children especially feel a responsibility to provide care to family members, out of a sense of love or respect, a feeling of moral obligation, a long history of association, and gratitude for past favors and mutual aid. Kin—particularly close kin—are supposed to provide help for as long as necessary, often without tangible or immediate rewards, and to be willing to take on emotional and instrumental care including, if need be, intimate or personal care such as bathing or toileting. When based on feelings of moral obligation and responsibility, care [from biological family members] is expected to endure as long as necessary, for years even, until the kin's capacity to provide technically competent care is far exceeded."³⁷

Challenge 3 — Unequal Treatment Under Laws, Programs and Services

The emergence of huge numbers of aging Americans raises new questions about roles and responsibilities in an aging society.



How will major institutions—including federal, state and local governments, employers, and the family—meet the needs of vast numbers of elderly people? With the development of social welfare programs in the second half of the 20th century, the U.S. government assumed a crucial role in helping people age successfully by providing older people with income and expanded access to health care and social services (see sidebar on next page). Today, the portion of the federal budget spent on older Americans is 30% and rising. There is no denying that government action has had a decisive, positive effect on the well-being of today's generation of older people.³⁸

Unfortunately, safety net programs and laws intended to support and protect older Americans fail to provide equal protections for LGBT elders. In large part, this is because they either do not acknowledge or provide protections for LGBT elders' partners and families of choice, or because they fail to recognize and address ongoing stigma and discrimination that result in substandard treatment of LGBT elders. We examine each of these problems in turn.

³³ Brian de Vries, "Gays and Lesbians, Later Life," *Encyclopedia of the Life Course and Human Development*, 2008.

³⁴ SAGE and Hunter College Brookdale Center.

³⁵ B. de Vries and P. Hoctel, "The Family Friends of Older Gay Men and Lesbians", in Teunis and Herdt (Eds.), Sexual Inequalities and Social Justice, Berkeley: University of California Press, pp.213-232.
³⁶ Ihid

³⁷ Barker, Herdt, and de Vries (2006).

³⁸ Harry R. Moody, *Aging Concepts and Controversies*, 6th Edition, 2010.

³⁹ Executive Office of the President, Office of Management and Budget, "The FY 2008 Performance Report of the Federal Government," January 2009. http://www.whitehouse.gov/omb/expectmore/2008Performance.pdf.

The U.S. Government's Increasing Role in Helping Americans Age Successfully

Key Federal Programs Serving Older Americans

Social Security (1935). The Social Security Act is the cornerstone of federal aging policy. Primarily thought of as a government pension program, Social Security provides (among other things) benefits to retirees and people with disabilities based on contributions to the program while they were working. Social Security can be expected to play an even more important role in the financial security of older Americans in the near future because of the decline in defined-benefit employer pensions and the low savings rate of the Baby Boom generation. A modest increase in the payroll tax would assure that all anticipated costs of the program would be met for the next 75 years. Federal spending on Social Security reached \$650 billion in 2009.³⁹

Medicare (1965). Established under the Social Security Act, Medicare provides health insurance coverage to Americans age 65 and over. Medicare does not always pay for all medical costs (premiums, deductibles and co-insurance are not covered), so some elders elect to purchase supplemental coverage called a Medigap plan. Despite this incomplete coverage, Medicare spending is growing both in absolute terms and as a percent of the federal budget. Medicare's growth is almost entirely due to an increase in health care costs as opposed to the effects of an aging population.⁴⁰ Total Medicare spending reached \$425 billion in 2009.⁴¹

Medicaid (1965). Established under the Social Security Act, Medicaid is the primary government funder of long-term care provided in nursing homes, assisted living facilities and via long-term home and community-based services (HCBS). Medicaid is a joint federal and state program and is the fastest-growing component of state budgets. Nearly 40% of all Medicaid benefits go to the elderly, chiefly for nursing home care. Total Medicaid spending reached \$224 billion in 2009.⁴²

The Older Americans Act (OAA) of 1965. This law created a national aging network of comprehensive services for older people, such as nutrition programs, senior citizen centers, home and community-based services, disease prevention/health promotion services, elder rights programs, and the National Family Caregiver Support Program. These services are administered through the National Aging Network, which includes the federal Administration on Aging (see below), State Units on Aging (which plan and disburse federal OAA funds), and Area Agencies on Aging (generally based in city or county governments and responsible for planning and organizing local services).

Key Federal Agencies Serving Older Americans

The Department of Health and Human Services (HHS) is a cabinet department of the U.S. government with the goal of protecting the health of all Americans and providing essential human services.

The Centers for Medicare and Medicaid Services (CMS)

is a federal agency within HHS that administers Medicare and works in partnership with state governments to administer Medicaid. CMS responsibilities also include setting quality standards for Medicaid-funded health service providers and long-term care facilities through its survey and certification process. The certification process is administered through the Joint Commission (formerly the Joint Commission on Accreditation of Health Care Organizations), an independent, nonprofit organization.

The Administration on Aging (AoA) is a federal agency within HHS. Established under the Older Americans Act, AoA, among other things, awards federal OAA grants to state agencies on aging, administers national caregiver support programs, administers long-term care ombudsman programs, awards discretionary grants to aging research organizations, and participates in joint efforts with other agencies such as CMS in executing some elements of the Medicare program. The 2009 federal AoA budget was \$1.3 billion.⁴³

The Department of Housing and Urban Development

(HUD) is a cabinet department of the U.S. government whose mission is to increase homeownership, support community development and increase access to affordable housing free from discrimination. HUD's major programs include: Community Planning and Development (including affordable housing and homelessness programs); Housing (including Supportive Housing for the Elderly); and Fair Housing and Equal Opportunity (which enforces federal laws against discrimination against minority households).

The Social Security Administration (SSA) is an independent federal agency that administers the Old Age, Survivors and Disability Insurance (OASDI) program (commonly known as Social Security), as well as the Supplemental Security Income (SSI) program, a needsbased program for people who are elderly or disabled. SSA also assists in enrollment for the Medicare program.

 Government laws and programs exclude LGBT partners. Many of the programs and laws designed to protect older Americans are founded on the presumption of marriage. Social Security provides extra benefits to spouses, for example, while estate tax law provides tax exemptions for estates passed between spouses. This marriage-centered approach hurts LGBT elders because only five states allow same-sex couples to marry.44 Furthermore, the Defense of Marriage Act (DOMA) prevents the federal government from recognizing state marriages between LGBT individuals even when they do occur. The result: even legally married same-sex couples aren't recognized under any of the myriad federal programs that provide safety and support for older Americans. From Social Security and Medicaid to 401(k)s, pensions, veterans benefits, and employee benefits such as spousal health care coverage for retired workers, partnered LGBT elders face major disparities that have real and lasting impacts on their financial security and health and wellbeing, when compared to heterosexual married couples.

The inability of most same-sex couples to marry (and the federal government's refusal to recognize their marriages when they occur) also has a profound negative emotional impact on LGBT elders. Research indicates that marriage can lead to better health and psychological and material well-being. Marriage also reduces the need to rely on formal services and is the traditional basis for a broad range of informal support, especially among older men.⁴⁵

Government laws and programs do not recognize families of choice. Laws that presume close biological families also hurt LGBT elders. Rules surrounding everything from hospital visitation to inheritance rights prioritize blood relatives over beloved partners, friends and caregivers who happen not to be related by blood. This is true even though, for many LGBT elders, blood relatives may be non-existent, estranged or hostile. Because families of choice receive very limited legal recognition, many LGBT elders put in place a series of complex and often expensive legal arrangements to protect the relationships they cherish. Others, however, cannot afford the necessary legal documents and procedures, or do not know they need them (58% of Americans lack a basic will).46 While the presumption of biological families disproportionately hurts LGBT elders, it also harms any older American (e.g., an older widow without children) who relies on a family of choice rather than a spouse or blood relative.



The federal government and most states exclude same-sex couples from laws and programs designed to protect older Americans. The older couples pictured above temporarily set aside these disparities to celebrate their long-time relationships at the 2008 Thunderstorm Pride March.

 Government laws and programs fail to recognize and address stigma and discrimination. Advocates are still trying to gain basic protections for LGBT elders, such as a federal employment non-discrimination law and state non-discrimination laws that include public accommodations (which would cover nursing homes, senior centers, etc.) Even where legal protections exist, ensuring effective implementation and enforcement is an ongoing struggle; few aging services providers are aware of their responsibilities under the law. Ironically, this historically sanctioned discrimination against LGBT people creates a catch-22 where government agencies do not research or collect data on LGBT elders, but in turn use this very lack of data to argue against a documented need to better serve this population. For example, while the Older Americans Act includes a focus on vulnerable populations, few Area Agencies on Aging explicitly recognize LGBT elders as vulnerable.

⁴⁰ Congressional Budget Office, "The Long-Term Outlook for Health Care Spending," 2007, http://www.cbo.gov/ftpdocs/87xx/doc8758/11-13-lt-health.pdf.

⁴¹ Executive Office of the President, Office of Management and Budget (2009).

⁴² Ibid

⁴³ Administration on Aging website, accessed January 10, 2010, http://www.aoa.gov/AoARoot/Press Room/News/2009/12 18 09.aspx.

In Massachusetts, Connecticut, Iowa, Vermont, and New Hampshire, marriages for same-sex couples are legal and currently performed. New York and the District of Columbia recognize same-sex couples who were legally married in other states, but do not perform same-sex marriages within the state/district. Finally, California recognizes couples who were married between June 16, 2008 and November 4, 2008—i.e., after a Supreme Court decision granting same-sex marriage rights, but before a constitutional amendment in the November 2008 election that again banned marriage for gay couples.

⁴⁵ Ingrid Arnet Connidis, *Family Ties and Aging*, Second Edition, 2010.

⁴⁶ Lawyers.com, "Many Americans Leave Loved Ones Vulnerable, Due to Lack of Estate Planning, New Survey Finds," May 24, 2004, accessed February 16, 2010 at http://research.lawyers.com/Estate-Planning-Survey.html.

Figure 5: The Three Challenges Obstruct LGBT Elders' Successful Aging

How Barriers Impede Successful Aging





Reduced Financial Security

- Inequitable state and federal safety net programs, e.g., Social Security benefits, Medicaid long-term care eligibillity/asset protection
- Inequitable treatment of retirement plans; employer pensions and health benefits; and inheritance

Reduced Health/Health care

- · Health disparities not adequately addressed
- Government provides limited caregiver support for families of choice
- Health care providers can be hostile or lack cultural competency
- Nursing homes leave LGBT elders especially vulnerable
- Medical decision-making laws exclude families of choice



- Hostile or culturally incompetent treatment in services for the aged
- Isolation from LGBT community
- Discrimination in housing access

How the Three Challenges Impede LGBT Elders' Successful Aging

The next three sections of the report show in greater detail how the challenges identified above diminish LGBT elders' prospects for successful aging. The report looks at problems and solutions in three key areas: financial security for LGBT elders; good health and health care; and social and community support (see *Figure 5*). Each section includes detailed analysis of the laws and attitudes that make successful aging more difficult for LGBT elders, plus recommendations to address these obstacles.

AT ISSUE: FINANCIAL SECURITY FOR LGBT ELDERS

Government income programs, housing subsidies, and access to affordable health care and longterm care all play a critical role in



helping American elders avoid poverty. Most older Americans have minimal retirement savings; median household liquid assets for Americans total only \$35,200.⁴⁷ Even with important programs like Social Security in place, median annual income for Americans age 65+ is \$38,304 for married couples, and only \$15,928 for non-married elders.⁴⁸

Furthermore, despite the supports available to them, many older Americans still do not escape poverty. About 10% of American elders live below the official poverty line of \$9,944

for an older individual, with another 6% classified as nearpoor, meaning their income falls under 125% of the poverty level. 49 Combined, about one in six elders is poor or near-poor, and it remains to be seen how the recent economic crisis will impact these poverty rates. Also, older Americans may actually be poorer than these statistics suggest because the methods for determining the poverty level have not changed since the 1950s. The prevailing methodology is based primarily on the cost of food and creates a flat poverty level that is applied uniformly to all age groups. Older Americans, however, spend a far higher percentage of their income on health care and prescription drugs, where costs have skyrocketed in recent years—so their living expenses often are higher than the general population. For example, a recent study by the New York City Center for Economic Opportunity, which modernized the methodology for determining poverty levels, found that 32% of older New Yorkers lived in poverty, versus 18% when looking only at the official federal poverty line (although the same study found poverty rates for those under 18 remained more or less unchanged at 27% using either methodology).50

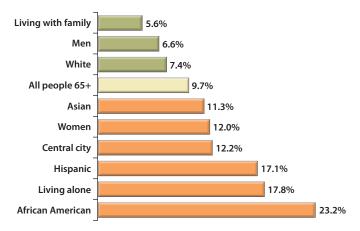
⁴⁷ AARP, The State of 50+ America, 2007; excludes housing and certain other tangible benefits like real estate, vehicles, business property.

⁴⁸ Office of Social Security Administration, *Income of the Aged Chartbook*, 2006, released October 2009. Data is for households headed by a person age 65 or older.

⁴⁹ U.S. Department of Health and Human Services, Administration on Aging, 2008. Poverty rate Is 9.7%, and near-poor rate is an additional 6.4%.

^{50&}quot;The CEO Poverty Measure," The New York City Center for Economic Opportunity, August 2008 working paper.

Figure 6: People Age 65+ Living Below the Poverty Level



Source: U.S. Administration on Aging, A Profile of Older Americans: 2008.

Figure 7: Rate of Poverty

9.1%

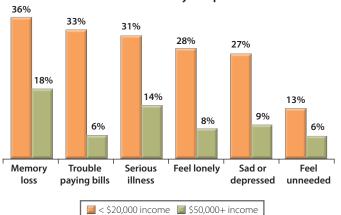
4.6%

4.9%

Senior straight Senior gay Senior lesbian couples couples

Source: Goldberg, Naomi G. "The Impact of Inequality for Same-Sex Partners in Employer-Sponsored Retirement Plans," The Williams Institute, May 2009

Figure 8: Low Income Correlates with Many Problems Faced by People 65+



Source: 2009 Pew Research Center poll of adults age 65+: 285 with incomes <\$20,000 and 273 with incomes >\$50,000.

An additional consideration in assessing the financial security of older Americans is the dramatic difference in financial status within the elderly population. The effects of race, gender and living alone can be profound, as shown in *Figure 6*. For example, elderly African Americans are more than three times as likely as elderly Caucasians to live in poverty, while elderly Hispanics are more likely than the older population as a whole to be poor and in need of long-term care. Elderly women also are highly vulnerable: nearly three out of four older Americans who fall below the poverty line are women,⁵¹ and retirement incomes for older women average only about 55% of that for comparable men.

Assessing LGBT Elders' Financial Well-Being

When many people think of LGBT elders, they often picture affluent individuals or couples living comfortable, urban lives. Contrary to the common stereotype, however, LGBT older adults as a group are poorer and less financially secure than American elders as a whole.

Many older LGBT people lived the majority of their working years in an era when discrimination was legal (as it still is in many parts of the country), job opportunities were limited, and the jobs available to LGBT people were less likely to include health benefits or pensions. For LGBT elders, a lifetime of employment discrimination translates into earnings disparities, reduced lifelong earnings, smaller Social Security payments, fewer opportunities to build pensions, and more limited access to health care than their heterosexual peers. Government safety net programs such as Social Security and Medicaid also often exclude and otherwise fail LGBT elders, creating further economic challenges in their later years. Additionally, living alone is a significant risk factor for poverty among all older adults. Because LGBT older adults are more likely to live alone than the general aging population, they are at a higher risk of poverty.

While no good data exist on poverty rates of transgender elders, independent analysis by UCLA's Williams Institute shows that older gay and lesbian couples face higher poverty rates than married heterosexual couples (see *Figure 7*). Lesbian elders are particularly disadvantaged because of the combined effects of their sexual orientation and the gender gap in wages and savings. In fact, older lesbian couples are twice as likely to be poor as heterosexual couples.⁵² Older lesbian couples are also more likely than heterosexual couples to qualify for public assistance such as Supplemental Security Income (SSI) (72% more likely) or public assistance income (84% more likely).⁵³

⁵¹ U.S. Department of Health and Human Services, Administration on Aging, 2008.

⁵² Goldberg (2009).

⁵³ Ibid.

Overall, 42% of all LGBT elders said "financial problems" are a big concern in their lives. One-third said they are poorly prepared for retirement, and 47% reported having less than \$10,000 in savings and other assets. Fully 30% are concerned about meeting their housing and shelter needs.⁵⁴ Not surprisingly, lesbians are more likely than gay men to worry about outliving their income (60% vs. 55%).⁵⁵

Lack of financial security among elders dramatically impacts not only their standard of living, but also their mental and physical health. Almost all of the challenges of old age are felt more acutely by those in lower income groups, when compared to their peers at the higher end of the scale, as shown in *Figure 8*. Older adults with incomes under \$20,000 a year are three times as likely as those with incomes greater than \$50,000 to say they experience loneliness or often feel sad or depressed. The lower-income group is also twice as likely to suffer memory loss or serious illness.

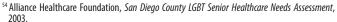
Unequal Impact: Government Programs and LGBT Elders' Finances

The lifetime of discrimination faced by LGBT elders—combined with the resulting effects on financial security—are compounded by major laws and safety net programs that fail to protect and support LGBT elders equally with their heterosexual peers. As a result of this unequal treatment, it is more difficult for LGBT elders to achieve financial security for themselves or their partners, relative to the heterosexual population. In this section, we review how major laws and programs discriminate against LGBT older adults.

Social Security

Social Security is the single most important financial safety net program for older adults in the U.S. Almost all elder households (89%) receive Social Security, and almost a third of single retirees receive income only from Social Security (see *Figure 9*).⁵⁶ The poorest fifth of retired couples rely on Social Security for 80% of their income.⁵⁷ Lacking Social Security, the poverty rate among older adults would rise from just under 10% to almost 50%.⁵⁸

American elders are not automatically granted Social Security; rather, their eligibility and benefit amounts are based



⁵⁵ MetLife Mature Market Institute (2006).



Diane Schroer stands before the Library of Congress, where her job offer was revoked after she came out as transgender. Many LGBT elders have faced such job discrimination over their lives, making it more difficult for them to save for retirement.

Military Hero Faces Job Discrimination Based on Gender Transition

During her 25 years in the United States Army, Diane Schroer, retired from the Army as a Colonel, had been an Airborne Ranger, Special Forces officer, and winner of numerous decorations and medals. She was handpicked to lead a classified national security operation in which she reported directly to Vice President Cheney.

When she retired in 2004, Schroer wanted to put her experience and knowledge of terrorism to good use and found employment as a terrorism and international crime research analyst with the Library of Congress. However, when Schroer told the Library that she was transgender, and wanted to begin work as a female, the job offer was rescinded and she found herself unemployed.

Despite Schroer's knowledge, background, and hands-on experience tracking and targeting international terrorist organizations, the Library of Congress decided she was "no longer a good fit" because, among other reasons, they thought she would not be taken seriously by her peers or by Congress after her transition.

"After risking my life for more than 25 years for my country, I was told that I was not worthy of the freedoms I worked so hard to protect," Schroer said. "I want to be judged by my abilities rather than my gender."

On September 19, 2008, a federal court ruled that under Title VII of the Civil Rights Act of 1964 the Library of Congress had illegally discriminated against Schroer because of her sex. The court's ruling was groundbreaking because it found that discriminating against someone for transitioning from one gender to another is sex discrimination under federal law.

Today, Schroer is enjoying life with her partner and her dog, and is working for the government once again doing what she knows and loves—protecting her country.

Source: http://www.gillfoundation.org/equal-opportunity/career/aclu/

⁵⁶ 2006 Figures from "A Profile of Older Americans: 2008," Administration on Aging, U.S. Department of Health and Human Services, 2008.

⁵⁷ Ibid.

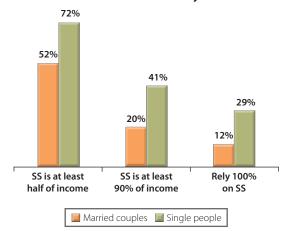
⁵⁸ U.S. Department of Health and Human Services, Administration on Aging, 2008. Current poverty rate among elders is 9.7%, with an estimated 47% living below the poverty line were it not for Social Security.

on how much they contribute to Social Security in the form of mandatory payroll taxes throughout their working lives. Despite paying into Social Security in the same manner as their heterosexual counterparts, LGBT elders are not equally eligible for Social Security benefits. The biggest difference in treatment between LGBT and heterosexual elders is that committed same-sex couples are denied the substantial Social Security benefits provided to married couples. The Social Security benefits denied to LGBT elders include the "spousal benefit," the "survivor benefit" and the "death benefit."

- The "spousal benefit" allows any person who has been or is married to receive the greater of the Social Security benefit that he or she has earned over a lifetime, or 50% of the benefit that his or her past or current spouse has earned (the theory being that one spouse was caring for children and will have lower or no earnings). For example, a wife who has never worked may nonetheless claim \$500 monthly in Social Security if her husband receives \$1,000 monthly. At worst, the lack of spousal benefits can cost an LGBT elder up to \$14,076 a year in lost benefits (assuming one partner earns the maximum monthly Social Security payout and the other does not qualify for Social Security due to lack of legal recognition).60
- The Social Security "survivor benefit" allows a surviving heterosexual spouse (or ex-spouse) to receive the greater of his or her individual benefit or 100% of the spouse's benefit amount. For example, the otherwise ineligible homemaker in the previous example receives \$1,000 monthly upon her husband's death, whereas a lesbian widow without work history receives nothing.⁶¹ In 2004, the Human Rights Campaign (HRC) estimated the average annual impact of the lack of a survivor benefit on a gay man or lesbian who earned less than his or her deceased partner was \$5,528.62 Given that the median income for households of single individuals over age 65 (including widows and widowers) is \$15,928,63 this difference in Social Security payments can literally mean the difference between a survival income and living in poverty. At worst, the lack of survivor benefits can cost an LGBT elder up to \$28,152 a year in lost benefits (assuming one partner earned the maximum monthly Social Security payout and the other does not qualify for Social Security due to lack of legal recognition).64
- Social Security pays a one-time "death benefit" of \$255 when a spouse dies, which often helps cover funeral and burial or cremation expenses.

Of the Social Security benefits denied LGBT elders, the lack of survivor benefits is the most harmful. Not only has the

Figure 9: Percent of Households with High Reliance on Social Security Income



Source: 2006 Figures; "A Profile of Older Americans: 2008" Administration on Aging, U.S. Department of Health and Human Services, 2008.

Figure 10: Annual Social Security Income of Older Couples 2005/2006



Source: Goldberg, Naomi G. "The Impact of Inequality for Same-Sex Partners in Employer-Sponsored Retirement Plans," The Williams Institute, May 2009

⁵⁹ This is both because same-sex partners are seen as legal strangers under DOMA and because the Social Security Act's current definitions of "wife" and "husband" rely on gender-specific pronouns (e.g., a person is a wife of an individual if she is married to him).

⁶⁰ Assuming the worker retires at age 66 and receives the maximum benefit of \$2,346 per month, the worker's spouse would be eligible for a spousal benefit of \$1,173 per month, or \$14,076

⁶¹ This is true even if the heterosexual couple is divorced, as long as they had been married at least 10 years.

⁶² \$5,528 is the average difference in Social Security benefits between two same-sex partners. HRC provides the following example: If one partner earns \$10,000 per year in Social Security income and the other earns \$4,472 and the higher-income partner dies, the surviving heterosexual partner now gets the \$10,000 per year while the surviving gay partner only gets the \$4,472 per year. Lisa Bennet and Gary J. Gates, "The Cost of Marriage Inequality to Gay, Lesbian and Bisexual Older Adults," HRC Foundation Report, 2004.

⁶³ Social Security Administration, "Income of the Population 55 or Older, 2006," February 2009.

⁶⁴ Assuming the worker retires at age 66 and receives the maximum benefit of \$2,346 per month, the worker's surviving spouse would be eligible for a survivor's benefit of \$2,346 per month, or \$28,152 per year.

surviving partner just been widowed, but the legal invisibility of the partner's relationship with the deceased may now leave him or her in financial crisis.

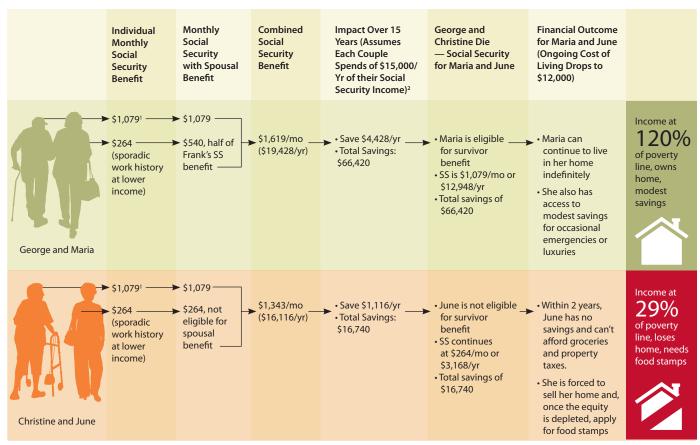
Data show the grim effects of this unequal treatment—lesbian couples receive an average of 31.5% less in Social Security, and gay couples receive 17.8% less, when compared to heterosexual couples (see *Figure 10*),⁶⁵ yet same-sex and heterosexual couples are similarly dependent on Social Security to maintain a living-wage income. For example, in households where both partners are over age 65, Social Security accounts for 33.4% of the income of retired heterosexual couples, 31.1% of the income of retired gay male couples and 36.2% for retired lesbian couples.⁶⁶

Over time, the effects of this unequal treatment compound, as shown in *Figure 11*, potentially leaving a same-

sex couple in poverty, while providing adequate financial security for a heterosexual couple with an identical initial financial situation.

The inequities in Social Security benefits can also create significant hardship for single LGBT elders. Overall, single older adults are highly reliant on Social Security, with 41% of these adults relying on Social Security for 90% of their income. While LGBT elders are much more likely than their heterosexual peers to be living alone, many were once in long-term committed relationships – and many are, in fact, widows or widowers. Any heterosexual elder who has been married for a minimum of 10 years and is not currently remarried is eligible for spousal and survivor benefits. However, LGBT elders are not eligible for benefits based on past committed relationships.

Figure 11: Compounding Effects of Social Security Inequities Can Leave LGBT Elders in Poverty



^{1.} The average Social Security payout for a retired worker.

^{2.} Assumes each couple owns their home and has very modest expenses; however a similar scenario would arise where couples spend more but rely on other sources of income for those additional expenses (e.g., each couple spends \$30,000 per year and relies on \$15,000 of earned income).

⁶⁵Goldberg (2009). Refers to households with at least one member age 65 or older.

⁶⁶ Ibid. The William's Institute used data from the American Community Survey; therefore, the data is slightly different from that of the Social Security Administration, but is still directionally correct. For example, the Williams Institute report states that Social Security provides 33.4% of the income for an average older heterosexual couple, while the Social Security Administration reports that Social Security provides 31.7% of income for an average older heterosexual couple.

^{67 2006} Figures from "A Profile of Older Americans: 2008," Administration on Aging, U.S. Department of Health and Human Services, 2008.

Medicaid and Long-Term Care

While Medicare pays for much of the everyday health care costs of American older adults, it generally does not cover the costs of institutional care provided in nursing homes or assisted living facilities, nor does it cover long-term home and community-based services (HCBS).⁶⁸ An older person requiring these long-term care services must pay for them privately, have long-term care insurance that pays for the care, or, lacking these resources, qualify for long-term care under Medicaid.⁶⁹

Medicaid has been and still is the single largest funder of long-term care in the U.S.⁷⁰ Until recently, Medicaid funding for long-term care focused almost exclusively on institutionalized care. However, Medicaid is increasingly shifting funds towards services that allow older Americans to "age in place" in their communities. Though still a relatively small portion of overall Medicaid long-term care funding, states are now authorized to provide in-home care services as long as they are no more costly than institutionalization.⁷¹ Therefore, HCBS have become an increasingly large part of state Medicaid services.⁷² This makes Medicaid relevant both to the 4% of older adults who live in institutional settings,⁷³ and to the estimated 65%-70% of elders who will need some other form of long-term care services.⁷⁴

Regardless of where services are provided, long-term care is costly. A year's stay in a nursing home averages \$68,000 nationwide⁷⁵ and in-home services cost an average \$18,000 per year, although these costs are often much higher for individuals needing more intensive in-home services.⁷⁶ Only about 10% of all older adults have long-term care insurance,⁷⁷ and since most cannot afford to pay long-term care costs out of pocket, most older adults who require extended long-term care apply under Medicaid.

Qualification rules vary by state, marital status, and the type of care received. Generally, however, elders are required to "spend down" income and assets on long-term care services until they are largely or almost entirely depleted. For married heterosexual applicants, Medicaid has exemptions to avoid requiring a healthy partner to live in poverty to qualify a spouse for long-term care. Under these rules, if one spouse needs longterm care through Medicaid (the "long-term care beneficiary"), the other spouse (generally referred to as the "healthy spouse" or the "community spouse")78 may keep the home, substantial assets and a living-wage income. Unfortunately, these spousal impoverishment protections do not apply to many types of family structures including same-sex couples, families of choice (such as two friends who own a home together), or elder heterosexual couples who live together but cannot afford to or choose not to marry. This different treatment is described below:

Fewer Assets Exempted in Medicaid Eligibility Formulas

For a heterosexual spouse to qualify for either institutional care or HCBS, Medicaid typically pools the couple's assets and allows the community spouse to keep the greater of 100% of the assets up to \$21,912, or 50% of the assets up to a maximum of \$109,560.⁷⁹ In contrast, an LGBT elder must always apply as a single person⁸⁰ and is therefore only entitled to keep a mere \$2,000 in countable assets. The same-sex community partner (a legal stranger under the law) can keep any and all assets in his or her own name, but is not entitled to any assets or property held by the partner receiving long-term care.⁸¹ Whether this different treatment hurts or helps same-sex couples depends on their total assets and who owns them.

⁶⁸ According to longtermcare.gov, Medicare coverage of home health care is "limited to reasonable, necessary part-time or intermittent skilled nursing care and home health aide services, and some therapies that are ordered by your doctor and provided by Medicare-certified home health agency. Medicare does not pay for ongoing personal care or custodial care needs only (help with activities of daily living)." http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care.aspx#National.

⁶⁹There are other federal public programs, such as the Older Americans Act, or state-funded programs, that pay for some long-term care services, but Medicaid is by far the biggest public funder of long-term care.
⁷⁰ Over half (52%) of residents in nursing homes are Medicaid recipients. From Across the States: Profiles of Long-Term Care and Independent Living, AARP, 2009.

Note, however, that the availability of Medicaid HCBS is still somewhat restricted; as a result, many elders requiring in-home services pay out of pocket or receive these services through their local Area Agencies on Aging. Once long-term care needs become more extended, elders are more likely to require care through Medicaid.

⁷² Services covered include: case management, homemaker services, home health aides, personal care, adult day health, rehabilitation, respite care, day treatment, partial hospitalization services, psychosocial rehabilitation services, mental health and other services. From Gary Smith et. al., "Understanding Medicaid Home and Community Services: A Primer," U.S. Department of Health and Human Services, October 2000.

⁷³ In 2007, 4.4% of the 65+ population lived in institutional settings, 1.3% for age 65-74, 4.1% for age 75-84 and 15.1% for age 85+. From *A Profile of Older Americans*: 2008, Administration on Aging, U.S. Department of Health and Human Services, 2008.

74 65% estimate is from P. Kemper et. al., "Long-term Care Over an Uncertain Future: What Can Current Retirees Expect?" Inquiry 2005; 42(4): pp. 335-350; 70% estimate is from the National Clearinghouse for Long-Term Care Information. http://www.longterm.care.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care.Costs_Of_Care.aspx. According to the Kaiser Family Foundation: Medicaid/SCHP: Medicaid/S Long-Term Care Beneficiaries: An Analysis of Spending Patterns, 2006, http://www.kff.org/medicaid/7576.cfm, about 44% of Medicaid Long-Term Care spending was on nursing facilities while 41% was on home health and personal care services. HCBS now account for 65% of all Medicaid community-based long-term care spending.

75 National Center for Long-Term Care Information, http://www.longtermcare.gov/LTC/Main_Site/Understanding_Long_Term_Care/Costs_Paying/index.aspx, 2008. Costs averaged \$74,000 in the MetLife Mature Market Institute study (2006).

⁷⁶ National Clearinghouse for Long-Term Care Information (2008).

"" Protecting The Value Of Long-Term Care Insurance," Medical News Today, June 8, 2009.

⁷⁸ The terminology of "institutionalized spouse" and "community spouse" is most common. However, it presumes a model where Medicaid assistance ends in institutionalization, as opposed to a HCBS model where both spouses remain in the community. Therefore, newer sources often use the term "healthy spouse" to refer to the spouse of a Medicaid recipient, thought this term is equally imperfect as the spouse of the Medicaid recipient may or may not be healthy.

79 These are 2009 asset limits; limits are adjusted annually. In most states, a couple with assets of \$30,000 would keep \$21,912 while a couple with assets of \$100,000 would keep \$50,000, though note that rules vary somewhat by state (for example, some states allow the community spouse to keep 100% of the assets up to the \$109,560 cap). For simplicity, we use the most typical state rules, rather than the exceptions, in our analysis. Note that spousal impoverishment protections are mandator for spouses of institutionalized residents, but rules vary by state in terms of protections for spouses of HCBS recipients. Some states provide standard protections including a spousal allowance of up to \$1,750 per month, and other states simply provide a spousal allowance at the minimum SSI level.

⁸⁰ A same-sex partner must apply as single because, even if married, that marriage will not be recognized.
⁸¹ Non-countable assets include: personal possessions; one motor vehicle as long as it is used for transportation of the applicant or a household member; the applicant's principal residence up to \$500,000 in equity (though states may raise the equity limit up to \$750,000, and states vary in whether the Medicaid applicant must prove a reasonable likelihood of being able to return home); prepaid funeral plans; a small amount of life insurance; and inaccessible assets such as certain types of trusts.

Generally speaking, the current rules hurt the poorest same-sex couples (who make up the majority of couples) while protecting a wealthy minority of same-sex couples, as explained below. Medicaid rules:

- HURT a same-sex community partner with individual assets under \$21,912 (the most common scenario).82 For example, Joe must enter an institution and he has \$100,000 in assets. If Joe is heterosexual and his wife Sally has \$20,000 in assets, Sally keeps \$60,000 (half of the combined assets of \$120,000).83 If Joe is gay, and his partner George has \$20,000 in assets, George can only keep his own \$20,000. George is \$40,000 worse off than Sally.
- HELP a same-sex community partner with assets over \$109,560. For example, Joe must enter an institution and he has \$50,000 in assets. If Joe is heterosexual and his wife Sally has \$200,000 in assets, Sally can keep \$109,560 (half of \$250,000 is \$125,000, but \$109,560 is the maximum allowable under the law). If Joe is gay, and his partner George has \$200,000 in assets, George can keep his own \$200,000. George is \$90,440 better off than Sally.
- May either HURT OR HELP a same-sex community partner with assets between these boundary scenarios. The same-sex community partner is hurt if he or she has fewer assets than the long-term care beneficiary, and helped if he or she has more assets. For example, Joe must enter an institution and he has \$20,000 in assets. If Joe is heterosexual and his wife Sally has \$50,000 in assets, Sally receives \$35,000 (half of \$70,000). If Joe were gay and his partner George had \$50,000 in assets, George could keep the \$50,000 in his own name, making George \$15,000 better off than Sally. However, if Joe had \$100,000 in assets and Sally had \$50,000, she could keep \$75,000 (half of \$150,000), whereas Joe's partner George could still only keep the \$50,000 in George's name, making George \$25,000 worse off than Sally.

When a heterosexual spouse enters a nursing home, the community spouse can keep the couple's home (without equity limit), household goods, an automobile, and burial funds until his or her own death. In contrast, a same-sex community partner may lose the couple's home, depending on who officially owns it. If the home is in the name of the community partner, it is fully protected since they are legal strangers. If the home is jointly owned, the couple risks losing the home, and Medicaid will almost certainly place a lien on the home, creating problems if the long-term care beneficiary dies or the community partner wants to move. If the home is in the name of the long-term care beneficiary, the community partner risks losing the home immediately and will certainly lose it upon the death of the partner in long-term care.

Note that this situation puts same-sex couples in a dilemma, since joint property ownership is often recommended for inheritance purposes, but may put a couple at risk of losing the home if one partner is institutionalized. Also, unlike a married couple, a same-sex couple cannot evade asset spend-down rules or protect their home by transferring assets or property to the community partner. Medicaid will "look back" for five years for any asset transfers, and, if it finds these, evoke a "penalty period," which in effect costs the applicant a sum equivalent to that of the asset transfer.85

See *Figure 12* for an example of how current Medicaid spend-down rules can impoverish same-sex couples and leave them homeless.

Less Income Exempted in Medicaid Eligibility Formulas

To assess an individual's eligibility for care, Medicaid only considers the income of the long-term care beneficiary (the community spouse can keep all of his or her individual income). Medicaid sets a maximum allowable personal income for the long-term care beneficiary and then requires the remaining income to pay for long-term care expenses. The income limit (known as the personal maintenance allowance) varies by state and type of care. For institutionalized care, on average, all but about \$60 per month must go towards nursing home expenses. However, since HCBS recipients must cover their own living expenses, most states allow HCBS recipients to keep, at a minimum, the Supplemental Security Income (SSI) rate of \$674 per month, though many allow higher maintenance allowances.

⁸² Given that the median older American household has financial assets of only \$35,200, excluding home and property values (Across the States: Profiles of Long-Term Care and Independent Living, AARP, 2009), an LGBT community spouse might be expected to have individual median financial assets of half of this household amount, or \$17,600. Therefore, we can infer that the majority of same-sex community spouses have less than \$21,912 in assets and are hurt by the inequitable Medicaid spend-down requirements.

⁸³ Note that this is the minimum amount Sally could keep. Some states would allow Sally to keep 100% of the assets up to the legal maximum, or \$109,560.

⁸⁴www.elderlawanswers.com

⁸⁵ For example, if you live in a state where the average monthly cost of care has been determined to be \$5,000, and you give away property worth \$100,000 during the look-back period, you will be ineligible for benefits for 20 months ($$100,000 \div $5,000 = 20$).

^{*}The basic Medicaid rule for nursing home residents is that they must pay all of their income, minus certain deductions, to the nursing home. Deductions include a \$60-a-month personal needs allowance (this amount may be somewhat higher or lower in particular states), a deduction for any uncovered medical costs (including medical insurance premiums), and, in the case of a married applicant, an allowance for the spouse who continues to live at home if he or she needs income support. A deduction may also be allowed for a dependent child living at home.

⁸⁷ The income limit and methodology for setting it varies by state and is generally based on some multiple of the federal Supplemental Security Income (SSI) rate or federal poverty level.

Figure 12: How Medicaid Asset Spend-Down Rules Can Impoverish Same-Sex Couples

	Initial Assets	Medicaid Spend-down	Final Assets	
George (I/t care recipient) Maria (community spouse)	\$25,000 in joint savingsHome worth \$90,000	 Maria can keep 100% of first \$21,912 Maria can keep home 	Maria keeps: • \$21,912 in savings • \$90,000 home	\$22K savings
Christine (I/t care recipient) June (community spouse)	 \$25,000 in joint savings Home worth \$90,000 in Christine's name 	 Medicaid requires spend-down of half of the joint savings When Christine dies two years later, Medicaid sues June, who has inherited the home, for back costs, forcing sale of the home 	 June keeps \$12,500 in savings June is homeless 	\$12.5K savings

For married couples, the rules are more generous than they are for single elders. Medicaid law generally allows a married person to keep his or her own personal maintenance allowance and to share some or all of his or her remaining income with the healthy spouse. This income sharing is capped at the maximum spousal allowance set by Medicaid, generally \$1,750 per month.⁸⁸

Therefore, a single HCBS recipient might only be allowed an income of \$674 per month, while a couple in the same state might be able to keep \$2,424 per month in joint income (\$674 for the Medicaid recipient and \$1,750 for the healthy spouse). This profoundly disadvantages single elders because, while the cost of living for a couple averages only 35% higher than the cost of living for an individual, ⁸⁹ Medicaid might allow a heterosexual couple to keep over three-and-a-half times as much income.

Medicaid treats same-sex couples the same way as single elders. While heterosexual couples can use the income of the long-term care beneficiary to supplement the income of the community spouse, same-sex couples have no such option. So if George, who is heterosexual, earns \$2,000 in monthly income and is married to Maria, who earns \$750 in monthly

income, Maria can use George's income to supplement her own, leaving Maria at the maximum spousal allowance of \$1,750 (her \$750 in income plus \$1,000 from George). However, if Christine, who is lesbian, earns \$2,000 in income and was partnered with June, who earned \$750 in income, June would only be left with her own \$750 in income, leaving her well below the poverty line (see *Figure 13*).90 Once again, this different treatment only negatively impacts the poorest LGBT elders.91

⁸⁸ Spousal allowance limits vary by state. \$1,750 is the most typical limit for 2009, though the allowance may be as high as \$2,739 per month for institutional care. Spousal allowances for the spouse of a HCBS recipient vary by state but generally fall between the SSI rate of \$674 per month and the more typical limit of \$1,750. Methodology for setting the allowance limit varies by state and often includes complicated formulas that incorporate the community spouse's cost of housing.

http://www.elderlawanswers.com/resources/article.asp?id=7228&Section=4&state.

⁸⁹ MAP analysis based on the difference of the Federal Poverty Line in 2009 for an individual vs. a two-person household, as found at http://aspe.hhs.gov/poverty/09poverty.shtml.

OF For example, assume that Fred has \$3,500 per month in retirement income while Tom only has \$300 per month in retirement income. If Fred is institutionalized, Tom is not entitled to any of Fred's income, and must live off of \$300 per month. If Fred requires HCBS, Fred might be entitled to keep \$674, leaving Fred and Tom to live on a combined income of \$1,074 (Fred's income plus Tom's income). A heterosexual couple in an identical situation might be entitled to \$2,424 per month (\$674 plus the \$1,750 spousal allowance).

⁹¹ Wealthier couples or community spouses, whether LGBT or heterosexual, have sufficient income that they would not require (or be eligible for) the spousal income supplement.

How Medicaid Treats the **Final Monthly** Income as Percent **Initial Monthly** Income Given a \$1,750 Income of of Federal Poverty Income **Spousal Income Allowance Community Spouse** Level • Maria has \$1,750 in \$2,000 • \$60 personal allowance 194% • \$1,000 to supplement monthly income (well above community spouse Only \$940 of poverty line) • \$940 goes to nursing George's monthly home to defray Medicaid's income pays for Medicaid • Can keep \$750 in income > \$750 George (I/t care recipient) Maria (community spouse) June has \$750 in • \$60 personal allowance \$2,000 83% • \$1,940 to pay for nursing monthly income line) • A full \$1,940 of home care Christine's monthly Can keep \$750 in income income pays for Medicaid Christine (I/t care recipient)

Figure 13: How Medicaid Income Rules Can Impoverish Same-Sex Couples

Partner of Alzheimer's Patient in Danger of Losing Couple's Home of 44 Years

June (community spouse)

SAGE clients George, 79, and Ray, 83, have been together for 51 years, the last 44 of which they lived together in their New York City apartment. Ray's health has deteriorated over the past six years as his Alzheimer's disease interferes with daily activities and his relationship with George. Both fear that Ray may soon need to move to a nursing home so that his health can be monitored by professionals, leaving George in a precarious financial situation.

Because the government does not recognize their relationship as the marriage they believe it to be, all of Ray's



income will go to the nursing facility, leaving George to live on his single income that is far lower than Ray's. If the men were legally married under federal law, George would be eligible for spousal impoverishment protections. As it is, though, George will not be able to remain in their home on his own, forcing him to move into a smaller, less expensive apartment, or to accept a total stranger as a roommate in the home that Ray and George have shared, in every way, as a married couple. Both options are undesirable, but having no other choice, George has begun the search for a less expensive apartment as Ray is currently waitlisted at four nearby nursing facilities.

Tax-Oualified Retirement Plans

Tax-qualified retirement plans, such as IRAs, are one of the most common forms of retirement savings in the United States. Under the Pension Protection Act of 2006 and the Worker, Retiree and Employer Recovery Act of 2008, "non-spouse" recipients can now inherit tax-qualified retirement plans without paying taxes on the entire lump sum amount during the year they receive the funds. They can instead withdraw the funds and pay taxes on them over the recipient's lifetime, dramatically reducing their overall tax liability. Thus any "single" person (including a member of a state-sanctioned same-sex marriage, e.g., in Massachusetts) may designate a partner, relative, close friend or other loved one as beneficiary.

While the new law is certainly an improvement for LGBT and single elders, it still leaves some gaps. Surviving heterosexual spouses can leave inherited retirement accounts to grow tax-free until they reach age 70½, but "non-spouse" beneficiaries cannot. Nor can "non-spouse" beneficiaries simply roll plan assets over into their own IRAs. Rather, they must start drawing down a minimum amount of funds each year beginning the year after the original accountholder dies. 96

Over time, this different treatment can have a significant impact on retirement savings and income, especially for those who inherit an account earlier in life. Take the example of a widow who inherits a \$50,000 IRA at age 49½ and invests this amount for a 5% return. A heterosexual widow could use this account to draw \$10,864 per year in after-tax income for 15 years starting at age 70½, while a lesbian widow could draw only \$9,582 in after-tax income for the same period—a difference of \$1,282 per year. Using the same assumptions except changing the age of the widow to 39½, a heterosexual widow could draw down \$17,696 per year in after-tax income, compared to \$14,491 for a lesbian widow, a difference of \$3,205 per year. See Figure 14.

Employee Pensions/Defined-Benefit Plans

Pensions provide an important source of retirement income, with over 40% of older households receiving income from pension plans⁹⁹ and 53% of workers age 50-64 having pension benefits in their current jobs.¹⁰⁰ Under federal law, the pension of a married earner automatically defaults to the Qualified Joint and Survivor and Annuity (QJSA) option, which makes the pension payable (albeit with a smaller monthly payment) over the lifetimes of both the earner and his or her spouse.¹⁰¹ A second option, the Qualified Pre-retirement Survivor Annuity (QPSA), allows the worker's surviving spouse to receive the pension if the worker spouse dies before retiring.¹⁰²

Employers may offer either or both options to coupled LGB employees, but most do not. Of employers surveyed

Figure 14: Difference in Annual Retirement Income from Inherited IRA

Annual Income from Inheritance Drawn Down from Age 65-80



⁹² Tax-qualified retirement plans include 401(K)s, 403(B)s, 457s and IRAs. These plans are eligible for favorable tax treatment. Contributions and earnings on those contributions are tax-deferred until withdrawn for each participant.

⁹³ The PPA allowed companies to optionally offer these "inherited IRA" plans, while WRERA made it mandatory to offer these plans.

⁹⁴ The beneficiary withdraws funds regularly in amounts based on the beneficiary's life expectancy as dictated by the IRS life expectancy table—so a 50-year old beneficiary must withdraw 1/34th of the funds at age 50, 1/33rd of the funds at age 51, etc. See http://www.irs.gov/pub/irs-pdf/p590.pdf for more information.

⁹⁵ Note that married LGBT spouses are still considered unmarried under the current federal law.

Withdrawals must start the year after the death of the original account holder and the beneficiary must take a minimum distribution every year based on his or her life expectancy, whereas a heterosexual spouse could let the account grow tax free until age 70½.

⁹⁷ MAP analysis. Assumes that the heterosexual widow invests the full amount at a 5% compounded return. At age 70½, she then decides to draw down the account in equal amounts over 15 years, at a retirement marginal tax rate of 15%. By contrast, the same-sex widow must start withdrawing from the account at age 50½ in accordance with the IRS life expectancy table. She pays 25% tax on these withdrawals until she retires at age 65, at which point her marginal tax rate drops to 15%. She puts the withdrawals in a savings account, where interest earnings are also taxed at 25% until age 65, then at 15%. Like the heterosexual widow, she earns a 5% gross compounding rate of return on any principal. Also like the heterosexual, widow at age 70½, she then decides to draw down the remaining IRA in equal amounts over 15 years (at a retirement marginal tax rate of 15%) in addition to her retirement savings, which are not taxed beyond tax on interest earned (since she has already paid tax on these funds when initially withdrawn from the IRA). In this scenario, the heterosexual widow can take home \$11,392 per year in after-tax income (combining withdrawals from the inherited IRA and her savings account), versus \$10,061 for the same-sex partner. Scenario uses IRS life expectancy table found at http://www.irs.gov/pub/irs-pdf/n590.pdf

⁹⁸ Same analysis as above, except the lesbian widow must start withdrawing funds at a 25% tax rate at age 40½.

⁹⁹ Figures are for 2006. From "Fast Facts and Figures," Social Security Administration, 2008. In 2006, 29% of older households received income from private pension plans and 14% received income from government pensions.

¹⁰⁰ The State of 50+ America, AARP, 2007.

¹⁰¹ Single heterosexual elders may also receive pension or survivor income from an ex-spouse, e.g., as part of a divorce settlement or because the pension holder did not change the joint survivor option despite a break in the relationship.

¹⁰² If the worker spouse dies before retiring, the other spouse gets the pension in the year in which the deceased spouse would have started receiving the pension.

for HRC's 2010 Corporate Equality Index who offer defined-benefit plans, only 56% of employers offered QJSAs for same-sex partners, and only 45% offered them QPSAs.¹⁰³ This is despite the fact that QJSAs are cost-neutral to the employer¹⁰⁴ and QPSAs increase the employer's cost by only about 0.2% to 0.3%.¹⁰⁵ For heterosexual couples, QJSAs are considered so important that they are the automatic default under federal law,¹⁰⁶ and it is mandatory that employers offer QPSAs.

Lack of these options can deprive surviving partners in same-sex couples of needed pension income that is available to their heterosexual peers. Similarly, when these options are extended only to legally married spouses, it prevents single elders from protecting "non-spouse" loved ones such as friends, relatives or caregivers.

Unfortunately, even if all same-sex couples were offered QJSAs tomorrow, these changes would likely come too late for elders who are already retired. This is because QJSAs must be elected before retirement so the payment amount can be reduced accordingly. It would likely be infeasible to offer these options retroactively.

However, with more than half of workers age 50-65 today expecting to receive a pension from their current employers, QJSAs would allow them to protect those they love after retirement; and QPSAs would offer security to a loved one in case of death prior to retirement.

Defined-Contribution vs. Defined-Benefit Plans

Defined-Benefit Plan (traditional pension or fixed pension) – In these plans, an employee receives a set monthly amount upon retirement, guaranteed for life or for the joint lives of the employee and his or her spouse. This benefit may also include a cost-of-living increase each year during retirement. The monthly benefit amount is based on the participant's wages and length of service.

Defined-Contribution Plan – Most tax-qualified retirement plans, such as 401(K)s, are defined-contribution plans. In these plans, which are becoming increasingly common, the employer and employee make pre-determined contributions to a participant's account during employment, but with no guaranteed retirement benefit. The ultimate benefit is based exclusively on the contributions to, and investment earnings of, the plan. The benefit ceases when the account balance is depleted, regardless of the retiree's age or circumstances.

Retiree Health Insurance Benefits

Federal tax law currently allows an employer to provide health insurance to the heterosexual spouse of an employee or retired employee as a tax-free benefit.¹⁰⁷ However, when employers offer the same benefit to same-sex couples, federal law treats the value of the partner's insurance as taxable income and the LGBT retiree then pays income taxes on this benefit.¹⁰⁸

Taxation of health benefits costs the average LGBT employee with domestic partner benefits \$1,069 more per year in taxes than a married heterosexual employee with the same coverage. Because of these disparities, many samesex elders simply are not offered, or cannot afford to receive, domestic partner benefits. Slightly more than half (54%) of large firms electively offer health insurance to domestic partners of LGB workers; for the overwhelming majority of these firms (88%), the cost of offering this insurance is less than 2% of total benefit costs. It is not clear how many of the employers with more expansive benefits offer health insurance benefits to retired employees, though almost one-third of all large companies nationwide do so. Ita

Regulation of employee benefits falls under the federal Employee Retirement Income Security Act (ERISA), which does not recognize same-sex domestic partners because of DOMA. Therefore, even states with marriage equality cannot require employers to offer benefits to same-sex couples (though employers can offer these benefits electively).

Human Rights Campaign, "Corporate Equality Index 2010," http://www.hrc.org/documents/HRC_Corporate_Equality_Index_2010.pdf.

¹⁰⁴ A simplified example illustrates how this works. Bob has a life expectancy of 15 years at retirement. His pension is \$10,000 per year. Therefore, his company expects the cost of his pension to be \$150,000 (15 x \$10,000). Bob elects the QJSA so that his wife, Sue, will continue to receive income upon Bob's death. The combined life expectancy for the couple is 20 years. Therefore, Bob and Sue now receive \$7,500 per year in pension income, for an expected cost of \$150,000 (20 x \$7,500).

¹⁰⁵ Gary A. Shulman, Qualified Domestic Relations Order Handbook, 2006, p 7-7. For example, participants who have this plan in place for 10 years would suffer only a 2-3% reduction in accrued benefits.

¹⁰⁶ Employee Retirement Income Security Act as amended by the Retirement Equity Act of 1984. Note that for same-sex couples and elders, unless an employer electively chooses to offer QJSAs to same-sex couples, the default pension distribution is that of a "single" person, meaning most same-sex couples are not able to provide income protections for a surviving spouse.

¹⁰⁷ At time of writing, health care reform includes debate on taxation of high-cost health care plans (e.g., plans costing over \$25,000 annually).

When these benefits are offered, the IRS typically requires employers to determine a fair market value of the benefit, report it on the W-2 form, and then tax it.

¹⁰⁹ Lee Badget, "Unequal Taxes on Equal Benefits: The Taxation of Domestic Partner Benefits," Center for American Progress and The Williams Institute, December 2007.

¹¹⁰ SpecSummary: United States Salaried: 2007–2008, Hewitt Associates, 2007.

[&]quot;Benefit Programs for Domestic Partners and Same-Sex Spouses," Hewitt Associates, July 2005.

¹¹² According to the Kaiser Family Foundation, 31% of companies with 200 or more workers offer retiree health benefits to supplement Medicare for former employees age 65 and older.

Trooper Denied Pension of 15-Year Partner Killed in Line of Duty

On Christmas Day 2009, Missouri State Highway Patrol Corporal Dennis Engelhard, 49, was killed by a car that lost control in the snow as Engelhard was placing flares near the scene of a minor accident. Official information released by the Highway Patrol described Engelhard as single. However, Engelhard, openly gay, left behind a partner of 15 years, Kelly Glossip, who was not mentioned in the obituary or recognized at the funeral.

Glossip said his relationship with Engelhard was no secret—they lived together in a modest home they owned together, and Glossip was listed as Engelhard's emergency contact. They also showed up together at a Fourth of July party attended by other troopers. Glossip, on medical leave from his job in patient billing due to back problems, relied on Engelhard to help pay the mortgage and other bills, and to support a teenage son from a previous marriage. He now wonders how he will make ends meet.

If Engelhard had been married, his spouse would be entitled to lifetime survivor's benefits from the state pension system—more than \$28,000 a year. But neither the state Highway Patrol pension system nor Missouri law recognizes domestic partners.



Kelly Glossip poses for a photo as he holds a picture of himself and longtime domestic partner Dennis Englehard, Friday, Jan. 29, 2010, in Robertsville, Mo. Glossip said he was both grieving a death and struggling financially after Englehard was killed in the line of duty, leaving Glossip with no right to his partner's pension.

"The partner, plain and simple, is out of luck," said state Rep. Mike Colona. "I'm outraged that that's the situation, but it's the status of the law."

BackStoppers, which provides assistance to the families of local officers killed in the line of duty, gave \$5,000 to Engelhard's parents after he was killed. "The parents are the legal next of kin," said BackStoppers director Ronald A. Battelle. The MASTERS, a fraternal organization for Missouri state troopers, also typically helps family of patrol members who die in the line of duty—including up to \$50,000 in mortgage payments. However, at the time of this writing, the organization is still deliberating whether to provide assistance to Glossip.

"We have never paid benefits to a girlfriend or boyfriend," said Fred Mills, one of the group's directors. "It's always been spouse and/or children."

Glossip still lives in the house he shared with Engelhard, and is dismayed at the fact that he has been unfairly treated. "It just hurts so bad. I am his spouse — we loved each other," he said. "I wouldn't want anyone else to have to go through this."

Source: www.stlouistoday.com, "Trooper's Partner May Not Get Benefits," January 30, 2010; and Associated Press (M0), "Late Highway Patrol Trooper's Partner Laments Lack of Legal Protection," February 1, 2010.

Estate Taxes

As of this writing, federal estate tax law is in flux. The current law expired in 2010, eliminating all federal estate taxes. However, unless Congress acts, estates over \$1 million in assets will be subject to tax as of 2011.113

While only a small fraction of all estates are affected by the estate tax, the burden can be especially significant for, and grossly unfair to, higher-net-worth same-sex couples who are affected. The federal government allows a surviving heterosexual spouse to inherit all of the couple's assets without incurring any tax penalty. By contrast, a same-sex partner pays taxes of 45% on any inheritance over the federal exemption limit. If the 2011 exemption limit is \$1 million per individual, it will affect any same-sex couple with over \$2 million in joint assets (home values are included in the estate valuation.)¹¹⁴ UCLA's Williams Institute estimates that, in 2011, same-sex couples affected by estate taxes will lose an average of \$1.1 million per couple due to inequitable laws.115

In addition to the federal estate tax, 23 states and the District of Columbia collect estate and/or inheritance taxes. 116 In all of these states, transfers of assets to a spouse are exempt from the tax—and in some states, transfers to children and close relatives are also exempt. 117 Some of these states treat same-sex couples the same as heterosexual couples, and most states have an exclusion of at least \$2 million per individual (or \$4 million per couple), meaning any unfair taxation primarily affects higher-net-worth couples. However, a small number of states tax "non-spouse" asset transfers of much smaller amounts, as shown in the Table 1. For example, Ohio taxes estates over \$338,333 and Pennsylvania has a 4.5%-15% inheritance tax on all estate transfers between legal strangers, 118 meaning the surviving same-sex partner could end up having to sell the home to pay the estate or inheritance tax.

Veteran's Benefits

Over 25% of elders in the United States are military veterans. 120 The U.S. Department of Veterans Affairs provides a variety of benefits to veterans' heterosexual spouses, including pensions paid to the spouse of a service member killed in combat, medical care, and home loan guarantees. These benefits are not available to same-sex couples and impact gay and lesbian service members in three ways:

• First, under Don't Ask, Don't Tell, gay and lesbian service members may entirely lose the pension and other benefits they have earned through long years of service after being unfairly discharged simply because of their sexual orientation.

Table 1: Worst States for Same-Sex Couples Passing on an Estate¹¹⁹

State	Estate Tax Limit	Inheritance Tax
Indiana	N/A	1% to 20%
Kansas	\$1 million	N/A
Kentucky	N/A	4% to 16%
Minnesota	\$1 million	N/A
Nebraska	N/A	1% to 18%
New York	\$1 million	N/A
Ohio	\$338,333	N/A
Oregon	\$1 million	N/A
Pennsylvania	N/A	4.5% to 15%
Rhode Island	\$675,000	N/A
Tennessee	\$1 million	N/A

¹¹⁴ Assuming a couple has \$2 million in joint assets, upon death, the surviving partner is assumed to already own \$1 million of the assets and to inherit the other \$1 million of the assets. Therefore, a \$1 million individual estate tax limit protects couples with up to \$2 million in joint assets.

115 Michael D. Steinberger, "Federal Estate Tax Disadvantages for Same-Sex Couples," Williams Institute, March 2009. This report notes that same-sex couples are also "excluded from Familyowned Farm and Closely Held Business Provisions in the estate tax, further limiting their ability to transfer assets to their children." The discussion of this provision is beyond the scope of this

Retirementliving.com, http

¹¹⁹This list does not include the District of Columbia, Iowa, Maine, Maryland, Massachusetts, and New Jersey, which have various lower-limit estate and inheritance taxes, but exempt same-sex married couples and/or domestic partners.

There were 9.2 million veterans aged 65 and older in 2008. Source: U.S. Department of Veterans Affairs, unpublished data. http://www.census.gov features_special_editions/014342.html. Total population aged 65 and older in 2008 is 36.8 million.

¹¹³ According to the Economic Growth and Tax Relief Reconciliation Act of 2001, the estate tax is repealed in 2010, but then the act "sunsets" in 2011 and the estate tax reappears with an applicable exclusion amount of \$1 million per individual or \$2 million per couple. However, under the Obama plan detailed during the 2008 campaign, the estate tax would be locked in permanently at the \$3.5 million exemption rate, with estates above that value taxed at 45%. It is widely expected that this solution will be implemented before 2011.

¹¹⁶ An inheritance tax is an assessment made on the portion of an estate received by an individual (e.g., John inherits \$75,000 and must pay tax on it). An estate tax is levied on an entire estate before it is distributed to individuals (e.g., George leaves an estate of \$500,000; the state taxes this estate before distributing the remaining funds). As of 2009, the District of Columbia and the following states impose a separate state estate tax: Connecticut, Delaware, Illinois, Kansas, Maine, Maryland, Massachusetts, Minnesota, New Jersey, New York, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, and Washington. The following states collect a state inheritance tax: Indiana, Iowa, Kentucky, Maryland, Nebraska, New Jersey and Pennsylvania. (Note that Maryland and New Jersey collect both state inheritance taxes and state estate taxes). http://wills.about.com/od/ur

Retirementliving.com, http://www.retirementliving.com/RLtaxes.html.
 As of 2009, the District of Columbia, Kansas, Maine, Maryland, Massachusetts, Minnesota, New Jersey, New York, Ohio, Oregon, Rhode Island and Tennessee all have estate taxes at or below \$1 million, and therefore, would have the greatest potential adverse consequence for LGBT elders bequeathing assets. See http: htm. States such as lowa provide equal treatment for married same-sex couples, but still tax gifts to families of choice at exemption levels lower than most other states. As of 2009, Indiana, Iowa, Kentucky, Maryland, Nebraska, New Jersey and Pennsylvania collect a state inheritance tax. Of these, all states exempt transfers between spouses, while only New Jersey and Maryland exempt transfers between same-sex partners. http

- Second, benefits available to heterosexual spouses of veterans—such as bereavement counseling, death pensions, vocational training, education, certain medical care, home loan guarantees, and a burial flag—are not available to same-sex partners. For example, a same-sex partner would not receive dependency and indemnity compensation of \$1,154 per month if his or her partner was killed or totally disabled in the line of duty, despite this benefit being available to heterosexual spouses. Additionally, same-sex couples are not eligible for the needsbased death benefit paid to an un-remarried surviving spouse of a deceased wartime veteran.¹²¹
- Third, veterans' hospitals fall under federal law and therefore do not recognize same-sex partners or families of choice, raising issues around visitation rights and medical decision making if a veteran obtains medical services through these providers.¹²²

Inheritance Laws

The death of a life partner is devastating for all elders. However, heterosexual spouses take for granted that, when one person passes, the couple's relationship and the life they built together will be both recognized and valued under the law, and their life savings and family home will pass to the surviving spouse. Same-sex couples have no such assurance.

In most cases, same-sex couples must put in place a series of specific and often expensive legal arrangements to try to ensure that financial decision making and inheritance will pass to a partner. Common documents that specify inheritance include a will, a revocable living trust (which is more difficult to contest than a will), and a pour-over will (which ensures that anything left out of the living trust is included). A financial power of attorney designates someone who can act as a financial agent in case of incapacitation or death. Unfortunately, many elders are not aware of the need for these documents, while others do not have the means to seek professional help and may end up without the proper legal documents (or with documents that are improperly executed).

Without these documents, a complex set of state laws, known as intestacy laws, automatically direct who will inherit property. Rules vary by state but generally prioritize spouses and then legal family members, meaning a life partner or members of a family of choice can be totally shut out of shared retirement savings and/or the family home. Same-sex couples who can legally marry in their state have the same right to inherit as heterosexual couples; and a few states, such as Colorado, provide mechanisms for domestic partners to designate each other to inherit property in the absence of a will. However, most state intestacy laws do not recognize domestic partner relationships.

Legal Documents Can Cost LGBT Older Adults Thousands

A recent *New York Times* analysis estimated that gay couples might spend "\$5,500 more than their heterosexual counterparts on their additional paperwork," including a revocable living trust, a pourover will, financial powers of attorney, health care proxies, living wills and a domestic partnership agreement.¹²⁴

Real-life costs are often much higher. Legal documents for Illinois couple Stephen Lev and Chad Feltrin included four powers of attorney (two each); two privacy waivers that allow each access to the other's medical records; two wills; and a trust for the property they own together. Similarly, Howard Wax and Robert Pooley, Jr., who have been together nine years, paid \$10,000 for an attorney to help them draw up wills, trusts, and financial and medical powers of attorney that together approximated some of the legal protections of marriage.

"I feel at least like we're secure now," said Wax. "It's not perfect, but we're OK." 125

Even with legal documents in place, LGBT elders, whether single or coupled, may face legal challenges from biological family members, incurring additional expense.

¹²¹ The deceased veteran must have been discharged from service under other than dishonorable conditions, and must have served at least 90 days of active military service, one day of which was during a war time period. If he or she entered active duty after September 7, 1980, generally he or she must have served at least 24 months or the full period for which called or ordered to active duty. A heterosexual surviving spouse receives this death benefit if his or her countable income is below a yearly limit set by law, currently \$7,933 for a spouse without a dependent child. The yearly limit on income is set by Congress. The VA pays the difference between the spouse's countable income and the annual rate of payment established by Congress. From U.S. Department of Veterans Affairs https://www.vba.va.gov/VBA.

¹²² This issue is discussed in greater detail in the Medical Decision Making section of this report.

¹²³ Financial powers of attorney can also be changed at any time, as long as a person is still of sound mind. Potential powers conferred on the agent include using assets to pay bills and other expenses; buying, selling, maintaining, and paying taxes on real estate or other property; collecting inherited property; collecting public benefits (e.g., Social Security, Medicare, veteran's benefits); investing money in stocks and bonds and managing retirement accounts; making transactions with banks or other financial institutions; buying or selling insurance policies; and filing and paying taxes.

¹²⁴ Tara Bernard and Ron Lieber, "The High Price of Being a Gay Couple," New York Times, October 2, 2009.

^{125 &}quot;\$10,000 for Peace of Mind: Same-sex Couples Find Replicating Legal Protections of Marriage Costly," McClatchy-Tribune News Service, January 21, 2010, drawn from: http://www.cleveland.com/nation/index.ssf/2010/01/10000 for peace of mind same-s.html.

Survivor Challenged for Home and Assets of Partner of 28 Years

For 28 years, Frank Vasquez and Robert Schwerzler shared a life together in rural Washington state, including a home, business and other property. When Schwerzler died suddenly, leaving all of the couple's property titled only in his name and no legal documents stipulating his wishes, Vasquez was left with no claim to the assets they had accumulated over the years.

Schwerzler's elderly siblings — his legal heirs — demanded that Vasquez move out of the house and turn over the business and all the couple's other assets to them, contending that Schwerzler had not been gay and that Vasquez had been merely a boarder taking advantage of Schwerzler's generosity. After a series of trials and legal appeals, the dispute was settled, with Vasquez retaining the ability to stay in his home but receiving no financial assets for his ongoing living expenses. He therefore ended up with only a small portion of what he would have received had Washington's inheritance laws automatically recognized same-sex couples. 126



Terry Barnett, the attorney for Frank Vasquez whose long-time companion died without a will, leaves the podium after presenting arguments to the state Supreme Court Tuesday, Feb. 13, 2001 in Olympia, Washington.

LGBT legal services organizations have collected many stories of surviving partners of long-term same-sex relationships losing their homes and life savings to hostile and/or acquisitive members of the deceased partner's family. Additionally, single LGBT elders who are estranged from their biological families may end up unintentionally leaving their life savings to relatives who disparaged them, rather than loved friends or trusted caregivers.

Recommendations: Helping LGBT Elders Achieve Financial Security

Achieving financial security for LGBT elders will require the pursuit of a comprehensive advocacy agenda that explicitly focuses on an issue-by-issue approach to solving the inequities outlined above. LGBT advocacy organizations do not need to advance this agenda on their own. Many of the safety net gaps that affect LGBT elders also affect at least one of the following: elder heterosexual domestic partners, single elders, widows, widowers, or any elder outside the bounds of an existing, federally recognized marriage. Advocates of all stripes should therefore work together to build an inclusive agenda that improves the financial security of LGBT and other elders.

The recommendations outlined below call for action at both the federal and state levels. Because many of the

inequalities faced by older same-sex couples stem from a lack of relationship recognition, we consider efforts to secure relationship recognition rights and to overturn the federal DOMA¹²⁷ as part of an LGBT aging agenda (though they are normally not explicitly recognized as such). While legal recognition of same-sex relationships would address many of the inequities in government safety net programs, the uncertain timeline associated with this approach, coupled with the fact that it still would not help many LGBT elders, means we must also examine broader ways to ensure that LGBT elders can achieve financial security.

At the federal level, many inequities could be addressed by adding and defining a category of person who is not a spouse, but who would be treated as a spouse (such as a permanent partner) under federal laws. This approach could cover all LGBT elders, whether or not they could legally marry, and could be used across myriad federal programs such as Social Security, Medicaid and more (see sidebar on next page).

¹²⁶ Excerpted/adapted from Lambda Legal at http://www.lambdalegal.org/in-court/cases/vasquez-v-hawthorne.html.

At the urging of LGBT advocates, Congress introduced a bill to repeal DOMA in September of 2009. There are also three current federal lawsuits challenging DOMA, including *Gill v. Office of Personnel Management*, a lawsuit launched by Massachusetts against the federal government, and a case filed in the California federal court by Ted Olson and David Boies.

Proposed Immigration Statute Offers a Model for Including LGBT Elders in Federal Safety Net Programs

The Uniting American Families Act (UAFA) is a proposed bill that provides a model for including same-sex relationships in federal legislation. This bill, reintroduced in the House and Senate in February of 2009, aims to permit U.S. citizens and permanent residents to file a visa petition on behalf of their foreign national same-sex "permanent partners," allowing them to immigrate to the U.S. and adjust their status to become lawful permanent residents.

To achieve this goal, the draft legislation seeks to add the term "permanent partner" to the sections of current immigration law that refer to married couples. However, the UAFA does not alter the federal definition of marriage, so it does not conflict with DOMA.

UAFA provides a legal definition of a permanent partner as someone who is:

- 1.In a committed, intimate relationship with another individual age 18 or older in which both individuals intend a lifelong commitment;
- 2. Financially interdependent with the other individual;
- 3. Not married to, or in a permanent partnership with, any other individual;
- 4. Unable to contract with the other individual a marriage cognizable under the law; and
- 5. Not a first, second, or third degree blood relation of the other individual.

UAFA provides one example of how advocates could pass laws protecting LGBT elders despite DOMA (i.e., by creating a new general definition of "permanent partner" which is recognized under federal law). An alternative or complementary approach would be to recognize state civil unions and domestic partnerships as also creating "permanent partners."

Due to the complexities of state law, a specific state-bystate policy agenda is beyond the scope of this report. But generally speaking, there are opportunities at the state level to advance equality on Medicaid rules, pensions and domestic partnership benefits for government employees, estate and inheritance taxes, and inheritance rights. In addressing these issues, advocates in some states tend to opt for omnibus legislation that addresses several topics simultaneously. For example, Colorado's 2009 Designated Beneficiary Agreement Act creates a registry that allows one person to designate another for one or all of a multitude of rights listed on a single form, without the cost of hiring a lawyer. The act entitles designated beneficiaries to certain inheritance protections, medical decision making, visitation rights, and decision making about disposition of remains—as well as adding several rights not previously available under Colorado law, such as the ability to file a wrongful death lawsuit on a partner's behalf. In contrast, advocates in Maryland are tackling discrete issues separately, first securing passage of a bill that allows samesex partners who meet certain criteria to make medical and burial decisions for each other, and at the time of this writing, lobbying to pass a bill that exempts same-sex partners from a 10% state tax applied when someone other than a spouse inherits property. 128

Even if a policy issue is unlikely to come up for debate in the near future, the important work of defining policy recommendations, building a coalition of supportive allies, and advancing policy priorities can start happening now. The advocacy agenda to help LGBT and other elders achieve financial security is summarized in *Table 2*.

¹²⁸ Maryland currently taxes inherited property at a rate of 10%, unless that property is passed to a spouse, child, parent, grandparent, stepchild/stepparent or sibling.

Table 2: Recommendations: Helping LGBT Elders Achieve Financial Security

Broad-Based Financial Security Solutions Repeal DOMA · Advocate or litigate to repeal DOMA. DOMA repeal is critical to extending the federal safety net to same-sex couples in states that provide marriage equality. • However, DOMA repeal provides an incomplete solution as it would: • Only help the minority of LGBT elders who live in states where they can legally marry. Not automatically result in equal treatment of same-sex couples by the federal government (for example, some federal programs, such as Social Security, have an embedded opposite-sex definition of a spouse that is independent of DOMA and would still need to be changed). Gain marriage • Advocate state-by-state for marriage equality or other relationship recognition rights that extend and relationship critical state-based legal protections to committed same-sex couples. recognition state- However, with DOMA in place, winning marriage rights in a state will not in and of itself address the by-state most pressing financial obstacles faced by older same-sex couples, which primarily relate to lack of relationship recognition by the federal government. Pass the federal • Advocate to pass ENDA, including protections based on gender identity and expression. This is **Employment Non**critical to securing the financial health of LGBT elders as lifetimes of employment discrimination **Discrimination Act** result in lower earnings, lower savings, and lower Social Security benefits. (ENDA) Failing passage of federal ENDA, advocate for state-based employment protections for LGBT people. **Social Security Solutions**

Revise the federal Social Security Act to provide benefits to domestic partners

- Define and advocate for policy solutions that:
 - Make "permanent partners," "domestic partners" or those in "civil unions" eligible for spousal Social Security benefits; 129
 - Update the Social Security Act (SSA) definitions of "wife" and "husband" so they no longer rely on gender-specific pronouns.
- This issue should be a stand-alone movement priority for LGBT advocates meaning that advocacy on Social Security solutions should not take a backseat to advocacy on marriage equality or other issues. It should be a priority in its own right.
- Note that the SSA's different-sex definition of spouse means that DOMA repeal will not automatically result in Social Security benefits for married same-sex couples.

Medicaid Solutions

Revise the federal Medicaid Act to extend financial protections to domestic partners and families of choice

- Define and advocate for policy solutions that make "permanent partners," "domestic partners," those in "civil unions," or other financially interdependent individuals eligible for Medicaid spousal protections.
 - This could be done by adding domestic partners to the enumerated list of non-spousal persons
 who may receive assets or income from a person who is spending down in order to qualify for
 Medicaid payment of long-term care.¹³⁰
 - For example, currently siblings who own a home together can transfer the home to the other sibling without incurring a penalty, and a parent can transfer property to a disabled child, a child under 21, or an adult child who has lived with and provided care to the parent for the past two years.
- As is the case with Social Security solutions (see above), this issue should be a stand-alone movement priority for LGBT advocates.
- Repeal of DOMA would secure equal treatment for married same-sex couples in the states with marriage equality.
 - Massachusetts is currently suing the federal government over this issue, arguing in part that DOMA requires the state to violate the constitutional rights of its citizens by treating married same-sex couples differently when determining Medicaid eligibility.

¹²⁹ This could be done both by creating a unique definition of domestic partner for this act for which any same-sex couples would qualify, and/or by recognizing formalized unions in other states (domestic partnerships, civil unions, marriages) as domestic partners for the purposes of Medicaid.

130 Ibid.

Advocate for states to electively extend spousal impoverishment protections to domestic partners and financially interdependent elders ¹³¹

- States, which under the Medicaid Act share costs with the federal government, can extend spousal impoverishment protections to same-sex couples, domestic partners, and other financially interdependent individuals at the state's expense.
- For example, Massachusetts and Vermont extend spousal impoverishment protections to married samesex couples, while Washington state passed legislation that prevents the recovery of assets transferred to a domestic partner where a similar asset transfer would have been allowed a heterosexual couple.¹³²

Advocate for states to adopt broader interpretation of spend-down and cost recovery rules in order to protect same-sex couples and financially interdependent elders¹³³

- States can be encouraged to take maximum advantage of the flexibility in interpreting existing federal Medicaid spend-down and cost recovery rules. For example, states may currently opt to:
 - Allow long-term care beneficiaries to keep their homes as long as they express an intent to return home (rather than requiring medical proof of their ability to return home). This would allow a domestic partner or friend to remain in the home.
 - Allow an individual to qualify for Medicaid without having to sell and spend-down the assets of a jointly owned home. (If a house is jointly-owned, one state might force the applicant to sell the home while another state might allow the healthy co-owner to continue living in the home.)
 - Avoid placing a lien on a jointly-owned home.
 - Not pursue the sale of a home for cost-recovery purposes when that home is jointly owned, or when this type of cost-recovery would cause an "undue hardship" to a person living there.
- Medicaid rules allow an exception on cost-recovery that causes an "undue hardship," but there is limited federal guidance about what this means. Advocates can encourage states to more readily use the undue hardship clause to protect the homes of same-sex couples and families of choice (these regulatory changes can be made without an act of Congress).
 - Washington State will be the first to explicitly adopt this broader reading of the law.
 - Maryland advocates are urging state leaders to allow long-term care beneficiaries to transfer some assets and property to their community spouse, stop imposing liens on a home that is lived in by a community spouse, and stop seeking recovery from an estate of a deceased long-term care beneficiary during the lifetime of the surviving same-sex partner.

Advocate for states to allow single recipients of Medicaid-funded HCBS to retain a greater living wage • The minimum personal income allowable for a single or widowed HCBS recipient is often too low to maintain a reasonable standard of living (while couples can keep much higher income levels). This gross inequity has drawn the attention of the National Senior Citizen's Law Center in addition to advocates in Washington state, who are pushing for higher income minimums for single HCBS applicants. These same advocates also want non-married applicants registered under the state's domestic partnership law to be able to use their income to support low-income domestic partners in the same manner as legally married couples.

¹³⁴ Despite the estimated cost of living for a couple being only 35% higher than the cost of living for an individual, Medicaid might allow a couple to keep over three-and-a-half times as much income. MAP analysis based on the difference of the Federal Poverty Line, 2009, for an individual versus a two-person household, as found at https://aspe.hhs.gov/poverty/09poverty.shtml.

¹³¹ The complexities of state rules make a state-by-state recommendation beyond the scope of this report. The report recommendations outline where states have flexibility. State advocates should analyze their states' Medicaid policies and identify opportunities for change

¹³² In Washington state, the legislature has enacted the following protections for domestic partners: "The department shall establish procedures consistent with standards established by the federal department of health and human services and pursuant to 42 U.S.C. Sec. 1396p to waive recovery when such recovery would work an undue hardship. The department shall recognize an undue hardship for a surviving domestic partner whenever recovery would not have been permitted if he or she had been a surviving spouse. The department is not authorized to pursue recovery under such circumstances." Wash. Rev. Code § 43.20B.080(5)(a); see also Wash. Admin. Code 388-527-2750(1)(c).

¹³³ Because Medicaid is a joint federal-state program, Congress and the federal Centers for Medicare and Medicaid Services (CMS) set out the main rules under which Medicaid operates. While each state runs its own program, it must conform to federal guidelines to receive federal money. Therefore, while the general framework for Medicaid is the same throughout the country, eligibility rules vary by state.

Tax-Oualified Retirement Plan Solutions

Amend ERISA to allow "non-spouse" beneficiaries to draw down inherited IRAs on the same schedule as spousal beneficiaries

- A coalition effort could be helpful on this issue as it affects all non-spouse beneficiaries. For example, the mainstream aging community publicly led the recent advocacy campaign for the Pension Protection Act and the Worker, Retiree, and Employer Recovery Act, both of which significantly benefited non-spouse beneficiaries of tax-qualified plans. Both acts were passed under the Bush administration (an administration unfriendly to LGBT issues).
- Since ERISA supersedes state employment law, 135 state advocacy is not useful here.
- · Repeal of DOMA would help secure equal treatment for married same-sex couples in the states with marriage equality. 136

Employee Pension Solutions

Amend ERISA to create a designated "non-spouse joint survivor" for QJSAs or QPSAs, and make it mandatory that businesses offer this option as part of their pension plans¹³⁷

- Amend ERISA so any person receiving a pension can electively choose any other individual for a QJSA or QPSA (e.g., two friends should be able to designate each other).
- Since ERISA supersedes state employment law, state advocacy is not useful here.
- · Repeal of DOMA would secure equal treatment for married same-sex couples in the states with marriage equality.

Encourage employers to electively offer QJSAs and QPSAs to LGBT employees

- · Work with private employers, unions, state and local governments, and pension plan providers to encourage them to electively offer QJSAs and QPSAs to same-sex partners and other financially interdependent individuals.
- HRC's Corporate Equality Index tracks and holds private employers accountable in this effort.

Employee Health Insurance / Domestic Partner Benefits Solutions

Advocate for federal legislation that provides equal treatment for domestic partner benefits

- · Advocate for federal legislation that would end the taxation of benefits provided for same-sex and heterosexual domestic partners and other "non-spouse" beneficiaries (such as families of choice) under employers' health plans.
- HRC, in coalition with a group of more than 50 major U.S. employers, has worked to define and advocate for such a bill, currently called "The Tax Equity for Domestic Partner and Health Plan Beneficiaries Act/Tax Equity for Health Plan Beneficiaries Act (DP Tax)."138 There are also efforts to pass provisions to this effect within larger health care reform efforts underway in 2010.
- · Repeal of DOMA would secure equal treatment for married same-sex couples in the states with marriage equality.

Lobby relevant states to eliminate state taxes on domestic partner benefits

- · Advocates in relevant states can independently lobby to eliminate their state's portion of the domestic partner benefits tax. Some states (such as New York) mimic federal tax guidelines and, by default, impose an additional state tax on domestic partner benefits.
- · Unfortunately, state advocacy only eliminates the smallest (state) portion of the benefits tax in addition to requiring a state-by-state effort. Conversely, eliminating domestic partner benefit taxation at the federal level under ERISA would resolve taxation at the state level in all states since ERISA supersedes state law.

¹³⁵ ERISA allows employers operating in multiple states to follow one set of rules (rather than potentially 50 different sets of state rules). Therefore, even states with marriage equality cannot require employers to recognize same-sex married couples for pensions or other benefits since, under DOMA, ERISA does not currently recognize same-sex relationships.

Employers to recognize same sex married couples for perisons of other benefits since, under both, this does not currently recognize same sex readarships.

136 ERISA does not provide a clear definition of "spouse"; therefore, without DOMA, the meaning of spouse would be based on state law.

137 Employees designating a "non-spouse survivor" or a QPSA could be charged the 0.2-0.3% extra cost to also make this option cost-neutral to employers. However, since same-sex couples either cannot marry of on not have their marriages recognized, employers should continue to provide QPSAs for same-sex domestic partners at no charge.

elections/5671.htm, "The bill would exclude the value of employer-provided health insurance for a domestic partner or other non-138 According to HRC's website, http spouse beneficiary from an eligible employee's income, as it does for benefits provided for a spouse or dependent. This legislation does not mandate that employers provide coverage to non-spouse beneficiaries. Nor does it establish criteria for determining which beneficiaries qualify. . . . The bill simply eliminates the unfair taxation of benefits that employers choose to provide. The bill would also make clear that domestic partners or non-dependents can be included in pre-tax cafeteria plan elections, permit Voluntary Employees' Beneficiary Associations (VEBAs) to provide full benefits to domestic partners and non-dependents, and extend Health Related Savings Accounts to cover domestic partners and other non-dependents. Finally, the bill would equalize the treatment of health coverage for spouses and for domestic partners and other non-dependents for payroll tax purpose."

Work with employers to electively offer domestic partner benefits

- Work with governments, private employers, unions, and others to encourage employers to selectively offer domestic partner benefits. Some employers have even considered increasing the salary of LGBT employees to help pay for their additional tax burden.
- HRC's Corporate Equality Index tracks and promotes the success of this effort in private industry.

Estate Tax Solutions

Advocate for federal legislation that provides equal estate tax treatment for domestic partners

- Define and advocate for policy solutions that exempt "permanent partners," "domestic partners" or those in "civil unions" from federal estate taxes.
- Repeal of DOMA would secure equal treatment for married same-sex couples in the states with marriage equality.

Advocate for relevant states to eliminate state-based estate and inheritance tax for domestic partners

- Since estate and inheritance taxes vary, state advocates should analyze their laws and identify any needed action. For example:
 - Advocates in Maryland helped pass a law to exempt domestic partners from the state's 10% inheritance tax, which also applied to the inheritance of jointly-owned homes.

Veterans Benefits Solutions

Advocate for federal legislation that provides equal treatment to the partners of LGBT veterans

- Define and advocate for policy solutions that make veterans' spousal benefits available to the "permanent partner," "domestic partner," or "civil union partner," of a veteran.
- Repealing DOMA would secure equal treatment of married same-sex couples in the states with marriage equality.
 - Massachusetts is currently suing the federal government over this issue, arguing in part that DOMA requires the state to violate the constitutional rights of its citizens by not allowing veterans' same-sex partners to be buried in Massachusetts veterans' cemeteries.

Fight for repeal of Don't Ask, Don't Tell

Advocate to allow LGBT people to serve openly in the military, without fear of losing retirement benefits if discovered. (Not only does DADT unfairly discharge LGBT service members, it denies them the benefits they are due after their service to their country and creates a climate of fear that encourages elder veterans to stay in the closet.)

Inheritance/Power of Attorney Solutions

Advocate in relevant states for more inclusive default intestacy laws

 A state-by-state analysis of intestacy laws is beyond the scope of this report. State advocates should analyze current laws and, where relevant, advocate to allow domestic partners to inherit without a will.

Advocate for relevant states to make it easier to designate a domestic partner or other loved one for inheritance

- Advocates should define and advance policies that make it easy for elders to designate a domestic partner or member of a family of choice.
 - For example, the Colorado Domestic Partner registry allows individuals to fill out and submit a form that, among other things, allows a person to designate another individual for inheritance purposes.

AT ISSUE: HEALTH AND HEALTH CARE

Health and health care become increasingly important issues for people as they age. Only a minority of elders in the United States feel their health is excellent or very



good: 38.3% of all people 65+, 42.3% of those age 65-74, and 33.8% of those age 75+. Forty-one percent of people age 65+ have disabilities that affect their ability to accomplish the tasks of daily living. 140

How the Health Care System Fails LGBT Elders

LGBT elders often find it more difficult than others to receive the health care they need for five major reasons:

- 1. **LGBT elders' health disparities are overlooked and ignored.** Governments and service providers rarely track, and are largely unaware of, the health disparities of LGBT elders. For example, LGBT elders are more likely to delay getting needed care, and they have higher rates of HIV/ AIDS and chronic mental and physical conditions.
- 2. There is limited government and social support for families of choice. LGBT elders rely on family-of-choice caregivers, who often do not receive the same legal or social recognition as biological family caregivers.
- 3. Health care environments often are inhospitable to LGBT elders. Many professional caregivers are not accepting of, or trained to work with, LGBT elders. These providers may be hostile, discriminatory, or simply unaware that LGBT elders exist.
- 4. **Nursing homes often fail to protect LGBT elders.** Nursing home rules, together with prejudice and hostile treatment on the part of staff and fellow patients, can create unwelcoming environments for elders who are unable to advocate for themselves.
- 5. Visitation policies and medical decision-making laws often exclude families of choice. Without complex and often expensive legal arrangements in place, LGBT elders' partners or other loved ones may be shut out of medical decision making or denied visitation.

The following section explains these issues in more detail and proposes solutions for addressing the most critical problems.

Inattention to LGBT Elders' Health Disparities

The federal government does not collect data about the health of LGBT older adults (or about the interactions between sexual orientation, gender identity and expression, and aging),

and little research has been done on the topic. For example, the most widely referenced federal health survey, the National Health Interview Survey, excludes LGBT people.

Data collected through the California Health Interview study,¹⁴¹ as well as a handful of private studies, nevertheless suggest that later life brings with it some unique physical and mental health issues for LGBT persons (see *Figure 15*). Many of these challenges are attributable to the cumulative effects of a lifetime of stigma.

Due to factors such as low rates of health insurance coverage, high rates of stress due to systematic harassment and discrimination, and lack of cultural competency¹⁴² in the health care system, LGBT people are at a higher risk for cancer, mental illnesses, and other diseases, and are more likely to smoke, drink alcohol, use drugs, and engage in other risky behaviors. People who are both LGBT and members of a racial or ethnic minority often face the highest level of health disparities.¹⁴³

Still, we can only estimate the full extent of LGBT health disparities due to a consistent lack of data collection. Among the key areas of disparity are access to health care, HIV/AIDS, mental health, and chronic physical conditions.

Figure 15: Heterosexual adults are more likely to report having excellent or very good overall health.



Source: Massachusetts Department of Public Health, The Health of Lesbian, Gay, Bisexual and Transgender (LGBT) Persons in Massachusetts, 2009.

Access to Health Care

LGBT people are more likely to delay getting needed care and prescriptions, and are more likely to resort to visiting emergency rooms for care (see *Figure 16*). Since LGBT people often do not want to disclose their sexual orientation or gender identity in health care settings for fear of discrimination and provider bias, they are less likely to seek timely treatment.

143 See "How to Close the LGBT Health Disparities Gap: Disparities by Race and Ethnicity," Center for American Progress, December 2009.

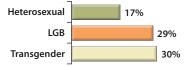
¹³⁹ Across the States: Profiles of Long-Term Care and Independent Living, AARP, 2009. ¹⁴⁰ *Ibid*.

¹⁴¹ The California Health Interview Study is one of the very few comprehensive, ongoing state-level health surveys that regularly collect information on sexual orientation. Although this study cannot be generalized to the national LGB population, the Williams Institute estimates that LGB adults living in California make up about 15% of the national LGB population. Massachusetts is the only state to include a question on gender identity in its health survey.

¹⁴² The U.S. Department of Health and Human Services defines cultural competency as "a set of cultural behaviors and attitudes integrated into the practice methods of a system, agency, or its professionals that enables them to work effectively in cross-cultural situations."

Figure 16

LGB adults are more likely to delay or not seek medical care. % of adults delaying or not seeking health care



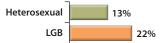
Source: Center for American Progress analysis of 2007 California Health Interview Survey data; Transgender Law Center, State of Transgender California, March 2009.

Lesbian and bisexual women are less likely to receive mammograms. % of women receiving a mammogram in past 2 years



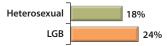
Source: Center for American Progress, How to Close the LGBT Health Disparities Gap, 2009. Center for American Progress analysis of 2007 California Health Interview Survey data.

LGB adults are more likely to delay or not get needed prescription medicine. % of adults delaying or not getting prescriptions



Source: Center for American Progress analysis of 2007 California Health Interview Survey data.

LGB adults are more likely to receive health care services in emergency rooms. % of adults receiving ER care



Source: Center for American Progress analysis of 2007 California Health Interview Survey data.

LGBT people as a whole also are more likely to delay testing and screening for certain illnesses like heart disease and breast cancer. Transgender people who are visibly gender non-conforming face particular barriers as they access health services since they cannot hide their transgender status from hostile health care providers.

HIV/AIDS

At the top of the list of health disparities facing LGBT elders is HIV/AIDS. One quarter of the 1.1 million Americans infected by HIV are over age 50.144 The number of new HIV diagnoses among people age 50 to 59 increased 32% from 2004 to 2007.145 The portion of people living with AIDS who are older than 50 is now more than double that of people under age 24, due in part to life-saving and life-prolonging drug treatments.146 Yet there are almost no HIV prevention programs targeted at older adults; and doctors and other health care providers do not generally talk to their older patients about HIV/AIDS risks (or even sex in general).

The Long-term Effects of Living with HIV

Most news accounts today call HIV a chronic, manageable disease. But patients who contracted the virus just a few years ago are showing signs of what's being called premature aging. Early senility turns out to be an increasingly common problem. One largescale, multi-city study released its latest findings this summer that over half of the HIV-positive population is suffering some form of cognitive impairment. Doctors are also reporting a constellation of ailments in middleaged patients that are more typically seen at geriatric practices, in patients 80 and older. They range from bone loss to organ failure to arthritis. Making matters worse, HIV patients are registering higher rates of insulin resistance and cholesterol imbalances, and they suffer elevated rates of melanoma and kidney cancers and seven times the rate of other non-HIV-related cancers.

— New York magazine, November 2009¹⁴⁷

In the next 10 to 20 years, programs and institutions serving the elderly – everything from community senior centers to inhome health aides to nursing homes and hospice facilities – will see a dramatic influx of people with HIV/AIDS. Management of HIV in older people is even more difficult than it is in younger people, due to older adults' higher levels of chronic diseases and use of multiple medications. Researchers are still uncovering the long-term effects of drugs to treat HIV, and there is uncertainty about how HIV/AIDS drugs interact with other medications common in old age (for example, drugs to treat high blood pressure or high cholesterol). Similarly, experts have done very little research into "co-morbidity" – the impact of having HIV/AIDS along with another serious illness in old age.

Doctors are beginning to see patients who have been living with HIV/AIDS for many years suddenly develop multiple chronic conditions as they enter their late 50s and early 60s. Examples of these conditions are kidney failure, severe depression, cancer and osteoporosis — diseases and conditions normally associated with people in their late 70s and 80s. One study of HIV/AIDS and aging found that over half of HIV-positive older adults had depression, a portion much larger than the general population

¹⁴⁴ U.S. Centers for Disease Control, 2008.

¹⁴⁵ *Ibid*.

¹⁴⁶ Ibid

¹⁴⁷David France, "Another Kind of AIDS Crisis: Why a Number of HIV Patients Are Aging Faster," New York Magazine, November 1, 2009. https://nymag.com/health/features/61740/#ixzz0WPI6MeND.

of older adults.¹⁴⁸ Studies of surviving partners have shown evidence of survivor guilt, negative impacts on self-esteem and identity, and (especially among HIV-positive partners) deteriorated health, death anxiety, and suicidal ideation.¹⁴⁹

Mental Health

Numerous studies have shown that the LGBT population as a whole has higher rates of smoking, alcohol use, and drug use (see *Figure 17*). For example, a study undertaken in San Francisco found that prevailing rates of substance use (smoking, alcohol, illicit drugs), obesity, suicide, depression, and interpersonal violence were three to ten times higher among LGBT populations than in the general U.S. population.

There is no reason to think that these mental health-related disparities would disappear in older populations, and service providers working with LGBT elders attest to the existence of significant substance abuse issues among this population. Furthermore, 24% of midlife lesbians and gay men reported at least one chronic condition, several of which were related to lifestyle factors, such as smoking, ingesting alcohol or taking illicit drugs—all known to be major ways lesbians and gay men cope with psychosocial stress, especially at younger ages.¹⁵⁰

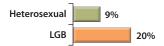
A 2006 study reported evidence of higher levels of depression and psychological distress among midlife and older lesbians and gay men, which the researchers attribute to the accumulated effect of a lifetime of stigma.¹⁵¹ "Minority stress," defined as chronic stress related to stigmatization and actual experiences of discrimination and violence, has also been found to increase loneliness in LGB older adults.¹⁵²

Chronic Physical Conditions

Limited available studies also suggest higher levels of chronic and other health problems relative to the broader population (see *Figure 18*). One San Francisco study found LGBT people age 50+ reporting problems such as asthma and diabetes at rates that were similar to those usually found among people a decade older (perhaps related to higher rates of substance abuse, obesity, and depression found in the same study).¹⁵³ Adelman and colleagues, in their large community-based empirical study, found higher rates of chronic disease and disability (including HIV/AIDS) among older gay men,¹⁵⁴ while another study notes

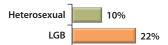
Figure 17

LGB adults are more likely to experience psychological distress. % of adults experiencing psychological distress in past year



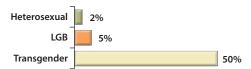
Source: Center for American Progress, How to Close the LGBT Health Disparities Gap, 2009. Center for American Progress analysis of 2007 California Health Interview Survey data.

LGB adults are more likely to need medication for emotional health issues. % of adults needing medication for mental health



Source: Center for American Progress, How to Close the LGBT Health Disparities Gap, 2009. Center for American Progress analysis of 2007 California Health Interview Survey data.

Transgender adults are much more likely to have suicide ideation. % of adults reporting suicide ideation



Source: Center for American Progress, *How to Close the LGBT Health Disparities Gap*, 2009. Figures represent the simple averages of suicide ideation rates from multiple surveys and reports, including: Movement Advancement Project, *Advancing Transgender Equality*, 2009; and Massachusetts Department of Public Health, *The Health of Lesbian*, *Gay*, *Bisexual and Transgender* (*LGBT*) *Persons in Massachusetts*, 2009.

LGB adults are more likely to have problems with alcohol abuse. % of adults reporting alcohol abuse



Source: Center for American Progress, *How to Close the LGBT Health Disparities Gap*, 2009. Figures represent the simple averages of alcohol abuse rates from multiple surveys and reports: Movement Advancement Project, *Advancing Transgender Equality* (2009) and Center for American Progress analysis of 2007 California Health Interview Survey data.

LGB adults are more likely to smoke cigarettes.

% of adults who smoke



Source: Center for American Progress, How to Close the LGBT Health Disparities Gap, 2009. Figures represent the simple averages of smoking rates from multiple surveys and reports: Center for American Progress analysis of 2005 California Health Interview Survey data and Massachusetts Department of Public Health, The Health of Lesbian, Gay, Bisexual and Transgender (LGBT) Persons in Massachusetts (2009).

¹⁴⁸ S. Karpiak, R. Shippy, and M. Cantor, Research on Older Adults with HIV. New York: AIDS Community Research Initiative of America, 2006.

¹⁴⁹ Dean Blevens and James L. Werth, Jr., "End-of-Life Issues for LGBT Older Adults," in Douglas Kimmel, Tara Rose, and Steven David, editors, LGBT Aging: *Clinical Perspectives*, 6th Edition, 2006. Page 215.
¹⁵⁰ Barker, Herdt, and de Vries (2006).

¹⁵¹ Brian de Vries, "Gays and Lesbians, Later Life," Encyclopedia of the Life Course and Human Development, 2008.

¹⁵² Kuyper and Fokkema (2009).

¹⁵³ Barker, Herdt, and de Vries (2006).

M. Adelman, J. Gurevitch, B. de Vries, and J. Blando, "Openhouse: Community Building and Research in the LGBT Aging Population," in Kimmel, Rose and David (2006),pp. 247-264.

Figure 18

LGB adults are more likely to have cancer. % of adults ever diagnosed with cancer



Source: Center for American Progress, How to Close the LGBT Health Disparities Gap, 2009. Center for American Progress analysis of 2007 California Health Interview Survey data.

Health Issues for Transgender Elders

Health issues for some transgender persons are likely rendered more complicated by the interaction of the aging body with the introduction of hormones for those who have transitioned from one biological gender to another. Long-term hormone use could interact with an aging body and related health issues and medications in ways that most health care providers do not know or understand.

Very little is known about aging, disease and longevity among transgender people. Some clinicians are concerned about higher risk of diabetes among transgender people undergoing hormone therapy;¹⁵⁷ high rates of polycystic ovarian¹⁵⁸ disease and strokes among transgender men;¹⁵⁹ and hypertension risk¹⁶⁰ and blood clots in transgender women using progesterone and estrogen.¹⁶¹

One of the biggest known health issues for transgender elders is that Medicare generally does not cover transition-related care. This means transgender elders who have undergone years of hormone therapy may suddenly find they cannot afford this care, despite the fact that abruptly stopping hormone treatment may be both physically and emotionally traumatic.

that older lesbian and bisexual women may suffer higher rates and earlier onset of common disorders such as diabetes and rheumatoid arthritis and certain illnesses such as cancer.¹⁵⁵

Limited Support for Family-of-Choice Caregivers

About 65% to 70% of elders will need some form of long-term care services; 162 even minimal assistance might make the difference between aging in place in their home and community or having to enter a nursing home. As discussed earlier in this report, LGBT elders are less likely to have spouses, children or biological family members to provide this care. A national survey of lesbian and gay Baby Boomers surfaced concerns about where and how their future care needs might be met, with one in five lesbian and gay Boomers not sure who would provide care for them if the need arose. 163 Several studies of LGBT older people have noted sizable numbers of respondents (10% to almost 25%) who were unable to identify someone on whom they could call in times of need. 164

Government programs and laws that facilitate long-term care of loved ones at home generally presume that the care is provided by a spouse or biological kin. Yet if LGBT elders have anyone to care for them, those caregivers are often friends, rather than family. Such family-of-choice caregivers are often treated less favorably under the following laws:

- The federal Family and Medical Leave Act (FMLA). The FMLA requires public and large private employers to grant up to 12 work weeks of unpaid annual leave to care for a spouse, child or parent (except in-laws) with a serious health condition. The FMLA gives these caregivers flexibility, leave and a job guarantee. However, LGBT caregivers caring for a partner or family-of-choice member risk losing their jobs. This exclusion may also prevent an LGBT elder from receiving needed care from a partner or loved one.
- State laws on family and medical leave. Most state laws also do not recognize family-of-choice caregivers. However, state laws can and sometimes do raise the floor of medical leave requirements to cover LGBT elders. For example, the California Family Rights Act (CFRA) requires large employers to give 12 weeks of unpaid leave to care for a seriously ill domestic partner (registered domestic partners are entitled to the same benefits as heterosexual spouses).

¹⁵⁵ J.C. Barker, "Lesbian Aging: An Agenda for Social Research," Gay and Lesbian Aging: Research and Future Directions, 2004, pp .29-72.

¹⁵⁶ Brian de Vries, "Aspects of Life and Death, Grief and Loss in Lesbian, Gay, Bisexual and Transgender Communities," in Kenneth J. Doka and Amy S. Tucci (Eds.), Living with Grief: Diversity in End-of-Life Care, 2009.

¹⁵⁷ Dahl, Marshall; Feldman, Jamie; Goldberg, Joshua, and Jaberi, Afshin, "Physical Aspects of Transgender Endocrine Therapy, Guidelines for Transgender Care," 2006.

¹⁵⁸ Moore, Wisniewski and Dobbs, "Endocrine Treatment of Transsexual People: A Review of Treatment Regimens, Outcomes, and Adverse Effects," Journal of Clinical Endocrinology & Metabolism 88(8), 2003.
159 Ibid.

¹⁶⁰ Dahl, Feldman et all (2006); van Kesteren, Asscheman, Megens, Gooren, "Mortality and Morbidity in Transsexual Subjects Treated with Cross-Sex Hormones," (1997)

¹⁶¹ Moore, Wisniewski and Dobbs, "Endocrine Treatment of Transsexual People: A Review of Treatment Regimens, Outcomes, and Adverse Effects," Journal of Clinical Endocrinology & Metabolism 88(8), 2003.
162 See footnote 74.

¹⁶³ MetLife Mature Market Institute (2006).

¹⁶⁴ Brian de Vries, "Aspects of Life and Death, Grief and Loss in Lesbian, Gay, Bisexual and Transgender Communities," in Kenneth J. Doka and Amy S. Tucci (Eds.), Living with Grief: Diversity in End-of-Life Care, 2009.

• The National Family Caregiver Support Act (NFCSA). The NFCSA provides federal funding for state programs that support family and other caregivers of older Americans (by providing information, training, individual counseling, support groups and respite care, among other things). This caregiver support is critical—half of supported caregivers surveyed said the care recipient would have required nursing home placement if not for this program. 165 Unfortunately, neither LGBT elders nor the local agencies that distribute NFCSA funds are aware that the broad language of NFCSA means LGBT caregivers are largely covered and eligible for this support. 166 Of the limited federal funds that are allocated to caregiver support programs, local agencies have dedicated almost no funds to programs tailored to meet the needs of LGBT caregivers. 167

An Often Inhospitable Health Care Environment

When informal care by family and friends is not available, LGBT elders often must rely on professional caregivers. Caregiving services fall along a "continuum of care" (see *Figure 19*). At the lighter end are interventions such as meals on wheels and friendly visitors who provide social support for an elder. Heavier interventions include nursing homes. Providers along this continuum—HCBS providers, pharmacists, medical and hospital staff, nursing home and assisted living facility staff—may be hostile towards LGBT elders, untrained to work with them, or unaware that that LGBT elders even exist.

Past experiences of discrimination often make LGBT elders reluctant to disclose their sexual orientation to health care providers. LGBT elders also tend to withhold other information from providers and to avoid seeking medical care they need. 169 For example, LGBT service providers note that even the assumption that an older man is being cared for by his "wife" may make a gay elder uncomfortable talking to a service provider. To ward off harassment, LGBT elders may "degay" their homes before a HCBS caregiver arrives (e.g., hide family pictures or ask a same-sex partner to temporarily leave), a process that can be emotionally and physically trying for an older person with serious health care needs.

In a large 2006 study, less than half of lesbian and gay Boomers were strongly confident that health care professionals would treat them with dignity and respect. A full 12% had absolutely no confidence that the health care system would treat them respectfully. 170 LGBT elders' concerns about health providers appear well founded:

 Openhouse in San Francisco reports that mainstream service providers often say they do not serve any LGBT elders and therefore have no problems related to cultural competency around LGBT issues.¹⁷¹



Older same-sex couples like these two SAGE volunteers are not granted leave to take care of one another under federal law.

The Importance of Home and Community Based Services (HCBS)

Home and Community Based Services (HCBS)¹⁶⁸ are one of the most important types of care for American elders. HCBS help elders with the tasks of daily living, and provide needed social interaction and support. HCBS are varied and can include:

- · Case management;
- Information and outreach;
- · Transportation programs;
- In-home services such as meals, home repair, home help and health aides;
- Community services including senior centers, social programs, friendly visitor programs, recreational activities, support groups, congregate meals, adult day care; employment and pension counseling; elder abuse prevention; and education.

These services help elders age in place, receive needed nutrition, and combat loneliness, depression and other mental health challenges.

^{165 2007} Administration on Aging study of caregivers nationwide.

For the most part, the NFCSA recognizes caregivers may not be related by blood or marriage. According to the 2006 amendment to the Older Americans Act, "the term 'family caregiver' means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual." This definition includes the family members of LGBT people, such as a partner, a partner's children, or an LGBT elder's non-biological, non-adoptive children. It also includes caregivers who aren't family members per se but are still full-time caregivers to older individuals.

¹⁶⁷ SAGE, It's About Time: LGBT Aging in a Changing World; SAGE Fourth National Conference on LGBT Aging Conference Report: Policy Recommendations, 2009. Currently, we know of only one grant, given to SAGE in the amount of \$300,000, earmarked to support LGBT caregivers.

Note that many aging advocates use the term HCBS to refer specifically to services provided through Medicaid long-term care programs. We use the term here more broadly to describe any aging services provided in the home and in the community, either through Medicaid or through the Administration on Aging.

¹⁶⁹ R. Klitzman and J. Greenberg, J., "Patterns of Communication between Gay and Lesbian Patients and their Health Care Providers," Journal of Homosexuality 42, 2002.

¹⁷⁰ MetLife Mature Market Institute (2006).

Figure 19: Support Systems Across a Continuum of Care

Lighter intervention Heavier intervention

- Senior center social and recreational opportunities and meals at neighborhood sites
- **Telephone reassurance** daily call with peer volunteer to monitor status and provide support
- Meals-on-Wheels home delivery of meals
- **Friendly visitor** volunteer offers social companionship to elder
- **Handyman** visitor does small repairs and home maintenance
- **Homemaker** visitor does light housekeeping and food shopping

- Paid or unpaid caregiver aide performs personal (but not health) care, e.g., bathing, dressing, grooming
- Home healthcare trained professional (e.g., nurse) administers medications and measures health status
- Mental health services counseling or psychological support services by trained professional
- Outpatient medical care checkups through therapeutic procedures short of hospital stay
- Adult day care supervision of dependent elderly by professionals/ paraprofessionals

- Board and care residential placement providing meals, housekeeping and medication reminders
- Intermediate care nursing home facility with <24-hour supervision and nursing care
- **Skilled nursing facility** home with 24-hour services by registered nurses
- Inpatient hospital care admission as an inpatient at an acute care facility

Source: Harry R. Moody, Aging Concepts and Controversies, 6th Edition, 2010.

- A 2008 study by the Public Advocate of New York found that in New York City's health care facilities, "LGBT individuals experience hostility and discrimination in care," and "concerns about homophobia and transphobia keep LGBT individuals from using health care services."
- In a health disparities study conducted with over 3,500 LGBT people in New York, nearly 8.3% of the LGBT adults surveyed reported being neglected by a caregiver because of their sexual orientation or gender identity, and 8.9% experienced financial exploitation or blackmail.¹⁷³
- A recent report notes that health providers "may lack knowledge about transgender and intersex anatomy, health disparities affecting LGBT people, and appropriate behavior dealing with young, elderly and 'closeted' LGBT individuals." 174
- The Movement Advancement Project's recent report on the transgender community shows that up to 39% of all transgender people face some type of harassment or discrimination when seeking routine health care.¹⁷⁵

Transgender people, in particular, fear discrimination by medical professionals. As noted by the Transgender Aging Network, "Trans individuals' non-congruent' bodies may lead to embarrassing, disrespectful, and perhaps even hostile treatment. ... These problems intensify as the trans person ages and begins to experience more acute and chronic

conditions and disabilities. ... Particularly worrisome to many trans elders is the prospect of needing intimate personal assistance from paid aides or, even worse, needing to reside in a nursing home."¹⁷⁶

Failure of Nursing Homes to Protect LGBT Elders

Just over 4% of American elders live in an institutional setting,¹⁷⁷ and the numbers are likely higher for LGBT older adults. Service providers such as SAGE have anecdotal data that, due to the lack of family caregivers, LGBT elders often face earlier institutionalization than their heterosexual counterparts.

LGBT elders in nursing homes and assisted living facilities are at particular risk of neglect and abuse, despite the fact that this treatment is in violation of federal law. Not only do LGBT elders face potentially hostile staff members, but there are other

¹⁷² Public Advocate for the City of New York, Improving Lesbian, Gay, Bisexual and Transgender Access to Health Care at New York City Health and Hospital Corporation Facilities, 2008.

¹⁷¹ Interview with Seth Kilbourne, ED of openhouse.

¹⁷³ Somjen Frazer for The Empire State Pride Agenda Foundation and the New York State Lesbian, Gay, Bisexual and Transgender Health and Human Services Network, LGBT Health and Human Services Needs In New York State, http://www.prideagenda.org/Portals/0/pdfs/LGBT%20 Health%20and%20Human%20Services%20Needs%20in%20New%20York%20State.pdf.

¹⁷⁴ Public Advocate for the City of New York, Improving Lesbian, Gay, Bisexual and Transgender Access to Health Care at New York City Health and Hospital Corporation Facilities, 2008.

¹⁷⁵ Movement Advancement Project, "Ádvancing Transgender Equality," 2009.

¹⁷⁶ Loree Cook-Daniels, Transgender Elders and Significant Others, Friends, Family and Allies: A Primer for Service Providers and Advocates, Transgender Aging Network, 2007.

¹⁷⁷ In 2007, 4.4% of the 65+ population lived in institutional settings: 1.3% for age 65-74, 4.1% for 75-84 and 15.1% for 85+. A Profile of Older Americans: 2008, Administration on Aging, U.S. Department of Health and Human Services, 2008.

Patient Sees Pervasive Discrimination in Health Care System

Amirah Watkins-Brown, 62, recalls growing up as a lesbian in Mississippi in the 1960s and 1970s. "It was crazy here," she said. "Women were raped for being lesbians, seen as spinsters who simply had not found the 'right man' yet. And so when I did come out to my mother, she expressed fear for my safety and said, 'I just don't want you to get hurt.""

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



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

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

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

considerable challenges, including hostile fellow patients; denial of visits from families of choice or from friends the staff does not approve of;¹⁷⁸ refusal to allow same-sex partners to room together; and refusal to involve families of choice in medical decision making, even when there are legal directives in place.

Hostility from fellow patients may cause LGBT elders to withdraw or be excluded from social activities, compounding feelings of isolation and loneliness. Similarly, an LGBT elder might not feel comfortable having a same-sex partner or LGBT friends visit because it can lead to harassment by staff, other patients or patients' families. For transgender individuals, staff members may refuse to place them in the sex-segregated ward that matches their gender identity; or they may refuse to respect the pronoun or clothing preferences of a trans elder.

These issues become even more of a problem when patients are mentally or physically incapacitated and unable to advocate for themselves, especially since friends and family of institutionalized elders often are unable to monitor conditions and care.

Few nursing home and assisted living providers have had any training in how to diffuse and counter hostility from other patients.¹⁷⁹ Staff may deal with this harassment by placing

patients in isolation. In one example, an openly gay man in a nursing home was regularly the target of protests from other patients (and their family members) on his floor. The facility moved him to a floor for patients with severe disabilities and/ or dementia. Without any family or friends to advocate for him, he eventually hanged himself.¹⁸⁰

Nursing homes are regulated under the federal Nursing Home Reform Act,¹⁸¹ which requires all nursing homes receiving federal funds¹⁸² (usually through Medicare or Medicaid) to make available to residents written policies (also known as a "resident bill of rights") describing the rights of residents, which must include:

¹⁷⁸ In some long-term care facilities, visiting hours and care decisions are restricted to immediate family members, where "family" or "immediate family" is undefined. Therefore, decisions as to who may qualify as family are at the discretion of the facility operator. Even when it is illegal to do so, staff may deny visits with family members or friends of whom they do not approve of (e.g., a same-sex partner). The Nursing Home Reform Act says family members can visit at any time, and nursing homes can place only "reasonable" restrictions upon visits from others (assuming that the resident wants to see the visitor).

¹⁷⁹ SAGE, It's About Time: LGBT Aging in a Changing World; SAGE Fourth National Conference on LGBT Aging Conference Report: Policy Recommendations, 2009.

Jane Gross, "Aging and Gay, and Facing Prejudice in Twilight," New York Times, October 9, 2007.
 A more detailed analysis of federal nursing home laws is available from the National Senior Citizens Law Center. See "Legal Protections for LGBT Seniors in Long-Term Care: A Preliminary

Analysis of Federal and California Law," NSCLC, 2009.

Read Almost all nursing homes receive federal funds. The requirements of the Nursing Home Reform Act apply to all residents of the facility, not just those who are the direct beneficiaries of the federal funds.

- The right to choose one's physician (thus allowing LGBT elders to choose LGBT-friendly doctors);
- The right to privacy, dignity and respect (which can help shield LGBT patients from hostile nursing home staff or residents);
- The right to use one's own clothing and possessions (allowing transgender elders to dress as the gender they feel they are—though transgender patients might not feel comfortable doing so);
- The right to be free from abuse and restraints;
- The right to voice grievances without retaliation;
- The right to receive any visitor of their choosing including outside counsel/assistance if filing a grievance.

While these rights theoretically provide some protections, many LGBT elders still hide their identities, feel uncomfortable launching complaints, or are not well enough to self-advocate.¹⁸³ Additionally, many patients, families of choice, and facility staff are unaware of these federal protections.

Hostility Forces Lesbian Woman to Leave Nursing Home

Even now, at 81 and with her memory beginning to fade, Gloria Donadello recalls her painful brush with prejudice at an assisted-living center in Santa Fe, N.M. Sitting with those she considered friends, "people were laughing and making certain kinds of comments, and I told them, 'Please don't do that, because I'm gay.""

The result of her outspokenness, Ms. Donadello said, was swift and merciless. "Everyone looked horrified," she said. No longer included in conversation or welcome at meals, she plunged into depression. Medication did not help. With her emotional health deteriorating, Ms. Donadello moved into an adult community nearby that caters to gay men and lesbians.

"I felt like I was a pariah," she said, settled in her new home.
"For me, it was a choice between life and death."

— Excerpted from "Aging and Gay, and Facing Prejudice in Twilight," *New York Times*, October 9, 2007

Lesbian Couple Suffers the Consequences of Inferior Elder Care

SAGE client Doloris, 74, shared a New York City apartment with Joan, her partner of almost a decade, until Joan's illness forced her into a nursing facility. Once Joan was there, she and Doloris discovered a persistent trend that would haunt the two of them for the rest of their lives: a complete lack of cultural competency and sensitivity in dealing with LGBT older adults.

Over the course of a year, Joan was admitted into three different nursing facilities, where her health needs were met with negligence and overall poor treatment. Joan suffered from a combination of severe dehydration, malnutrition, bed sores, and contracted legs, ultimately leaving her unable to walk. Although Doloris fought to have Joan returned to their home where Joan's health needs would be attended to, the court-appointed guardian refused to intervene, and after being admitted to the hospital three different times, Joan passed.

Compounding her grief, Doloris found herself suddenly facing the loss of the home she shared with her partner, as her landlord challenged her right to the apartment that her partner had leased. Although the two of them had a health care proxy and a signed domestic partnership agreement, Doloris' clear rights to the apartment became misconstrued because of their lack of a joint checking account and inability to get the domestic partnership agreement registered before Joan's passing. Additionally, one of the witnesses during the trial falsely testified to not knowing that Doloris or her partner were lesbians, sending a libelous blow to the validity of both her relationship and her rights to the apartment.

Although she was aided by a lawyer from the Gay Men's Health Crisis, Doloris ultimately lost her fight for the apartment, and she is now facing an impending eviction. She is currently contemplating an appeal, but few lawyers have expressed faith or interest in taking up her cause.

¹⁸³ Alliance Healthcare Foundation, *The San Diego County LGBT Senior Healthcare Needs Assessment*, 2003

Gay Man Held Involuntarily in Nursing Home While Partner Dies

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

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

At the same time, the staff at Harold's nursing home stopped putting Clay's calls through to him, isolating Clay from Harold. Soon after, Clay was also taken to the nursing home, where he was isolated from Harold and not allowed to even call him. After several weeks, the county put Clay into a different nursing home against his will, falsely claiming that



Clay had dementia. The nursing home staff told Clay that he was not allowed to leave the premises. While Clay was kept in the second nursing home, Harold died. The county worker responsible for informing Clay that Harold had died asked a neighbor of Clay and Harold's to do it for him, saying that he "did not want to deal with a gay boy."

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

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

Exclusion of Families of Choice in Visitation and Medical Decision Making

Heterosexual spouses take for granted that they will have access to each other's hospital rooms and be in charge of medical decision making, should one spouse be incapacitated. Same-sex couples have no such assurance.

Unless an LGBT elder has specific and often expensive legal arrangements in place, most states give priority to opposite-sex spouses and blood relatives for medical and long-term care decision making and visitation, rather than life partners or families of choice. HRC has categorized states by how they designate default medical decision makers as follows:¹⁸⁴

- **Tier 1** "LGBT-inclusive" states either offer marriage equality and treat heterosexual and same-sex spouses as equivalent, or they offer some other form of relationship recognition by placing a "domestic partner" on substantially equal footing to a heterosexual spouse.¹⁸⁵
- **Tier 2** "second-class status" states include "close friend" as a category on their surrogate lists, but it is usually one of the last relationships in the ranked list, meaning biological family will have priority over same-sex partners or families of choice. ¹⁸⁶

¹⁸⁴ Matthew Stiff, "Breaking Down Barriers: An Administrator's Guide to State Law and Best Policy Practice for LGBT Healthcare Access," Human Rights Campaign Foundation, May 2009.

¹⁸⁵ States are California, Connecticut, D.C., Hawaii, Iowa, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New Mexico, Oregon, Vermont, Washington.

¹⁸⁶ States are Alaska, Arizona, Delaware, Florida, Idaho, Illinois, Mississippi, New York, North Dakota, Pennsylvania, South Dakota, Tennessee, Utah, West Virginia, Wisconsin, Wyoming.

Figure 20: Health-Related Legal Documents

Written statement of health care instructions, called (depending on jurisdiction) "health care directive," "health care declaration" or "living will." Provides instructions in case the subject individual becomes incapacitated, but generally does not designate a surrogate agent.

Formal designation of a person to make health care decisions, called "health care power of attorney," "durable medical power of attorney" or "health care proxy." Allows individuals to name a trusted person to make medical decisions on their behalf if they become incapacitated (including hiring and firing medical personnel, granting visitation access, access to medical records, etc.).

These are often combined into an advance health care directive (AHD), a single document that names a health care agent and provides instructions about care.

 Tier 3 "legal stranger" states do not include the "close friend" option; therefore, same-sex partners (or members of families of choice) in these states effectively have no chance to be designated as surrogate medical decision makers for their incapacitated partners/loved ones.¹⁸⁷

Rules and terminology vary by state,¹⁸⁸ but LGBT elders who want to designate their own medical decision makers generally need both a living will (a set of health care instructions that outline their wishes for treatment should they become incapacitated) and a health care power of attorney (which designates a trusted person to make medical decisions on their behalf should they become incapacitated). These two documents are often combined into an advance health care directive (AHD). See *Figure 20*.

While obtaining an AHD seems straightforward in theory, it is far less so in practice. First, many elders are not aware of the need for, or do not have the means to obtain, these types of legal documents. For example, only about half of all elders (both heterosexual and LGBT) have a living will. Second, medical providers and long-term care facilities often ignore or challenge the AHDs of LGBT people. There have been numerous incidents of hospitals disregarding legally-valid medical powers of attorney or AHDs, or prohibiting same-sex partners from visiting with one another, even in cases involving critical injuries and illnesses (see sidebar on following page).

While this is illegal, many LGBT people do not have the resources to challenge these actions, nor can these actions usually be challenged in the timeframe required during a medical emergency. Federal protections theoretically exist under the Patient Self-Determination Act (PSDA) of 1990, but the degree to which providers are aware of this law, or whether it is enforced, is unclear. The PSDA requires many hospitals, nursing homes, home health agencies, and other health care providers to: inquire whether a patient has an AHD upon admission (and to make a note of this in their medical records); provide information about AHDs and allow the patient to create one; and educate staff and affiliates about AHDs.

In practice, to protect themselves, LGBT elders must remember to carry their AHDs with them at all times—if an individual is rushed to the hospital without these documents, a loved one can still legally be denied access (see sidebar on page 40). Finally, problems may arise when an elder travels out of state, as one state may not always recognize the health care directive of another state.

Similar issues arise over funeral decisions and disposition of remains, with states prioritizing blood relatives for these tasks unless an elder has appropriate legal documentation in place. Again, practices vary by state. Some states have a separate document or form that confers this authority, some allow an individual to confer this authority within another document

¹⁸⁷ States are Alabama, Arkansas, Georgia, Indiana, Kansas, Kentucky, Louisiana, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, North Carolina, Ohio, Oklahoma, Rhode Island, South Carolina, Texas, Virginia.

¹⁸⁸ State laws are not subject to DOMA; therefore, same-sex couples who can legally marry in their state are afforded the same legal protections as heterosexual couples. However, same-sex couples in other states, and single LGBT elders in all states, often face restricted access of loved ones such as life partners or other families of choice.

¹⁸⁹ Information on all elders from Pew Research Center (2005), "More Americans Discussing — and Planning — End-of-Life Treatment," which reports that 49% of those aged 63-77 and 58% of those aged 78-92 have a living will. http://people-press.org/reports/pdf/266.pdf; information on LGBT Baby Boomers from The MetLife Mature Market Institute(2006); 51% of LGBT Baby Boomers have yet to complete wills or living wills.

Partner of 33 Years Dies While Man Rushes Home to Retrieve Documents

John Crisci and Michael Tartaglia were partners for 33 years and thought they had obtained every protection available under Colorado law. But when Tartaglia died in January of 2004, Colorado law kept them apart, as shown in the following excerpt from the *Denver Post*:

In the mountain home he designed and built with Tartaglia, John Crisci takes a moment to collect himself, his eyes welling up with tears, as he recalls once more the events of Jan. 8, 2004.

"It doesn't get any easier no matter how many times you say it," he manages, his voice wavering. This is a story Crisci has told to the Colorado legislature, to newspaper reporters and to various groups throughout the state.

When Tartaglia collapsed at the gym on his 70th birthday, Crisci was with him. But the legal papers documenting the couple's relationship were at their home, 15 minutes away by car. So while an ambulance rushed Tartaglia to Denver's St. Anthony Central Hospital, Crisci could not be with him, as any spouse would expect to be.

"They just weren't going to allow it," Crisci said of the paramedics. Instead, he rushed home to retrieve his documents, then drove 30 minutes to the hospital, only to find his worst fears confirmed. Tartaglia was already dead. 191

such as the health care power of attorney or a will, and some states have weak protections for the deceased's preferences and only respect their wishes if they have a prepaid funeral (e.g., West Virginia). Still other states essentially allow next of kin to challenge and override any decisions made by the individual (e.g., Michigan).¹⁹⁰

Woman Removed from Dying Partner's Bedside

In 2005, Sharon Reed, a resident of Washington state, was repeatedly told to leave her dying partner's hospital room by a temporary night nurse at Seattle's University of Washington Medical Center. Reed had all the legal directives to serve as the health care agent for her partner of 17 years, Jo Ann Ritchie. Through the documents, Ritchie authorized Reed "[t]o provide for companionship for me and to be accorded the status of a family member for purposes of visitation" and "to provide for such companionship for me as will meet my needs and preferences at a time when I am disabled or otherwise unable to arrange for such companionship."

"The day before Jo died, she told me, 'I'm scared, don't leave me," said Reed. "I promised I would stay with her, but every time I tried to see Jo, [the nurse] would scream at me to get out of the room, 'You don't belong here.' She was very hostile from the beginning."

Reed told ABCNews.com that she felt she had let her partner down at the end of life. "Ours was the kind of relationship that had been a dream of a lifetime for both of us," said Reed. "We had spent the last 17 years buying a home, raising a child, being successful in our careers, having loyal friends and sharing time with our families. ... We absolutely adored each other and everybody knew it," she said.

Source: caselaw.lp.findlaw.com, ¹⁹² ABCnews.com

Recommendations: Helping LGBT Elders Achieve Good Health and Health Care

Given the sheer size of the U.S. health care system and the complex network of state and federal laws that regulate it (which are notoriously difficult to reform), multiple approaches to improving health care for LGBT elders are needed. The advocacy agenda to help LGBT and other elders achieve good health and health care is summarized in *Table 3*. Most of the recommendations center on state and local advocacy, education and training.

^{1999&}quot;Who Has the Right to Make Decisions About Your Funeral?" Funeral Consumers Alliance, http://www.funerals.org/your-legal-rights/funeral-decision-rights, accessed February 10, 2010.

¹⁹¹ Michael Mills, "Legal Rights for All Couples," *Denver Post*, August 20, 2006.

http://caselaw.lp.findlaw.com/scripts/getcase.pl?court=wa&vol=2008 app/607472MAJ&invol=4; referenced February 17, 2010.

Table 3: Recommendations: Helping LGBT Elders Achieve Good Health and Health Care

Health Disparity Solutions	
Collect and conduct research on LGBT elder health, mental health, and the long-term effects of HIV	 Collect LGBT data in all federal and state studies and surveys on physical and mental health. Ensure that these studies include age so LGBT health issues can be tracked over time and for various age cohorts. Advocate for medical research on the long-term effects of living with HIV/AIDS and
	recommended treatments.
Provide training on health disparities	Provide training on LGBT elder health disparities, including HIV symptoms, medications, interactions with other medications, and the need to talk to older patients about HIV prevention.
Provide coverage for LGBT elder medical needs	Advocate for Medicare and Medicaid to cover transition-related and routine care for transgender elders. Though the American Medical Association explicitly calls on public and private insurers to cover all medically necessary services for transgender people, many insurance carriers routinely refuse coverage for medically necessary care by excluding "transgender-related services," and such exclusions are frequently expanded by insurers and health care providers to prevent transgender people from accessing even routine care.
	• Ensure coverage of procedures not normally associated with older men but common in older men with HIV/AIDS (e.g., Medicare has rejected treatment for osteoporosis in men with HIV).
	• Mental health services should be covered at the same level as physical health services since research has shown that the LGBT population is seriously impacted by mental health concerns and substance abuse issues due to the stress of living under pervasive discrimination.
	• Do not deny coverage based on pre-existing conditions. Widespread employment discrimination and lack of relationship recognition leave more LGBT elders without prior insurance coverage. They are thus disproportionately affected by practices that preclude or limit coverage based on pre-existing conditions.
Target HIV prevention programs to older people	Advocate for cities, states and the federal government to fund HIV prevention and treatment programs for older LGBT adults. (This population requires specific programming since many older LGBT adults are closeted and less likely to hear prevention messages sponsored by the LGBT community. Partnerships with mainstream senior centers and aging services providers are likely needed.)
	HIV/AIDS prevention and treatment should be integrated with prevention and treatment programs for other STIs as well as for the most common co-morbidities affecting older adults, such as diabetes and heart disease.
Solutions to Support Family o	f Choice Caregivers
Advocate to broaden the definition of covered caregivers in the federal FMLA	Advocate for broadening the FMLA to apply to family-of-choice caregivers, including but not limited to domestic partners. This would also help heterosexual domestic partners, singles, widows and widowers—anyone who gives care to, or relies on care from, non-biological family members.
	• For example, the FMLA could adopt language similar to the National Family Caregiver Support Program, which broadly recognizes "an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual."
	• Repeal of DOMA would protect same-sex couples both in the states with marriage equality and in those with formalized domestic partnerships and civil unions, but would not help single LGBT elders or those in states without formal relationship recognition.

Advocate to broaden the definition of covered caregivers in state FMLAs

• States can and do create laws that provide broader medical leave than the federal government. States with more comprehensive policies include California, Connecticut, the District of Columbia, Hawaii, Massachusetts, New Jersey, New Mexico, Oregon, Rhode Island, and Vermont. Advocates in other states can urge state leaders to take similar action.

Educate LGBT elders about caregiver support services available under the National Family Caregiver Support Act and how to access these services

- Consider information outreach about NFCSA targeted specifically at LGBT elders.
- Advocate to ensure that educational and program materials provided by senior centers, mainstream aging organizations, and Area Agencies on Aging (local nonprofit and government agencies responsible for coordinating services for older adults)¹⁹⁴ are sensitive to and inclusive of LGBT elders.

Inhospitable Health Care Environment Solutions

Non-Discrimination Solutions

Pass non-discrimination acts (NDAs) or ordinances at the state or local level 195

- NDAs can provide legal recourse for LGBT elders who experience discrimination in a variety of settings, including senior citizen centers, low-income housing, hospitals, nursing homes, assisted living facilities, senior centers, etc. They can be crafted to address situations such as denied admission or involuntary discharge from a facility; harassment by facility staff, other residents/patients or visitors; and denial of clothing or pronoun use to fit the resident's/patient's gender identity or orientation.
- Unfortunately, some states pass NDAs that focus more narrowly on employment discrimination. Advocates should ensure NDAs also apply to specifically prohibit discrimination in public accommodations and housing. Furthermore, NDAs should prohibit discrimination based on both sexual orientation and gender identity/expression (not just sexual orientation).
 - Although 33 states have general NDAs covering employment discrimination, only 17
 provide non-discrimination protections in public accommodations based on sexual
 orientation and gender identity/expression; and four additional states offer protections
 based only on sexual orientation.

Increase awareness and enforcement of existing NDAs

- Awareness, enforcement and implementation of existing NDAs are a recurring problem. Many LGBT elders and aging services providers are unaware of existing laws or that the law applies to them. Also, many states have weak enforcement of these laws.
- Promote awareness of LGBT elder rights among medical providers and LGBT elders at the state and local levels. For example, SAGE and Lambda Legal are working with the New York City Bar Association to collect stories of discrimination in long-term care in New York and are also working with the New York State Attorney General to create and distribute written guidance to clarify existing laws. Local advocates have encouraged facilities to include information about LGBT rights in brochures and other materials.
- Advocate for elders who experience discrimination to ensure enforcement of the law.
 Litigating to enforce NDAs on behalf of institutionalized LGBT elders is difficult since
 many LGBT elders are not in a position to come forward with complaints of discrimination
 or harassment. However, a few high-profile cases could be transformative in educating
 providers about their legal obligations. Including LGBT elders in provider surveys may also
 uncover ongoing violations of NDAs.
- Increase awareness of existing NDAs and their requirements to provide additional weight to the need for cultural competency training.

¹⁹³ HRC website at http://www.hrc.org/issues/fmla_benefit.htm.

¹⁹⁴ AAAs are discussed in greater detail on page 54.

¹⁹⁵ There is no federal law to prohibit discrimination based on sexual orientation or gender identity/expression, and the proposed federal Employment Non-Discrimination Act (ENDA) has no provision for public accommodations. Therefore, protections from discrimination must be enacted at the state and local levels.

Encourage service providers to adopt their own nondiscrimination policies

- This can be done by working directly with providers, or through larger initiatives like HRC's and GLAM's Healthcare Equality Index, which rates health providers on their inclusiveness towards LGBT people and encourages providers to adopt more inclusive policies.
- Providers should include sexual orientation and gender identity/expression nondiscrimination policies in their staff manuals; ensure staff members are aware of the policies; and include information about LGBT rights in any brochures or other information provided to the families, friends, or caregivers of residents/patients.

Examine state public health laws, nursing home laws and assisted living facility laws for opportunities to protect LGBT elders

- State laws governing public health, nursing homes and assisted living facilities are complex and beyond the scope of this report. However, where they exist, they can theoretically be amended to include specific protections for LGBT people. For example, California has a separate state public health law that was amended to include non-discrimination based on sexual orientation.
- Ideally, any legislation would include funding to pay for related training and enforcement.

Cultural Competency Solutions

Develop scalable, technology-enabled cultural competency training to reach large numbers of health care providers

- Almost all mainstream aging services providers could benefit from sensitivity training on the needs of LGBT elders and technical training on LGBT-specific health risks, resiliencies and treatment options. SAGE and others already have developed curricula and training materials, but training is mostly local and opportunistic. Scaling these efforts has proven difficult, and the number of providers is overwhelming—there are more than 30,000 organizations and 50,000 volunteers providing HCBS nationwide. To scale these training efforts, advocates need to invest in technology and additional train-the-trainer solutions.
- The AoA's recent announcement that it will fund an LGBT Elder National Technical Assistance Resource Center is a step in the right direction, but the funding is only a fraction of what is needed to bring training efforts to scale.

Find ways to encourage providers to undergo training

- Many staff members will not make the time to participate in voluntary cultural competency training, even if they are generally supportive of the idea. In cases of hostile staff members, trainings can help them deal with their behaviors and focus instead on the value of providing high-quality care to everyone in need.
- Local groups can urge their regional AAAs, which control funding for direct service providers, to strongly recommend the training. Other potential levers include adjustments to state regulations for the training of health professionals (which may fall under a department of health, aging or commerce);¹⁹⁷ statewide anti-discrimination laws; and the policies of regional organizations that administer the accreditation of health care providers.

Work with organizations that accredit health service providers to develop standards for serving LGBT elders

- Various organizations accredit service providers who receive funds from sources such as Medicaid, Medicare or AAAs. Accreditation groups also provide best practice resources and training. Advocates can work with these groups to develop policies and standards for LGBT elder services.
 - The Joint Commission evaluates whether a facility is eligible for Medicare reimbursements. It is an independent nonprofit that evaluates and accredits more than 16,000 health care organizations and programs in the United States. In 2009, the Joint Commission released standards stating that patients have a right to care free of discrimination based on sexual orientation and gender identity/expression. 198
 - The American Medical Association has adopted 28 policies indicating the importance of culturally competent care that addresses the needs of the LGBT community.¹⁹⁹

organizations, rehabilitation centers, group practices, office-based surgeries, and other ambulatory care providers.

¹⁹⁶ All states have some type of law governing public health. In most states and at the national level as well, nursing homes and assisted living facilities are regulated separately from other types of elder care programs and services. Some states combine regulations for nursing homes and assisted living facilities under one law, some cover them under two separate laws, and some have no specific state laws for these institutions. Advocates in each state should analyze their current state laws and assess opportunities to protect LGBT elders.

¹⁹⁷ For example, in New York, health provider training is mandated by the New York Department of Health, which recommends a cultural competency module, but the training is both ill-defined and optional.
198 Facility types include hospitals, medical equipment services, hospice services and other home-based care organizations, nursing homes and other long-term care facilities, behavioral health care

¹⁹⁹ See <u>www.ama-assn.org</u>.

Help patients/residents who are mistreated to hold facilities accountable

• If a nursing home resident or a family member or friend thinks a facility is not providing adequate care or is jeopardizing the resident's health and well-being, a formal complaint can be filed against the facility.²⁰⁰ Nursing home residents or their families who are not able to navigate the government complaint process themselves can work with the long-term care ombudsman in their state (see below).²⁰¹

Advocate for better support of, and training for, long-term care ombudsmen

• The OAA requires every state to create an ombudsman program to "investigate and resolve complaints" of individuals in long-term care facilities." These ombudsmen also train facility staff on resident rights. Unfortunately, many ombudsman programs have limited staff resources, and most rely on volunteers. Advocates can lobby states to adequately fund ombudsman programs and educate and work with the programs on meeting LGBT elder needs.

Nursing Home Solutions

Seek to enforce protections for LGBT patients under the federal Nursing Home Reform Act (NHRA) and to educate providers about their responsibilities under this law

- Create legal strategies to enforce the NHRA where violations occur.
 - The Civil Rights of Institutionalized Persons Act (CRIPA) gives the Department of Justice standing to bring forward cases when NHRA violations occur.²⁰⁴ Advocates can educate and work with the DOJ and HHS to more strongly enforce the NHRA.
 - Note that the NHRA applies to almost all facilities, public or private, as long as they are certified to receive Medicaid or Medicare funding.

Work with HUD to create regulations that require nursing homes and assisted living facilities to allow samesex couples and families of choice to share a bedroom

• Creating this regulation within HUD, rather than under the Nursing Home Reform Act, would ensure assisted living and other facilities are also covered.

Visitation and Medical Decision-Making Solutions

Advocate in Tier 2 and Tier 3 states for more inclusive default medical decision making, funeral and disposition-of-remains laws (e.g., recognizing domestic partners even when AHDs are not in place)

- Since medical decision-making laws around funerals and disposition of remains are state laws, advocacy should focus on the state and local levels.²⁰⁵
- Advocates should lobby for laws that respect domestic partnerships and families of choice for decisions around medical procedures, funerals and disposition of remains—even where legal documents are not in place.
- For example, Maryland has passed bills that allow same-sex partners who meet certain criteria to make medical and burial decisions for each other.

²⁰⁰ In most states, complaints are made to state departments of health. Most states have a formal complaint process that needs to be followed, although faster action will be taken if the complaint alleges that a person's life is in jeopardy. Depending on the outcome of the investigation, a nursing home could face financial penalties, be required to undergo new staff training, or lose its eligibility to receive Medicare or Medicaid reimbursements.

²⁰¹ It is important to note that ombudsmen do not have direct authority to require action by a facility. Instead, they have the responsibility to negotiate on a resident's behalf and to work with other state agencies to ensure adequate and effective enforcement of existing laws and regulations.

²⁰² In 2007, for example, about 12,600 people provided 670,000 hours of volunteer time to serve long-term care facility residents through the program. That year, the program also employed 1,300 paid ombudsmen to oversee 16,750 nursing facilities with 1.8 million beds and 47,000 other residential care facilities with 1.1 million beds. *Source: The Basics: Older Americans Act*, National Health Policy Forum, George Washington University, April 21, 2008. FY2008 funding for the program was about \$82 million.

²⁰³ Additional needs include updated policies, modified case reporting systems, and training to give long-term care ombudsmen the tools they need to document, address, and resolve complaints of discrimination on the basis of sexual orientation and/or gender identity and expression. SAGE, It's About Time: LGBT Aging in a Changing World; SAGE Fourth National Conference on LGBT Aging Conference Report: Policy Recommendations, 2009.

²⁰⁴ http://www.justice.gov/crt/split/documents/philcomp.php

The exception to this is Veterans Administration health care facilities, which are regulated through the federal government and do not recognize same-sex marriages or partners. LGBT elders who get their health care through the VA system must be counseled and helped to have the appropriate health care directives in place.

Lobby relevant states to make it easier to designate a partner or loved one for medical decision making

- Where needed, advocate for state laws and policies that make it easy for elders to designate a domestic partner or member of a family of choice for medical decision making, inheritance and disposition of remains.
- The Arizona Advance Health Care Directive Registry allows residents to store living wills and power-of-attorney documents, which are then accessible 24 hours a day, seven days a week via a secure website. Users can also keep a registry card in their wallets, which doctors and nurses can then use to access the database and determine the type of end-of-life care a person wants, even if the person is incapacitated.²⁰⁶
- The Colorado Domestic Partner registry allows individuals to fill out and submit a form that, among other things, allows a person to designate another individual for medical decision making and disposition of remains.

Work with and educate hospitals, long-term care facilities, and other providers to enact LGBT-friendly policies related to visitation rights, AHDs, and surrogate medical decision making

• Best practices outlined by the Healthcare Equality Index (HEI, see sidebar on page 46.) include: creating visitation policies that incorporate a broad definition of "family" to be explicitly inclusive of same-sex relationships and the children of same-sex partners; honoring AHDs as valid, regardless of the state in which they were executed and who has been appointed as the designated agent; having AHD forms on-hand at admission so partners, spouses and friends can easily and quickly attest to their relationship; and educating staff members on the importance of AHDs.

Examine opportunities to promote hospital provision of AHDs under the Patient Self-Determination Act

- Educate relevant health care providers about this act and its requirements to ask about, and help patients create, AHDs upon admission.
- Examine opportunities to more widely implement the act or address ongoing violations.

Offering Culturally Competent Services

To ensure that they are offering culturally competent services for LGBT older adults in their communities, providers must ask themselves the following questions:

- Have we effectively made LGBT older adults aware of our services?
- Have we made our services genuinely welcoming to LGBT elders?
- Are our services appropriate for and acceptable to LGBT older adults?
- Are our services affordable to LGBT elders?

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

²⁰⁶ The Arizona Secretary of State's office oversees the registry. Each user receives a file number and password, which can be filed with their medical records. The service is free, although users still need to actually draft and finalize their living wills, powers of attorney, etc. The state's website provides instructions on how to prepare these documents on one's own or with the help of an attorney.

Examples from the Field: Advocates Work to Improve LGBT Elder Health and Healthcare

Healthcare Equality Index Benchmarks Facilities' Treatment of LGBT People

The Human Rights Campaign (HRC), in partnership with the Gay and Lesbian Medical Association (GLMA), recently launched the Healthcare Equality Index (HEI). The HEI



benchmarks health care facilities based on their treatment of LGBT individuals and families, and specifically looks at their policies related to visitation rights, AHDs and surrogate medical decision making. It also shares best practices with health care industry leaders.

The HEI currently rates 166 health care facilities. Nearly all are hospitals, but the HEI plans to recruit long-term care and assisted living facilities into the project, including questions related to room assignments for same-sex couples. Of the participating facilities, many are working with HRC and GLMA to understand how to improve their scores and service to LGBT people.

LGBT Groups Working to Build Awareness of Non-Discrimination Laws and Increase Compliance

For several years, LGBT aging activists have been working to address compliance with non-discrimination acts (NDAs), and this work is now becoming more organized. Recent developments include:

- The National LGBT Aging Roundtable identified a need for action to address the lack of awareness of existing non-discrimination laws and their applicability to elder-serving institutions.
- The National Gay and Lesbian Task Force completed a state-by-state overview of NDAs and distribution of Administration on Aging funds, which will help the roundtable's members better target their efforts.
- A coalition of LGBT aging groups in New York state have been working collectively on outreach and training in elder-serving institutions, with the goal of encouraging compliance. This model is being replicated in other states with non-discrimination acts.
- SAGE and the Equality Federation are working together to engage LGBT elders and state LGBT advocacy groups in this work.

Colorado Project Provides Cultural Competency Training, Materials for Health Providers

Project Visibility is a three-hour training program for administrators and staff at nursing homes, home care agencies, assisted living facilities, and other providers of direct services to LGBT elders. The training is usually done on site and includes a presentation, a manual, and a 20-minute film that documents the lives of LGBT elders. Although Project Visibility is a program of the Boulder County Aging Services Division, funding for its \$25,000 budgetandpart-timestaffpersoncomesalmost exclusively from individual and foundation donations. Project Visibility materials have reached thousands of employees of long-term care providers across the country.

In a recent program evaluation, 79% of 106 respondents said the training increased their awareness of the issues faced by LGBT elders; 83% said they better understand LGBT elders' fears; and 50% said they are more likely to consider that residents might be LGBT. The evaluation also found that 86% of participants no longer make assumptions about an elder's marital status or life experiences, and 57% ask older adults whom they consider to be their family.

Task Force Educates Boston-Area Agency Staff About LGBT Issues and Rights

The LGBT Aging Project's Open Door Task Force (ODTF) educates Boston-area provider staff, including staff at senior centers and AAAs, via multiple engagements to help reinforce training from one session to the next. ODTF staff members are explicit that they are not trying to change anyone's beliefs or moral convictions regarding LGBT issues and rights. The message is that health professionals do not have to agree with the political positions of LGBT advocates, but they do have a professional duty to treat all patients with dignity, respect and competency. One of the program's primary messages is that LGBT elders have likely had negative experiences with health care institutions over the course of their lives. As a result, even if a facility appears welcoming, there may still be a hurdle of distrust. Many LGBT elders stay in the closet rather than voicing concerns and needs and even remain silent when experiencing abuse at the hands of other patients or staff.

ODTF requires that each participating institution establish an internal taskforce on LGBT competency, thus facilitating institutional memory of the trainings and giving staff a place to go with questions, comments or concerns about the training.

New York Promotes Cultural Competency Training for Aging Services Providers

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

AT ISSUE: SOCIAL SUPPORT AND COMMUNITY ENGAGEMENT

As described earlier in this report, LGBT elders frequently lack access to traditional sources of social support, including partners, children and other blood relatives.



Although LGBT elders are far more likely to live alone, living alone should not be confused with living in social isolation, nor does it automatically mean that LGBT older adults are facing stresses that other older Americans are not. Research indicates great resiliency among LGBT older people; those who have navigated the challenges of the coming-out process and maneuvered through an extremely hostile world are often well-equipped to cope successfully with other life events as they age. Indeed, 40% of LGBT Baby Boomers say that being LGBT has helped better prepare them for aging.²⁰⁷ An elder with strong social networks, opportunities for community engagement, and access to health care and services can thrive. However, when an elder living alone lacks these support systems, he or she is at much greater risk.

Studies have shown how important alternative social networks are in reducing loneliness for LGBT individuals.²⁰⁸ In 2004 focus groups of LGBT older adults, all participants affirmed the importance of their membership in the LGBT community, especially in helping them be comfortable with their sexual orientation. Participants also repeatedly stressed the importance of having accepting social networks and strong familial relationships.²⁰⁹ Support from families of choice is especially critical given the high rates of chronic mental and physical conditions among LGBT elders. And, when an LGBT older adult loses a partner whom society often treats as merely a friend, rather than a spouse, the family of choice provides grieving support and an empathetic ear.²¹⁰

But not all LGBT adults have this kind of support. Despite their resilience and their strong connections to families of choice, social isolation has still been found to be higher among LGBT older adults than in the wider population of elders.²¹¹ Among the key reasons for this: in addition to being more likely to live alone, LGBT elders also are more likely to feel unwelcome in, or be unwelcome in, health care and community settings.

Research shows the harmful effects of social isolation, including higher depression, poverty, re-hospitalization, delayed care-seeking, poor nutrition and premature mortality.²¹² Helping LGBT elders address and overcome social isolation is key to the broader goal of increasing successful aging for this population.

Key Obstacles to Social Support and Community Engagement for LGBT Elders

In this section, we discuss the four major obstacles to social support and community engagement for LGBT elders, as follows:

- LGBT elders lack support from, and feel unwelcome in, mainstream aging programs.
- LGBT elders lack support from, and feel unwelcome in, the broader LGBT community.
- LGBT elders lack sufficient opportunities to contribute and volunteer.
- Housing discrimination adds to the challenges LGBT elders face in connecting to their communities.

We also offer recommendations for addressing these problems.

Unwelcoming Mainstream Aging Programs

Despite their need for strong social networks, LGBT people often feel unwelcome at senior centers, volunteer centers, or places of worship. Like health services providers described in the previous section of the report, senior centers and other aging services providers may never even consider that their clients might be LGBT. Few such agencies engage in outreach to the LGBT community, nor are they prepared to address incidents of discrimination toward LGBT elders by other older people.

Research has underscored the challenges facing LGBT elders at mainstream senior centers and other drop-in agencies: they may be denied services; face harassment from service providers or heterosexual older people; or feel that their specific needs are ignored. In a 1994 survey, 46% of Area Agencies on Aging surveyed said that LGBT people would not be welcome at their senior centers if their sexual orientation were known. Also, 96% did not offer services specifically for gay and lesbian elders and did not target outreach to them; and only 17% provided training to staff on sexual orientation (although 88% were willing to do so).

Not surprisingly, 72% of 121 gay and lesbian people surveyed as part of the study said they were tentative about using AAA services due to lack of trust of AAA personnel; only 19% reported involvement in a senior center.²¹³ LGBT aging

²⁰⁷ MetLife Mature Market Institute (2006).

²⁰⁰⁸ R. Shippy, M. Cantor, and M. Brennan, "Social Networks of Aging Gay Men," *Journal of Men's Studies*, Vol. 13, 2004.

²⁰⁹ Kimmel, Rose and David (2006), p. 233.

²¹⁰ Kimmel, Rose and David (2006).

²¹¹ Kuyper and Fokkema (2009).

²¹²L. Sederer, "Depression, Social Isolation, and the Urban Elderly." Conference on Geriatric Mental Health, New York, 2006.

²¹³ Robert Behney, "The Aging Network's Response to Gay and Lesbian Issues," Outward newsletter, the Lesbian and Gay Aging Issues Network of the American Society on Aging, Winter 1994.

providers such as SAGE report anecdotally that, while some progress has been made in recent years, the circumstances documented in the earlier AAA study are still quite prevalent. These conditions lead to LGBT elders avoiding local agencies and, as a result, missing out on the services and sense of community they provide to many older people.

Isolation from the Broader LGBT Community

The LGBT community is not a uniform community. Like America, it contains a mix of age, race, ethnicity, class and gender—characteristics that are often equally or more relevant to a person's sense of self than sexual orientation.²¹⁴

Several authors have commented that ageism is particularly strong within gay male communities.²¹⁵ Some have suggested that gay men are more likely to struggle with the physical changes of aging because, as a group, they may be more invested than lesbians in their physical bodies. To the extent that this is the case, some older gay men may confront a loss of social valuation as physical and sexual changes affect what has been a source of self-esteem.²¹⁶

Researchers have also found that many older LGBT people feel disconnected from or even unwelcomed by younger generations of LGBT people. One study found that 44% of older gay men felt ignored because of their age while 42% said the LGBT movement does not do enough to engage older LGBT people in social activities. ²¹⁷ In another study, older gay men felt marginalized from the gay community as they aged, and they perceived their aging to diminish their social support dramatically, while lesbians tended to have networks that were more resilient and showed less fluctuation in response to changes with aging. ²¹⁸

LGBT advocates and organizations are becoming more intentional about welcoming, involving, and harnessing the talents of LGBT elders. In addition, as the aging of the Baby Boom generation increases the visibility of LGBT older adults, LGBT organizations and movement leaders increasingly are paying attention to issues of ageism in the LGBT community.²¹⁹ However, there is still a great deal of work to be done to build bridges to this population, as large numbers of LGBT elders remain isolated from the broader LGBT community.

Insufficient Opportunities to Contribute

Some LGBT elders are not in a position to advocate effectively for themselves either because of advanced age and frailty or because they are closeted. But many LGBT older people are, or have the potential to be, powerful advocates for change. In addition, LGBT elders often are overlooked as potential volunteers and providers of social support for



SAGE Volunteer Appreciation Party, 2008

others. Not only can becoming active in this way reduce social isolation and provide a sense of purpose, adults who volunteer regularly have better physical and mental health.²²⁰

"At the same time the nation faces potential labor shortages in critical areas including education and health care, a new generation of older Americans would like to keep working—full-time, part-time, paid, and unpaid—in their so-called retirement years. Despite the potential win-win situation, there is little evidence that communities are prepared for this new environment. Barriers include ageism and negative attitudes towards older individuals, lack of a local inventory of community needs and older adult volunteers' skills, lack of ability by communities to match volunteer opportunities with appropriate volunteers, [and] few resources to inventory local community needs and older adult volunteers' skills."

-The Gerontological Society of America, *Civic Engagement in an Older America*, 2005

²¹³ Robert Behney, "The Aging Network's Response to Gay and Lesbian Issues," Outward newsletter, the Lesbian and Gay Aging Issues Network of the American Society on Aging, Winter 1994.

²¹⁴Kimmel, Rose and David (2006).

²¹⁵ Brian de Vries, "Gays and Lesbians, Later Life," *Encyclopedia of the Life Course and Human Development*, 2008.

²¹⁶ Kimmel, Rose and David (2006).

²¹⁷ Andrew Hostetler, "Old, Gay, and Alone?" in *Gay and Lesbian Aging Research and Future Directions*, 2004.

²¹⁸ This Chicago-based study assessed attitudes of 111 gay males and 49 lesbians, who ranged in age from 45 to 90 years (with a median age of 51 years). Judith C. Barker, Gilbert Herdt, Brian de Vries, "Social Support in the Lives of Lesbians and Gay Men at Midlife and Later," Sexuality Research & Social Policy: Journal of NSRC, Vol. 3, No 2, June 2006.

²¹⁹For example, the largest conference in the LGBT movement, The National Gay and Lesbian Task Force's *Creating Change*, had an entire programming track dedicated to LGBT elders issues at its 2010 conference.

²²⁰ P. Cullinan, "Late-life Civic Engagement Enhances Health for Individuals and Communities," *The Journal on Active Aging*, November-December 2006.

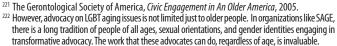
The federal government administers three major volunteer programs for older adults. These are: the Retired and Elder Volunteer Services Program (RSVP), which recruits 500,000 older Americans annually for various nonprofit volunteer positions; Foster Grandparents, which employs about 30,000 low-income older adults to work with needy families; and Senior Companions, which assists frail elders. However, each of these programs has income eligibility, service scope, and time commitment requirements that significantly limit participation.²²¹ Other national service programs such as AmeriCorps and the Peace Corps have traditionally favored youth and young adults.

In order to effectively engage the growing population of older adults, national volunteer programs such as these must be expanded and improved. Just as importantly, these programs must reach out and include LGBT elders, who may feel they would not be welcome as volunteers—for example, as a friendly visitor or foster grandparent. In one example of effective outreach, AmeriCorps volunteers in Boston met with and invited older adults from the LGBT Aging Project to participate in the Experience Corps program, which helps children learn to read.

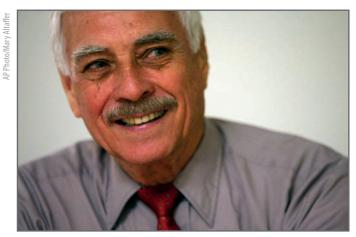
LGBT elders also can be mobilized more effectively to advocate on their own behalf. SAGE and other organizations working with LGBT older adults have long recognized that the greatest resource available to LGBT older adults is often themselves. Newer generations of LGBT older people include many who have been active for decades in progressive movements—including the women's movement, social responses to the AIDS epidemic, and the LGBT movement. These volunteers have extensive experience as change agents and can bring a wealth of commitment and expertise to the movement for equality and expanded services for LGBT older adults. Indeed, it was LGBT older adults who helped drive the grassroots development of SAGE and other LGBT aging organizations. These active and engaged older adults create new opportunities for LGBT aging services providers to find new advocates and supporters and expand their programming.²²²

Housing Discrimination

LGBT elders may be denied housing, including residency in mainstream retirement communities, based on their sexual orientation and gender identity and expression. This discrimination may separate LGBT elders from loved friends or partners, or push them into homelessness. LGBT elders may also feel the need to reenter or stay in the closet in order to obtain or maintain housing.



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



Garrison Phillips, 79, a Korean War veteran who now does volunteer work with SAGE, smiles during an interview with the New York Times, Friday, Sept. 12, 2008

Emerging Movement Shows the Power of LGBT Elder Activists

Nearly every LGBT aging organization that exists was started by a group of older activists. Examples include:

- Gay and Gray in the West, based in the Denver area, conducts outreach, trainings, advocacy and even a biennial conference through a vibrant, active group of volunteers. In 2008, the group advocated for inclusion in the GLBT Center of Denver's programs network; and in 2009, the two groups joined together to create SAGE of the Rockies.
- In Missouri, the Silver Haired Legislature is a formally elected body of citizens 60 years of age and older that promotes conscientious legislative advocacy for Missouri's older adults. Members of SAGE of Metro St. Louis sit on this body, which provides recommendations to the Missouri General Assembly.
- Old Lesbians Organizing for Change (OLOC) offers lesbian older adults an opportunity to engage in advocacy issues addressing ageism and sexism and anti-gay discrimination. Membership is limited to lesbians 60 and over.
- The SAGE Advocates program offers constituents in SAGE programs the opportunity to receive training on public speaking and advocacy, then engages them in aging advisory councils, testifying on behalf of LGBT older adults and meeting with elected officials.
- The Leadership Academy of Lavender Seniors of the East Bay in San Leandro, California, organizes an annual daylong training on how elders can get involved in local government advisory boards.²²³

While there are no assessments of housing discrimination against LGBT elders, the U.S. Housing and Urban Development (HUD) reports that some state and local studies have shown this sort of bias against LGBT people in general. For example, Michigan's Fair Housing Centers found that nearly 30% of same-sex couples were treated differently when attempting to buy or rent a home. Additionally, SAGE and other LGBT aging organizations report that fears of housing discrimination and unwelcoming communities are commonplace among their constituents. One recent study found that 33% of gay and lesbian respondents thought they would have to hide their sexual identity if they moved to a retirement home. These fears, combined with the lack of quality elder housing in general, create concern about housing options for LGBT elders.

To help address these and other concerns, HUD announced a series of proposals in 2009 aimed at ensuring that the agency's core housing programs are open to all, regardless of sexual orientation or gender identity. The proposed rules will clarify that the term "family" includes LGBT people as eligible beneficiaries of public housing and Housing Choice Voucher programs (which help families rent affordable homes). HUD also will require grantees and other HUD program participants to comply with local and state non-discrimination laws that cover sexual orientation or gender identity; and specify that any FHA-insured mortgage loan must be based solely on the credit-worthiness of a borrower. Finally, HUD will commission the first-ever national study of discrimination against LGBT people in the rental and sale of housing.

Other efforts to secure housing for LGBT elders include housing projects that target this population. Residential communities for LGBT older adults such as Rainbow Vision in Santa Fe and Triangle Square in Los Angeles have received considerable attention. Whether these communities can be replicated in sufficient numbers to serve as a systemic solution is unclear, as is the degree to which such communities would be preferred by a large proportion of LGBT older adults if they were widely available.

Recommendations: Helping LGBT Elders Secure Social Support and Community Engagement

LGBT elders are at particular risk of social isolation, due to issues such as estrangement from biological family members, discrimination and hostility in the mainstream aging community, lack of acceptance in the LGBT community, insufficient opportunities to give back to their communities as advocates and volunteers, and housing discrimination. The following are recommended solutions to these problems.

^{224 &}quot;Obama Administration to Ensure Inclusion of LGBT Community in HUD Programs," HUD press release, October 2009. http://portal.hud.gov/portal/page/portal/HUD/press/press-releases media advisories/2009/HUDNo.09-206.

²²⁵ M.J. Johnson, J.K. Arnette, and S.D. Koffman, S.D., "Gay and Lesbian Perceptions of Discrimination in Retirement Care Facilities, *Journal of Homosexuality*, 49(2), 2005.

Table 4: Recommendations: Helping LGBT Elders Secure Social Suppot and Community Engagement

Solutions for Making LGBT Elders More Welcome in General Aging Programs

Address cultural competency and discrimination issues among mainstream aging services providers and programs

- The problems of discrimination and lack of cultural competency by mainstream aging services providers, senior centers and community centers mirror those of health services providers. As with health services providers, it is important to train staff in mainstream aging programs to become more culturally competent.
- See recommendations in the "health" section.

Partner with aging services providers to welcome LGBT elders and increase on-site LGBT elder programs and services at mainstream facilities • LGBT advocates and LGBT aging organizations can work with local senior centers, community centers, government program providers and other aging services providers to provide LGBT elder programming within broader elder programming. Another priority is to encourage and support mainstream aging services providers to more effectively target and reach out to LGBT elders.

Solutions for Making LGBT Elders More Welcome in LGBT Programs

Make LGBT elders more welcome in the LGBT community at large

- Address ageism in the LGBT community. Encourage community dialogues or programs/ campaigns to counter ageism and build understanding between younger and older LGBT people.
- Increase LGBT elder programming offered by LGBT advocates. Because most LGBT older adults live alone, they need informal settings in which to meet others and establish communities. For example, LGBT aging advocates may partner with LGBT community centers to broaden LGBT elder programming. This will help to minimize isolation and loneliness, and develop support networks consisting mostly of people who know about an individual's sexual orientation. Programming may include drop-ins, peer-support or discussion groups, information and referral services, designated spaces for older adults, exercise and fitness programs, movie-going, museum and theater groups, dances, computer training and Internet access, speakers bureaus, community service projects, vacation cruises and day trips, hot meals, art classes and writing workshops, newsletters, and guest speakers.
- Conduct intergenerational programming. This might include one-on-one matching of youth and older adults, social events, or arts programming such as writing and photography workshops and exhibitions.
- Help LGBT elders connect through technology. Increased Internet-based social outlets are especially important for transgender elders whose smaller numbers make it more difficult to build local community.

Solutions to Increase LGBT Elder Opportunities to Contribute and Volunteer

Improve overall opportunities for all elders to engage in volunteerism and civic engagement

- Develop a national strategy for promoting new and meaningful volunteer and civic engagement opportunities for LGBT and heterosexual elders.
- Work with the AoA to develop a comprehensive strategy for engaging older individuals to address critical local needs of national concern.
- Work with AAAs to develop a needs and assets inventory to match the skills and talents of residents with programs that serve the local community.
- Educate volunteer organizations on the need to explicitly reach out to and welcome LGBT elders—and help them do so.

²²⁶ Kimmel, Rose and David (2006).

Involve LGBT elders in general LGBT and LGBT elder advocacy

- There are myriad opportunities to capture the valuable energy, experience and insight that LGBT elders bring the broader LGBT community. Indeed, more often than not it is LGBT older people themselves who have been the most effective voices for change in dialogues with public officials and policymakers.
- LGBT elder volunteers could work with AAAs to advocate for increased funding for LGBT elder programs or educate them about the needs of LGBT elders, or could help deliver cultural competency training to health and community service providers.
- Organizations might train a corps of local LGBT elders to serve as ombudsmen and patient advocates to help compensate for the lack of government funding for ombudsman programs and to ensure that such programs become a force for promoting fair treatment of LGBT older people in care settings.
- LGBT elders can spearhead community-based social and educational opportunities for LGBT older people; many of the elder-serving activities provided by SAGE and similar organizations are the result of volunteer leadership.
- LGBT elder volunteers also can provide certain direct services such as friendly visits.

Solutions to Help LGBT Elders Secure Needed Housing

Add sexual orientation to the non-discrimination provisions of the federal Fair Housing Act (FHA) and parallel state policies to render existing housing LGBT-friendly

- Include explicit non-discrimination policies and enforcement mechanisms for LGBT people in the FHA, which covers virtually all housing in the U.S. and enumerates protected categories.
- Link federal and state housing program funding to compliance with these policies.

Consider supporting LGBT elder housing projects

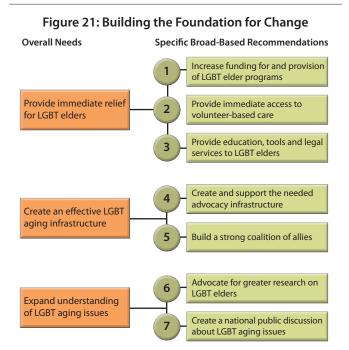
- Support feasibility studies for LGBT elder housing and further examine LGBT elders' interest in, and need for, this housing.
- While these solutions are attractive to many LGBT elders, they are also expensive, and are unlikely to be implemented at a national level. For example, openhouse in San Francisco has secured \$10 million in development funds to build an LGBT-oriented, full-service retirement community that has 60 units of housing, falling far short of the needs of the 25,000 LGBT residents in the surrounding area.

BROAD-BASED RECOMMENDATIONS: BUILDING THE FOUNDATION FOR CHANGE

The bulk of this report examines specific challenges facing LGBT elders in the areas of financial security, health and health care, and social support and community engagement, and offers specific recommendations for addressing these challenges. However, it is all too easy to focus on these individual challenges without examining the larger changes that need to happen in order to support this work. Therefore, this final section of the report offers cross-cutting recommendations for improving conditions for LGBT elders and creating the foundation for effective change. Priorities outlined in the following pages include: providing immediate relief to LGBT elders; building an advocacy infrastructure and a strong coalition of allies; and increasing understanding of LGBT elder issues through research and public education. See *Figure 21*.

Provide Immediate Relief for LGBT Elders

Many of the recommendations in the first half of this report will take time—time that some LGBT elders simply do not have. We must find a way to meet critical needs now, and we can do so by: 1) focusing on increasing funding for (and provision of) LGBT elder programs; 2) helping to meet immediate care needs by providing access to volunteer caregivers; and 3) providing education, tools, and legal services to LGBT elders. We now look at each of these first three broadbased recommendations in turn.



1. Increase Funding for and Provision of LGBT Elder Programs

The federal Administration on Aging spent more than \$1.3 billion on home and community services for elders in 2009;²²⁷ yet few funds have been allocated for LGBT aging issues to date. However, change is in the works. In October 2009, the U.S. Department of Health and Human Services (HHS) announced plans to establish the first-ever national resource center to help communities support and serve their LGBT elders. Then, in February 2010, HHS awarded SAGE a three-year, \$900,000 grant to create this center. The resource center will work with the AoA and other partners²²⁸ to provide training, education, tools and assistance to help communities across the country better serve and support LGBT older adults. Among other tools, SAGE plans to develop a comprehensive, web-based clearinghouse targeting mainstream aging providers, LGBT providers and LGBT older adults.

In addition to this larger change, the AoA has awarded the L.A. Gay & Lesbian Center an historic three-year grant, valued at \$380,000 in the first year, to expand its Senior Services Department. It was the first such award to an LGBT organization, signaling that the AoA is starting to be intentional about addressing the needs of LGBT elders.

Together, these changes highlight emerging opportunities for LGBT service providers to access public funds to meet the needs of LGBT elders. But the two grants outlined above are a drop in the bucket compared to the actual needs of LGBT elders. The first step toward securing additional funds is to understand the delivery of existing elder funds and programs.

The Older Americans Act (OAA) of 1965 gives the Federal government authority to fund and organize services for older Americans.²²⁹ The OAA, in turn, established the AoA as an agency within HHS. The AoA is now the chief federal agency advocating for older people (for a list of AoA funding priorities, see Appendix).

²²⁹ Age 60 years and older, priority is given to those most in need.

^{227 &}quot;HHS to Create a National Resource Center for Lesbian, Gay, Bisexual and Transgender Elders", HHS press release, October 2009, accessed at http://www.hhs.gov/news/ press/2009pres/10/20091021a.html.

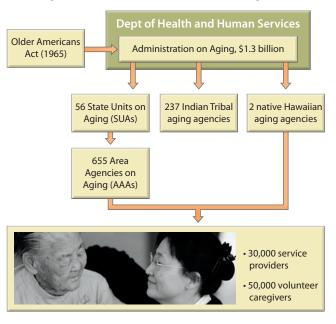
²²⁸ In creating the Resource Center, SAGE will forge a partnership with 10 organizations with expertise in a wide range of areas including mainstream aging, LGBT aging, cultural competency training and program evaluation. These organizations include PHI (a national training expert), the National Association of Area Agencies on Aging (n4a), the National Council on Aging's National Institute of Senior Centers, the American Society on Aging, the Brookdale Center for Healthy Aging and Longevity, Centerlink (the national association of LGBT community centers), GRIOT Circle, FORGE Transgender Aging Network, Third Sector New England/The LGBT Aging Project, and openhouse.

Federal AoA funds in turn flow through 56 state units on aging (SUAs), which then coordinate 655 local Area Agencies on Aging (AAAs),²³⁰ as well as Indian Tribal and Native Hawaiian aging agencies.²³¹ These agencies are responsible for a specific (usually local) geographic area, and they in turn partner with nearly 30,000 service providers (mostly local government agencies and nonprofit organizations) and about 50,000 volunteer caregivers to meet the area's needs (see *Figure 22*). The services delivered through these agencies cover everything from in-home health services and assistance with daily living to external services and programs such as transportation assistance, adult daycare, legal services, congregate meals and local senior centers.

SUAs and AAAs develop their plans and funding priorities in consultation with local advisors and community members, using townhalls and other means to solicit feedback from the general public. The SUA plans are brief and feature high-level themes with very few specific plans or program details. Each SUA then allocates federal dollars to its AAAs, which have flexibility to support the programs they think best meet local needs. Most AAA plans include an environmental overview of the 60+ population in their area, an assessment of current and future needs, and a summary of local strategies to support those needs. Plans may also include an analysis of short- and long-term trends affecting the region's aging population.

The OAA stipulates that "vulnerable populations" must receive extra attention in planning and funding, though it does not enumerate what these populations are. However, many SUAs and AAAs have enumerated lists of populations that they believe are especially vulnerable (although these lists rarely include LGBT elders). To the degree that advocates can expand definitions of vulnerable populations to include LGBT elders, or influence the planning and funding priorities of SUAs and AAAs, they can make great progress in securing funding, programs and services for LGBT elders.

Figure 22: HCBS Structure and Funding Flow



Aging and Disability Resource Centers May Be Central Point for Future Elder Funding

In 2003 the AoA and the Centers for Medicare and Medicaid Services (CMS) launched the Aging and Disability Resource Center (ADRC) initiative. The ADRC program helps states develop "one-stop shop" or "no wrong door" local centers that more effectively combine the two major funding streams for services to older adults—CMS and AoA.

ADRCs create a single point of entry to the public long-term care system; their mission is to streamline services and costs while helping older adults maintain independence in their homes. The government's long-term goal is to have ADRCs serve all individuals with long-term care needs regardless of age or disability.

Currently, 43 states have received grants from the federal government to operate ADRCs. However, in many states, ADRC services are also managed by local AAAs.

²³⁰ About half of the SUAs are located in umbrella health and/or human services agencies, while the remainder are independent departments or commissions of state government. Of AAAs, about 41% are private non-profit organizations, 32% are part of a city or county government, 25% are part of councils of government and 2% are Indian Tribal organizations or other entities. Source: Frank Burns et al., "2006 Survey of Area Agencies on Aging Preliminary Results," presented at that Annual Conference of the National Association of Area Agencies on Aging, August 8, 2006.

[&]quot;SUAs" is a general term, and states can give different names to these agencies. Examples include departments, bureaus, offices, commissions, or boards for the elderly, seniors, aging, older adults, adults with physical disabilities, etc. Similarly, AAAs also vary in name or structure from state to state and even within states. They can be established at the county, city, or regional level, and can either be public agencies or private nonprofit organizations. See www.eldercare.gov/Eldercare.NET/public/Network/sua.aspx.

Specific Recommendation for Increasing Funding for and Provision of LGBT Elder Programs	
Designate LGBT elders as a vulnerable population in laws and agency missions	It is difficult to overstate the importance of having federal, state and local funding agencies recognize LGBT elders as a vulnerable population. Designating LGBT elders as vulnerable would help drive:
	• Funding of LGBT elder programs;
	Services for LGBT elders (including greater inclusion of LGBT elders in general aging program design, delivery and outreach to make LGBT elders feel included and welcome);
	Cultural competency training of staff of aging agencies and service providers;
	Organizational non-discrimination policies and training;
	Data collection (aging agencies collect data on vulnerable populations to understand their needs and appropriately tailor services).
Encourage the AoA to publish policies identifying LGBT elders as vulnerable	Work with the AoA to draft guidelines, policies or new regulations that ask SUAs and AAAs to explicitly consider LGBT elders as a vulnerable population (among other populations). These actions would be administrative and would not require an act of Congress. (Since the OAA does not currently enumerate which populations are vulnerable, it would be challenging to amend the OAA to specifically recognize LGBT elders).
Encourage SUAs and AAAs to explicitly identify LGBT elders as vulnerable	• Unlike the AoA, many SUAs and AAAs do explicitly enumerate which populations they believe are most vulnerable. This in turn drives state and local planning, funding priorities, and the focus of local aging services providers. Advocates can work with SUAs and AAAs to educate them on the specific vulnerabilities of LGBT elders and to encourage them to add LGBT elders to their list of vulnerable populations.
	• Encouraging higher-level administrative guidance can be key in raising awareness of LGBT elders as a vulnerable population. For example, in New York City, the Department of Aging has identified LGBT elders as a vulnerable group for the purposes of issuing RFPs for federal caregiver funds. This increases the chances that LGBT care programs will be funded and that mainstream providers will think to provide or incorporate LGBT elder services.
Pass local or statewide health or aging regulations/ laws supporting LGBT elders	Depending on local law, advocates can lobby to pass local or state legislation or regulations that designate LGBT elders as a vulnerable aging population, and that mandate that any agency receiving public aging funds adopt comprehensive LGBT cultural competency programs.
	 For example, the Older Californians Equality and Protection Act mandates that the California Department on Aging and Area Agencies on Aging address LGBT older adults' needs by including them in needs assessments and area plans; providing LGBT cultural competency training to staff, contractors, and volunteers; and ensuring that all provided services are free of discrimination based on sexual orientation and gender identity.
	• Ideally, new legislation or regulations would include funding to pay for the training and also enforcement of the new laws or regulations. Frequently, funding needs to be secured through legislative means.
Advocate to secure funding for LGBT elder services through SUAs and AAAs	• SUAs and AAAs develop their plans and funding priorities in consultation with local advisors and community members. LGBT advocates can help drive awareness of, and funding to address, the specific needs of LGBT elders by becoming members of advisory boards, attending hearings, educating those who already advise these agencies, etc.

Provide technical assistance to help LGBT providers secure public funds

- Provide local LGBT service providers with toolkits and technical assistance on grantwriting (including sample grant applications) to make the grant application process less overwhelming and more successful.²³² These toolkits could also summarize available data on LGBT elders and their needs, so that providers can answer questions often asked in grant applications.
 - The National Gay and Lesbian Task Force has begun this daunting task with its guide, Find the Dollars You Deserve. A Road Map to Federal Funding for Aging Services: Navigating the Federal Government for Lesbian, Gay, Bisexual and Transgender Organizations.²³³ The guide examines various program areas and provides lists and descriptions of federal grant opportunities. However, due to local complexities, the guide does not provide specific grantwriting advice, but rather refers readers to their local AAA or SUA for application guidelines.
- Fund one or several grantwriting professionals to help local organizations work with AAAs to unlock public funds. (Given the lack of current funding for LGBT elder programs, this opportunity could provide a significant return on investment.)²³⁴
- Many LGBT advocates are unaware that they can bid for AAA funds under the National Family Caregiver Support Program, to deliver programs that are designed to address the caregiving needs of LGBT older adults.

Work to make general elder services and support programs inclusive of LGBT elders

- Educate mainstream elder service providers about LGBT elders and their needs.
- Develop and deliver model policies, best practices, and provider trainings to ensure that staff is willing and able to support LGBT caregivers, and that LGBT elders feel welcome in these programs.
- Work with AAAs to assess needs of LGBT elders, influence area plans, and get AAAs to offer specific services designed for LGBT elders and target outreach to them.
- Help create/strengthen community programs specifically for LGBT seniors at general aging facilities/programs.

²²²We recognize that application guidelines will vary by AAA and state. However, it is also true that most applications ask similar types of questions; therefore, LGBT organizations would benefit from toolkits that help them understand and think through how best to answer standard question types.

Accessed at http://www.thetaskforce.org/downloads/resources and tools/find the dollars.pdf

²³⁴ For example, SAGE New York secured a \$300,000 grant from the New York AAA, while the L.A. Gay and Lesbian Center secured a \$380,000 federal grant. It would only take one grant of this size to outweigh the cost of a professional grant-writing consultant.

Examples from the Field: Engaging AAAs in LGBT Elder Programming and Services

Florida AAA Program Reaches Out to LGBT Elders

The first—and still the only–federally funded LGBT elder day care program is located in Ft. Lauderdale, Florida, thanks to the efforts of Broward County Aging and Disability Resource Center/AAA Director Edith Lederberg. She attributes her engagement in LGBT aging issues to a former staff member, Noble McArtor, who was tragically killed in 2001.

"He really educated me about the gay population," Lederberg recalled. "I became very sympathetic, especially for those who were getting to the age where they needed some services, but did not feel they could go to the centers because they didn't feel comfortable."

Lederberg believed that a catalyst was needed. "The community needed someone who was an ally, and wasn't afraid of repercussions. I did it because it was the right thing to do." She began to move forward with plans to open an LGBT senior day care center.

One of the Broward County AAA's advisory board members was LGBT advocate Bob Tomasulo. With his help, Lederberg identified space on the campus of the Sunshine Cathedral (a Metropolitan Community Church) that was accessible and had ample parking. Lederberg also felt that the congregants of this LGBT-welcoming church would be a natural constituent group for the center.

When Lederberg began to move forward with the work, she immediately encountered barriers at all levels. "You can't imagine how many city commission meetings I went to," she laughed. But she persevered. "I think they relented because it came from an AAA director," she said. "They knew I wasn't going to let go. I was driven because I wanted to do it, especially after I lost Noble."

Today, the Noble A. McArtor Senior Day Care serves a diverse community of older adults.

Engaging LGBT Elders in Planning and Advocacy at Local AAAs

As these examples show, the voices of LGBT elders and advocates can help educate and influence state and AAA planning and programming. For example:

- GLBT Generations in Minneapolis worked with the University of Minnesota and the Twin Cities AAA to develop and distribute an online questionnaire about the visibility of LGBT older adults in elder-serving settings; the organization now is using this information in its training curriculum, "Training To Serve."
- New York State's LGBT advocacy group, known as The Empire State Pride Agenda, facilitates an LGBT health and human services network that includes a senior issues committee, which includes representation from various local LGBT aging programs. In 2005, after a series of meetings with the New York State Office for Aging, the committee was invited to help develop an advisory letter sent to all state AAAs. The letter, sent under the signature of the Commissioner, urged AAAs to include LGBT elders in their planning needs. Some AAAs, including the New York City Department for Aging, in turn urged service providers to pay attention to LGBT elders—and included LGBT cultural competency as a measured component in funding decisions.
- LGBT elder advocate Bob Tomasulo was part of the Broward County (Florida) AAA Board and helped establish the first LGBT senior day care program in the country (see adjacent sidebar). After that work was underway, he and his partner moved to North Carolina, where Tomasulo has become active as a volunteer with the Asheville AAA. He currently serves on the AAA board and also volunteers with its ombudsman program. "Wherever we are, we should step forth and join the (AAA) advisory board. Especially in communities that don't tend to think about LGBT older adults," Tomasulo said.

2. Provide Immediate Access to Volunteer-Based Care

During the AIDS crisis, the LGBT community rallied together to provide an unprecedented community response, finding ways to take care of those stricken by this deadly virus before (and after) government and health care providers finally recognized and responded to the crisis. The crisis facing LGBT elders is less dramatic and far more silent, but it is a crisis of care nonetheless. The LGBT and aging community must find ways to reach out, both to LGBT elders who need assistance with daily living, and to the many older people who still have much to contribute but do not feel welcome either in the LGBT community or in the general aging community.

LGBT aging services programs are starting to fill the service and caregiving gaps for LGBT elders by creating new support systems. However, the invisibility of LGBT elders, along with ageism in the LGBT community, mean that the level of community response and current models of service and care fall far short of what is needed. Expanded caregiving efforts are few, and those that exist are woefully under-resourced.

Some advocates are experimenting with a "Share the Care" model of caregiving that mobilizes small, often non-urban communities with sizeable LGBT populations (see sidebar). Others are creating programs that rely on lean, professionally-staffed initiatives to provide practical and emotional support to large numbers of volunteer caregivers for LGBT older people. Still others are trying to connect older LGBT people with established mainstream service networks, although the effectiveness of these efforts will be limited if personnel have not first received cultural competency training.

Advocates must continue to build and expand upon these burgeoning efforts. SAGE provides toolkits that help interested organizations create volunteer-based friendly visitor programs. In New York, SAGE built a program of its own by running an ad campaign on New York City subways and buses that raised the profile of LGBT aging issues and dramatically increased the organization's volunteer corps. These types of programs could also be extended to assist LGBT elders with the tasks of daily living.



Advocate Improves Lives of LGBT Elders with "Share the Care" Program

According to Nancy Bereano, 66, "Share the Care" arose from her experience as one of the caregivers for a cancer-stricken friend, Candice, during the last year of her life. "If Candice had been 73 instead of the 63 that she was, there wouldn't have been many of us to help her because we would have been in our 70s and 80s and be struggling with disability and sickness ourselves," Bereano said.

Bereano co-founded the Tompkins County Working Group on LGBT Aging in conjunction with a dozen grassroots activists and gerontological professionals, including the executive director of the local senior center. One of the group's first projects was to develop Share the Care as a program for LGBT older adults. Said Bereano, "Any group of kindred spirits can organize a Share the Care program."

Share the Care programs are usually built by accessing an older adult's family, friendship, and/or faith-based networks to be available during a time of crisis. LGBT elder Share the Care programs also draw on a larger, intergenerational LGBT community connected by their mutual LGBT status.

Excerpted with permission from Grant, J., "Outing Age: Public Policy Issues Affecting Lesbian, Gay, Bisexual and Transgender Elders," National Gay and Lesbian Task Force, 2010.

3. Provide Education, Tools, and Legal Services to LGBT Elders

Advocates can empower LGBT elders with useful information about a variety of issues, including:

- Financial and estate-planning;
- Medical and legal documents such as AHDs and end-oflife documents;
- LGBT elders' current rights under the law to fair treatment in senior centers, health services, long-term care facilities, etc.
- Services and tools available via the newly announced SAGE LGBT Elder National Technical Assistance Resource Center, including social networking tools, an "Ask the Experts" service, web-based trainings and other features.

Where possible, advocates should strive to provide information and assistance that is detailed and geographically appropriate (including referrals to local LGBT-friendly experts). Additionally, advocates can provide direct, hands-on legal and financial planning services and workshops, both to help LGBT older adults navigate existing inequalities under the law (e.g., inequitable Medicaid spend-down rules), and to help them redress illegal discrimination when it happens (e.g., discrimination against an LGBT elder in a nursing home). For example, the National Center for Lesbian Rights and SAGE have co-published an educational legal guide for LGBT older adults.²³⁵ The guide provides an excellent overview of the issues but, due to state-by-state legal variations, lacks specific state-based recommendations.



SAGE volunteer Gigi Stoll, right, helps Frank Carter straighten out a wheel chair order during her weekly visit. New York, 2008.

Create an Effective LGBT Aging Infrastructure

Improving the lives of LGBT elders is a major undertaking. There is a lot to be done. Progress will not happen without investment in two key precursors to change: infrastructure to support the movement's goals and sustain an effective advocacy effort; and new relationships and partnerships that can ensure broad-based support.

4. Create and Support the Needed Advocacy Infrastructure

LGBT aging has only recently emerged as an issue for advocacy and action. For example, it is hard to point to a single LGBT elder issue that receives national prominence on the level of efforts to overturn Don't Ask, Don't Tell; pass non-discrimination protections; or enact safe schools legislation.

SAGE, the leading organization specializing in LGBT aging issues, is just beginning to add advocacy and legislative work to its traditional focus on services and programming for LGBT older adults. Accordingly, over the past two years, SAGE has built a policy advocacy team of three full-time staffers, including a director of advocacy and director of federal government relations. In addition, SAGE employs paid lobbyists at the local, state and federal levels. SAGE can take the lead on LGBT elder issues, but given its relatively small budget (approximately \$5 million) and staff, currently it does not have the capacity to fulfill this role without significant reliance on partners and outside resources. For example, SAGE does not have a Washington, D.C. office, a dedicated policy analyst, report-writing capabilities, sufficient resources to create comprehensive policy recommendations, or the machinery to mobilize elder advocates nationwide.

SAGE affiliates and comparable organizations around the country are gradually building their capacity to engage in advocacy. But most local SAGE programs have annual budgets of less than \$200,000. SAGENet, the national network of SAGE affiliates, has no dedicated budget and instead relies on SAGE to subsidize the network's advocacy capacity-building efforts.

Adding to the challenge, general LGBT advocacy groups are currently engaged in high-profile, often-intensive debates around relationship recognition rights, adoption rights, non-discrimination laws, and other key issues. This leaves these organizations with little time and remaining resources to focus on LGBT elders. This lack of resources means LGBT elder issues do not receive significant attention in the political or public realm. For example, achieving parity in Social Security benefits for same-sex couples is not an insurmountable challenge, but

²³⁵ Planning with Purpose: Legal Basics for LGBT Elders, NCLR, June 2009.

it attracts little attention in comparison to achieving marriage equality and achieving other movement goals. Properly framed, ²³⁶ LGBT elder issues can gain significant support. Even if an issue is unlikely to be the focus of decisive Congressional or other political action in the near future, the important work of defining policy recommendations, building a coalition of supportive allies, educating the public, and advancing policy priorities can all start happening now.

At the federal level, the challenge is no longer defining an advocacy agenda, but rather how to develop, execute and support strategies and tactics to advance that agenda on multiple fronts. At the state level, similarly detailed agendas are lacking and would require a state-by-state analysis across key policy issues such as inheritance tax, medical decision making, and family leave.

Building an effective LGBT elder advocacy infrastructure in Washington, D.C., and the state capitals means investing far greater resources in the organizations that are best positioned to drive advocacy at the state and federal levels. It also means supporting convenings, coalition building and information sharing across organizations within the LGBT movement, as well as between LGBT and mainstream aging advocates.

For example, within the LGBT movement, the National LGBT Aging Roundtable meets annually for information sharing and networking. However, there is virtually no funding to support a coordinated effort to build advocacy capacity across roundtable members. Similarly, investment in and coordination of LGBT aging legal strategies is limited—at least relative to more established issues such as relationship rights, LGBT youth rights, etc. Finally, while collaborative advocacy work linking LGBT organizations and allies in the mainstream aging network is increasing, more support is needed for these activities, as discussed below.

5. Build a Strong Coalition of Allies

Organizations working for LGBT equality often lack expertise in the complexities of LGBT aging and have little capacity for undertaking a deep dive into these issues. To a certain degree this is true even for an organization like SAGE, which historically has been immersed in the service and care crises facing LGBT elders and therefore has yet to develop deep aging policy expertise. By contrast, mainstream aging organizations live and breathe issues such as Social Security, pensions, estate taxes, and the confusing tangle of government bureaucracies and service providers that work with older people. Thanks to the work of LGBT aging advocates, mainstream aging organizations gradually have shown more interest in and support for LGBT aging issues. These allies can bring resources, expertise, policy know-how, political relationships and influence, and the ear of the mainstream aging community to the LGBT aging agenda.

While to date, mainstream efforts to advance LGBT elder issues have been limited, this work lends itself to natural partnerships. Many LGBT aging issues described in this report also affect all single elders, widows and widowers, and heterosexual domestic partners; some of the issues even affect younger Americans. The summary table found in the report conclusion provides an at-a-glance view of where recommendations improve the lives not only of LGBT elders, but of heterosexual elders as well.

Thinking broadly (while not losing focus on LGBT older people) helps create alliances with mainstream organizations (aging or otherwise) and strengthens arguments for policy change. For example, many of the federal safety net programs that protect older people center on the presumption of marriage, but the majority of older Americans are not married. In fact, more than four out of five women over age 75 are widowed,²³⁷ and many issues affecting single LGBT elders also affect them.

So, how do we not only help LGBT older people, but also help change the lens through which the government views older adults as a whole? Below are three examples:

- The recently passed Pension Reform Act allows any person to designate any other person to receive the former's tax-deferred retirement plan and draw it down over time. This helps a younger, terminally ill woman who wants to give her retirement account to her nephew, as well as the single LGBT older person who wants to designate a lifelong friend.
- Advocates can work with assisted living facilities and nursing homes so that, where space allows, residents are able to share rooms with others of their choosing. This would mean two widows who are close friends could choose to room together, as could same-sex couples.
- All hospitals could institute policies asking elderly patients about advance health care directives, providing the forms where needed, and even helping patients complete the forms. This would help an older lesbian couple, but also a single heterosexual elder who wanted to designate a beloved caregiver as his or her medical proxy, or a young single person with deceased parents who wanted to designate a close friend.

²³⁶ Marriage message testing shows that many Americans are more sympathetic to the personal and emotional consequences of marriage inequality (e.g., lack of hospital visitation) than to the financial consequences. However, the public often mistakenly assumes that same-sex couples are more affluent than average Americans, and do not think about how lack of Social Security Survivor Benefits, for example, might impoverish a lesbian widow. Highlighting the real consequences of these inequities with moving, personal stories of their impact on same-sex elders is far more likely to create a sympathetic response.

²³⁷ U.S. Census Bureau.

Partnerships Possible at All Levels to Expand Advocacy

LGBT and mainstream aging organizations are already working together at the local, state, and national levels.

National example: The National Senior Citizens Law Center collaborated with SAGE, the National Gay and Lesbian Task Force, the National Center for Transgender Equality, and Lambda Legal in fielding a 2009-2010 survey of LGBT older adults, their friends and family members and aging services providers about the experience of LGBT elders in long-term care settings. This survey was intended to help define needed institutional advocacy efforts and asked questions such as whether LGBT elders experienced verbal or physical harassment or refusal to honor a medical power of attorney. NSCLC took the lead in creating and fielding the survey, working with its mainstream service provider contacts to distribute the survey and drive responses, which exceeded all partners' expectations.

State example: The Older Californians Equality and Protection Act, signed into law in 2008, was sponsored by Equality California (the state LGBT advocacy organization) and supported by mainstream partners including the American Society on Aging and the National Association of Social Workers. This legislation requires the California Department of Aging and Area Agencies on Aging to ensure that data gathering, annual plans, and service development

take into account the needs of aging LGBT Californians. These entities must also provide technical assistance to local agencies for the training of staff, contractors and volunteers regarding the unique needs of LGBT elders, and ensure that programs and services provided through the Older Americans Act and Older Californians Act in each planning and service area are available to all older adults.

Local example: When Eldon Murray, a longtime activist in the Milwaukee area, created SAGE Milwaukee, he met with the director of the Milwaukee County AAA to provide information on LGBT aging issues. The AAA Director invited Murray to join the AAA's advisory board. When Murray retired, SAGE Milwaukee Director Bill Serpe took his place on the advisory board. Serpe now serves as chair of the underserved populations work group and a member of the board of directors in the family care program, which is a separate division in the AAA. The inclusion of LGBT older adults has permeated policy and planning work throughout the agency, Serpe said. For example, a recent needs assessment survey distributed by the AAA included an opportunity for respondents to self-identity as LGBT, and that inclusive language is now in forms and surveys distributed by other county and city agencies. Because of the groundwork Murray provided, Serpe confirms that LGBT elders are always included in policy planning.

The question then becomes how to capitalize on these opportunities for partnership. Most LGBT aging organizations are local agencies and MAP's research suggests that they are fairly disconnected from mainstream aging groups. While there is often little reason for local LGBT groups to reach out to state or federal aging groups, relationships can and should be built at the local level to strengthen advocacy and service efforts. Similarly, state groups can partner with state groups, and national groups with national groups.

Coalition-building is an area where MAP believes additional funding would yield a several-fold return. The impact of pulling mainstream partners into the work of improving the lives of LGBT elders cannot be overstated. The LGBT community cannot be expected to do this work on its own, nor can it achieve the desired results through solitary advocacy. This movement needs partners and a broader base of support. However, fostering these partnerships requires time and dedicated resources.

For example, in 2009, for the first time, an LGBT organization (SAGE) was invited to sit on the Leadership Council of Aging Organizations (LCAO). The LCAO, which consists of 56 member organizations nationwide, is the nation's leading coalition of aging organizations, and uses its coalition strength to develop effective policy for the nation's diverse aging population. However, budget and staffing limitations have prevented SAGE from attending all LCAO meetings. Additionally, SAGE has forged increasingly strong relationships with national organizations like AARP, the National Council on Aging, the National Hispanic Council on Aging and the National Center and Caucus on Black Aged. However, limited resources have prevented SAGE from better leveraging these relationships for effective advocacy collaborations.

²³⁸ Analysis of 2009 MAP survey of LGBT organizations working on aging issues

Expand Understanding of LGBT Aging Issues

6. Advocate for Greater Research on LGBT Older Adults

There is very little data available about LGBT older people. Past research efforts have been hampered in part by a disregard for this population by government, philanthropy and academia; and in part by the fact that older LGBT people are less likely to be out. The list of needed data and research is long and includes health and mental health research, research into LGBT elder life and family situations, economic studies, research into incidents of discrimination, and more. This data is critical, both because it will help build better understanding and a more effective response to the needs of LGBT older people, and because it will help demonstrate just how big these needs are. Government agencies often will not provide grants for LGBT aging programs without data about the specific needs of this population, and yet this same lack of funds and attention makes it difficult for advocates to gather the data they require.

Advocates should encourage governments and agencies to collect LGBT data in all federal, state and local studies and surveys, including demographic studies, studies on physical and mental health, etc. At the federal level, advocates should work to revise Older Americans Act regulations to require state agencies receiving funding for data collection to include LGBT populations. At the state level, they should advocate for state laws such as the Older Californians Equality and Protection Act, which, as part of its scope, promotes greater data collection on LGBT elders.

Additionally, advocates should urge HHS to establish a dedicated Office of LGBT Health to help coordinate a consistent and scientifically driven response to LGBT health issues. This office could also ensure that any federally funded health study that collects demographic information include questions about sexual orientation and gender identity.²³⁹ The California Health Interview Study, one of the few state surveys that collects information on sexual orientation, provides experience in developing, field testing and analyzing demographic questions on sexual orientation.

7. Create a National Public Discussion About LGBT Aging Issues

Americans care about their elders. Yet issues such as lack of Social Security survivor benefits for same-sex widows or widowers are generally no more than a passing note buried in a broader discussion about LGBT equality. Why is this? One answer may be that Americans mistakenly believe LGBT people are more affluent than other Americans; therefore, the wider population is rarely moved to oppose laws that create economic hardship for LGBT people. However, Americans may respond positively to the real-life, and all-too-common, stories of elders who are impoverished by unjust laws—who lose all they own to estranged relatives of a deceased partner, who are turned away from hospital rooms, or who languish in institutions where they are shunned by patients or staff.

Using real and personal stories to educate Americans about how current inequities affect LGBT older adults provides an opportunity to change the national discussion around LGBT issues generally. The goal should be to illustrate the harms caused by current policies in a meaningful way, and to correct common misperceptions (e.g., the presumed wealth of LGBT people, or the notion that marriage at the state level achieves equality for same-sex couples, despite the total lack of recognition by the federal government). Aging issues are compelling and may help "moveable" audiences and politicians become more sympathetic to LGBT issues in general. Education on these issues also may help heterosexual elders become more accepting of LGBT older adults overall. Therefore, appropriate public, media and political education around the impact of these inequities is very important, both for its own sake, and as a mechanism to drive broader change.

²³⁹ Center for American Progress, "How to Close the LGBT Health Disparities Gap," December 2009.

²⁴⁰ MAP analysis of various polling and market research commissioned by LGBT advocates, 2006-2009.

CONCLUSION

The rapidly aging population raises new questions about how major institutions—including federal, state and local governments, employers, and the family—will meet the needs of vast numbers of elderly people. To date, government and other social institutions have responded to aging as a problem of loss and decline, providing backstops such as Social Security to keep older Americans out of poverty, and Medicare to cover their doctor and hospital care. As this report has shown, however, these backstops often do not protect all older Americans equally. LGBT Americans today bear the burden of decades of discrimination and social stigma.

It is a history that cannot be waved off as over and done—its consequences live on in the Social Security earnings of lesbian workers whose pay never came close to equaling that of their heterosexual peers, and in the refusal of many gay men to seek critical health and senior services because of the institutional hostility they have suffered in the past. And it is a history that lives on in the inequities and the prejudice that still face many LGBT elders today.

Adequately funding Social Security and other backstops is critically important to promoting successful aging for all elders. But it is not enough. With Americans living longer than ever before, government and other institutions have a responsibility to consider new ways to keep older people productive and engaged in their communities, and to promote new strategies for protecting their health and ensuring a decent quality of life. Doing these things will help not just LGBT elders but all older adults. And it will deliver real returns to society as older adults remain active in the workforce and in volunteer positions, and as they stay healthier and engaged for a longer time.

This report was intended to provide LGBT and mainstream aging organizations, Americans and their elected leaders with information, inspiration and ideas for improving the lives of LGBT older adults. LGBT older adults simply want the same chance as other older adults to achieve financial security, good health and health care, and strong social networks and opportunities for community engagement. We hope this report has outlined why and how LGBT elders face additional obstacles that stand in the way of successful aging, and we also hope that it lays the groundwork for solutions that will benefit all Americans, whether young, old, heterosexual, or LGBT.

Summary of Major Report Recommendations and Whom They Help

In the table on the following page we summarize the headline recommendations in this report and note three things about each one:

- 1. Which of the key challenges facing LGBT elders noted early in the report, will be addressed by the recommended action: social stigma and prejudice; reliance on informal families of choice; and/or unequal treatment under laws, programs and services.
- 2. Which of the major issues identified in this report the action will address: the financial security of LGBT elders; health and health care; or social support and community engagement.
- 3. What specific populations will be helped by the action: same-sex couples, heterosexual domestic partners, LGBT single older adults, heterosexual single older adults or a combination of these groups.

Summary of Major Recommendations and Whom They Help

Recommendation	Barrier(s) Addressed by Recommendation			How Recommendation Helps With Successful Aging			Whom Recommendation Helps			
	Stigma	Unrec- ognized Families	Unequal Laws	Financial Security	Good Health	Social Support	Same- Sex Couples	Hetero. Dom. Partners	Single LGBT Elders	Single/ Wiowed Hetero. Elders
				S		AA	MI	11	1	Lidels
Broad-Based Financial Security Solution	ıs									
Repeal the Defense of Marriage Act	√	√	√	√	√	√	√			
Gain marriage and relationship recognition state-by-state	√	√	√	√	√	√	√			
Pass the federal Employment Non- Discrimination Act	√		√	√			√		√	
Social Security Solutions										
Revise the federal Social Security Act to provide benefits to domestic partners		√	√	√			√	√		
Medicaid Solutions										
Revise the federal Medicaid Act to extend financial protections to domestic partners and families of choice		√	√	√			√	√	√	√
Advocate for states to electively extend spousal impoverishment protections to domestic partners and financially interdependent elders		V	V	V			√	√	√	√
Advocate for states to adopt broader interpretation of spend-down and cost recovery rules in order to protect domestic partners and financially interdependent elders		V	V	√			√	√	V	√
Advocate for states to allow single recipients of Medicaid-funded HCBS to retain a greater living wage		√	√	√					√	√
Tax-Qualified Retirement Plan Solutions	5									
Amend ERISA to allow "non-spouse" beneficiaries to draw down inherited IRAs on the same schedule as spousal beneficiaries		V	V	V			√	√	√	√
Employee Pension Solutions										
Amend ERISA to create a designated "non- spouse joint survivor" for QJSAs or QPSAs, and make it mandatory that businesses offer this option as part of their pension plans		√	√	√			√	√		
Encourage employers to electively offer QJSAs and QPSAs to LGBT employees and financially interdependent individuals		√	√	√			√	√		
Employee Health Insurance / Domestic	Partner Be	nefits Solu	utions							
Advocate for federal legislation that provides equal treatment for domestic partner benefits		V	√	√			√	√		
Lobby relevant states to eliminate state taxes on domestic partner benefits		√	√	√			√	√		
Work with employers to electively offer domestic partner benefits		√	√	√			√	√		

Recommendation	Barrier(s) Addressed by Recommendation			How Recommendation Helps With Successful Aging			Whom Recommendation Helps			
	Stigma	Unrecognized Families	Unequal Laws	Financial Security	Good Health	Social Support	Same- Sex Couples	Hetero. Dom. Partners	Single LGBT Elders	Single/ Wiowed Hetero. Elders
Estate Tax Solutions		ļ.								
Advocate for federal legislation that provides equal estate tax treatment for domestic partners		√	√	√			√	√		
Advocate for relevant states to eliminate state-based estate and inheritance tax for domestic partners		√	√	√			√	√		
Veterans Benefits Solutions										
Advocate for federal legislation that provides equal treatment to the partners of LGBT veterans		√	√	√			√	√		
Fight for repeal of Don't Ask, Don't Tell	√	√	√	√			√		√	
Inheritance/Power of Attorney Solution	s									
Advocate in relevant states for more inclusive default intestacy laws		√	√	√			√	√	√	√
Advocate for relevant states to make it easier to designate a domestic partner or other loved one for inheritance		√	√	√			√	√	√	√
Health Disparity Solutions										
Collect and conduct research on LGBT elder health, mental health, and the long-term effects of HIV			√		√		√		√	
Provide training on health disparities	√		√		√		√		√	
Provide coverage for LGBT elder medical needs			√		√		√		√	
Target HIV prevention programs to older people			√		√		√		√	
Solutions to Support Family-of-Choice (Caregivers					1				
Advocate to broaden the definition of covered caregivers in the federal FMLA		√	√		√		√	√	√	√
Advocate to broaden the definition of covered caregivers in state FMLAs		√	√		√		√	√	√	√
Educate LGBT elders about caregiver support services available under the National Family Caregiver Support Act and how to access these services		V	V		V		V		√	
Inhospitable Health Care Environment S	Solutions									
Pass non-discrimination acts (NDAs) or ordinances at the state or local level	√		√		√		√		√	
Increase awareness and enforcement of existing NDAs	√				√		√		√	
Encourage service providers to adopt their own non-discrimination policies	√				√		√		√	
Examine state public health laws, nursing home laws and assisted living facility laws for opportunities to protect LGBT elders	V		√		√		√		√	
Develop scalable, technology-enabled cultural competency training to reach large numbers of health care providers	V				V		V		√	

Recommendation	Barrier(s) Addressed			How Recommendation Helps With Successful Aging		Whom Recommendation Helps			n Helps	
	Stigma	Unrec- ognized Families	Unequal Laws	Financial Security	Good Health	Social Support	Same- Sex Couples	Hetero. Dom. Partners	Single LGBT Elders	Single/ Wiowed Hetero. Elders
Find ways to encourage providers to undergo training	√				√		√	,	√	7
Work with organizations that accredit health service providers to develop standards for serving LGBT elders	√				√		√		√	
Help patients/residents who are mistreated to hold facilities accountable	√		√		√		√	√	√	√
Advocate for better support of, and training for, long-term care ombudsmen	√		√		√		√	√	√	√
Nursing Home Solutions										
Seek to enforce protections for LGBT patients under the federal Nursing Home Reform Act and to educate providers about their responsibilities under this law	V		V		V		V		√	
Work with HUD to create regulations that require nursing homes and assisted living facilities to allow same-sex couples and families of choice to share a bedroom	V	V	V		V		V	V	√	√
Visitation and Medical Decision-Making	Solutions									
Advocate in Tier 2 and Tier 3 states for more inclusive default medical decision making, funeral and disposition of remains laws (e.g., recognizing domestic partners even when AHDs are not in place)		V	V		V		√	√	√	√
Lobby relevant states to make it easier to designate a partner or loved one for medical decision-making		√	√		√		√	√	√	√
Work with and educate hospitals, long- term care facilities and other providers to enact LGBT-friendly policies related to visitation rights, AHDs, and surrogate medical decision-making	V	V	V		V		V	V	√	√
Examine opportunities to promote hospital provision of AHDs under the Patient Self-Determination Act		√	√		√		√	√	√	√
Broad-Based Solutions to Social and Community Engagement										
Address cultural competency and discrimination issues in mainstream aging service providers and programs	√		√			√	√		√	
Partner with mainstream aging service providers to welcome LGBT elders and increase on-site LGBT elder programs and services at mainstream aging facilities	V		V			V	V		√	
Solutions for Making LGBT Elders More	Welcome i	n LGBT Pro	ograms							
Make LGBT elders more welcome in the LGBT community at large	√					√	√		√	
Solutions to Increase LGBT Elder Oppor	tunities to	Contribut	e and Volu	inteer						
Improve overall opportunities for LGBT (and heterosexual) elders to engage in volunteerism and civic engagement	√					√	V	√	√	√

Recommendation	by Recommendation				How Recommendation Helps With Successful Aging			Whom Recommendation Helps			
	Stigma	Unrecognized Families	Unequal Laws	Financial Security	Good Health	Social Support	Same- Sex Couples	Hetero. Dom. Partners	Single LGBT Elders	Single/ Wiowed Hetero. Elders	
Involve LGBT elders in general LGBT and LGBT elder advocacy	√					√	√		√		
Solutions to Help LGBT Elders Secure No	eded Hou	sing									
Add sexual orientation to the non- discrimination provisions of the Federal Fair Housing Act and parallel state policies to render existing housing LGBT- friendly	V		V			V	V		√		
Consider supporting LGBT elder housing projects	√		√			√	√		√		
Overall Broad-based Recommendations	;										
Increase funding for and provision of LGBT elder programs	√	√	√	√	√	√	√		√		
Provide immediate access to volunteer-based care	√	√	√		√	√	√		√		
Provide education, tools and legal services to LGBT elders	√	√	√	√	√	√	√		√		
Create and support the needed advocacy infrastructure	√	√	√	√	√	√	√		√		
Build a strong coalition of allies	√	√	√	√	√	√	√		√		
Advocate for greater research on LGBT elders	√	√	√	√	√	√	√		√		
Create a national public discussion about LGBT aging issues	√	√	V	√	√	√	√		√		

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APPENDICES

Glossary of Acronyms Used in This Report

AAA	Area Agency on Aging
AARP	AARP, formerly known as the American Association of Retired Persons (see foreword)
ADRC	
	Aging and Disability Resource Center (see page 55) Advance Healthcare Directive (see page 39)
AHD	
AoA	Administration on Aging (see page 8)
ASA	The American Society on Aging (see inside cover)
CAP	Center for American Progress (see inside cover)
CMS	The Centers for Medicare and Medicaid Services (see page 8)
DFTA	Department for the Aged (City of New York , see page 57)
DOMA	The Defense of Marriage Act (see page 9)
ENDA	Employment Non Discrimination Act (see page 26)
ERISA	Employee Retirement Income Security Act (see page 20)
FHA	Fair Housing Act (see page 53)
FMLA	The Family and Medical Leave Act (see page 33)
GLMA	Gay and Lesbian Medical Association (see page 46)
HCBS	Home and Community Based Services (see page 15)
HEI	The Healthcare Equality Index from the Human Rights Campaign (see page 46)
HHS	The U.S. Department of Health and Human Services (see page 8)
HRC	The Human Rights Campaign (see page 13)
HUD	The Department of Housing and Urban Development (see page 8)
IRA	Individual Retirement Account (see page 19)
LCAO	Leadership Council of Aging Organizations (see page 62)
LGBT	Lesbian, gay, bisexual and transgender (see page 1)
MAP	Movement Advancement Project (see inside cover)
NDA	Non-Discrimination Act (see page 42)
NFCSA	National Family Caregiver Support Act (see page 34)
NHRA	Nursing Home Reform Act (see page 44)
NSCLC	National Senior Citizens Law Center (see inside cover)
OAA	Older Americans Act (see page 8)
OASDI	Old Age, Survivors and Disability Insurance program (commonly known as Social Security, see page 8)
ODTF	Open Door Task Force from the LGBT Aging Project (see page 47)
OLOC	Old Lesbians Organizing for Change (see page 1)
PSDA	Patient Self-Determination Act (see page 39)
SAGE	Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (see inside cover)
SSA	The Social Security Administration (see page 8)
SSI	Supplemental Security Income (see page 8)
SUA	State Unit on Aging (see page 55)
RFAs	Requests for Application (see page 47)
PPA	Pension Protection Act (see page 19)
QJSA	Qualified Joint and Survivor Annuity option on an IRA (see page 19)
QPSA	Qualified Pre-retirement Survivor Annuity on an IRA (see page 19)
UAFA	The Uniting American Families Act (see page 25)
UCLA	University of California Los Angeles (see page 2)
WRERA	Worker, Retiree and Employer Recovery Act (see page 19)
* V I \L I \/ \	Worker, hearder and Employer necestery Net (see page 19)

Older Americans Act Funding Priorities²⁴¹

The Administration on Aging (AoA) received a \$1.52 billion budget appropriation for 2010 under the Older Americans Act (OAA). The OAA is considered to be the major vehicle for the organization and delivery of social and nutrition services to older adults and their caregivers. According to the AoA:

The AoA awards funds for nutrition and supportive home and community-based services to the 56 State Units on Aging (SUAs), 244 Tribal organizations, and 2 Native Hawaiian organizations. In addition, funds are awarded for disease prevention/health promotion services, elder rights programs (long-term care ombudsman program, legal services, and elder abuse prevention efforts), the National Family Caregiver Support Program (NFCSP) and the Native American Caregiver Support Program (NACSP).

OAA funding is allocated to each SUA based primarily on the number of persons 60 years of age and over (70 years of age and older for the NFCSP) in the state. Most states are divided into planning and service areas (PSAs), so that programs can be tailored to meet the specific needs of older persons residing in those areas. The SUA grants funds to the Area Agency on Aging (AAA) designated for each PSA. The AAA determines the needs of older persons in the PSA and works to address those needs through the funding of local services and through advocacy.²⁴²

The table below breaks out key programmatic areas and their 2010 allocated funds.

Program	Description	2010 Budget ²⁴³
Home & Community-Based Long-Term Care	Programs that help older adults maintain their independence and dignity in their homes and communities. Includes a range of supports for family caregivers.	
Supportive Services and Senior Centers	Multi-purpose senior centers that coordinate and integrate services for older adults such as congregate meals, community education, health screening, exercise/health promotion programs and transportation. Includes: • Transportation Services - over 28 million rides to doctor's offices,	\$368.3 million
	grocery stores, pharmacies, senior centers, meal sites, and other critical daily activities.	
	 Personal Care, Homemaker, and Chore Services - nearly 33 million hours of assistance to elders unable to perform daily activities (such as eating, dressing or bathing) or instrumental activities of daily living (such as shopping or light housework) 	
	Adult Day Care/Day Health Services - nearly 9 million hours of care for dependent adults in a supervised, protective group setting.	
	Case Management Services - nearly 4.5 million hours of assistance in assessing needs, developing care plans, and arranging services for older persons or their caregivers.	
Nutrition Services	Provides meals and related nutrition services to older individuals in congregate facilities and by home-delivery to older individuals who are homebound due to illness, disability, or geographic isolation. Includes: 1) Congregate Nutrition Services, 2) Home-Delivered Nutrition Services, and 3) Nutrition Services Incentive Program.	\$819.5 million

²⁴¹ All data from the Administration on Aging website, <u>www.aoa.gov</u>, accessed February 23, 2010.

²⁴²AoA website, http://www.aoa.gov/AoARoot/AoA Programs/OAA/Aging Network/Index.aspx, accessed February 26, 2010.

²⁴³ These numbers represent the 2010 Fiscal Year Appropriation by Congress. Note that breakdown of the AoA budget does not always parallel AoA program descriptions. Therefore, budgets were not always available for every program area.

 National Family Caregiver Support Program 	The National Family Caregiver Support Program offers services to support family caregivers including:	\$154.2 million
	Information to caregivers about available services,	
	Assistance to caregivers in gaining access to the services,	
	Individual counseling, organization of support groups, and caregiver training,	
	Respite care, and	
	Supplemental services, on a limited basis	
	Studies have shown that these services can reduce caregiver depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care.	
Grants for Native Americans	Grants to eligible Tribal organizations promote the delivery of home and community-based supportive services, including nutrition services and support for family and informal caregivers, to Native American, Alaskan Native and Native Hawaiian elders. These programs help to reduce the need for costly institutional care and medical interventions.	\$34.1 million
Aging & Disability Resource Centers	The Aging and Disability Resource Center Program (ADRC), a collaborative effort of AoA and CMS, is designed to streamline access to long-term care. The ADRC program provides states with an opportunity to effectively integrate the full range of long-term supports and services into a single, coordinated system. By simplifying access to long-term care systems, ADRCs and other single point of entry systems are serving as the cornerstone for long-term care reform in many states.	Funding is unclear
 Alzheimer's Disease Supportive Services Program 	The Alzheimer's Disease Supportive Services Program supports state efforts to expand community-level supportive services for persons with Alzheimer's Disease and Related Disorders and their caregivers.	\$11.4 million
Naturally Occurring Retirement Communities	Funding supports older adults living independently in geographically defined residential areas and building complexes. Labeled "NORCs" or "Naturally Occurring Retirement Communities", these residential entities provide: • Residential housing with supports; • Transportation for appointments and shopping;	No apparent appropriation in 2010 budget
	Referrals and follow-up	
	Coordination of non-professional services.	40.5 UII
Lifespan Respite Care Program	Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children or adults of all ages with special needs.	\$2.5 million

Health, Prevention and Wellness Program	Health, Prevention, and Wellness Programs provide elders with the tools to maintain their health, reduce their risk of developing chronic diseases, and manage their health to live as independently as possible. The centerpiece of these programs is the Evidence-Based Disease and Disability Prevention Program described below.	
Evidence-Based Disease and Disability Prevention Program	This program provides discretionary grants to implement evidence-based prevention programs. These programs help seniors to improve and/or maintain their physical and mental health, reduce their risk of falling, and better manage their chronic diseases. The program has been shown to be effective in helping people with chronic conditions change their behaviors, improve their health status, and reduce their use of hospital services. Topics covered include techniques for dealing with problems such as	\$21.0 million
	frustration, fatigue, pain and isolation; exercise for maintaining and improving strength, flexibility, and endurance; nutrition; appropriate use of medications, and communicating effectively with health professionals.	
 Diabetes Self Manage- ment Training (DSMT) Initiative 	AoA is working to implement Stanford's DSMT Program in 14 community-based settings in an effort to provide outreach, education, and treatment to minority older adults who have been diagnosed with diabetes. DSMT programs help older adults learn and adopt essential diabetes self-management techniques.	2010 funding is unclear but funding was less than \$500,000 in both 2008 and 2009.
· Hispanic Elders Project	Hispanic elders have a higher incidence of certain chronic diseases such as diabetes, heart disease and arthritis, than the rest of the U.S. population. To support the efforts of communities to improve the health of Hispanic elders, AoA and partners launched an initiative in 2007 in eight major urban areas. Under the leadership of the Area Agency on Aging, each of these communities formed broad-based coalitions to improve Hispanic elders' health.	2010 funding is unclear but funding was \$200,000 in both 2008 and 2009.
Elder Rights Protection		
Prevention of Elder Abuse, Neglect and Exploitation	This program trains law enforcement officers, health care providers, and other professionals on how to recognize and respond to elder abuse; supports outreach and education campaigns to increase public awareness of elder abuse and how to prevent it; and supports the efforts of state and local elder abuse prevention coalitions and multidisciplinary teams.	\$5.1 million

Long-Term Care Ombudsman Program

Long-Term Care Ombudsmen are advocates for residents of nursing homes, assisted living facilities and similar adult care facilities. They work to resolve problems of individual residents and to bring about changes at the local, state and national levels.

\$16.8 million

Today, each state has an Office of the State Long-Term Care Ombudsman, headed by a full-time state ombudsman. Thousands of local ombudsman staff and volunteers work in hundreds of communities throughout the country as part of the statewide ombudsman programs, assisting residents and their families and providing a voice for those unable to speak for themselves.

Program data for FY 2008 indicate that about 9,000 certified ombudsmen volunteers devoted 800,000 hours to serving facility residents and more than 1,300 paid ombudsman served in 572 localities nationwide. These volunteers and paid ombudsmen investigated over 271,000 complaints made by 182,506 individuals and provided information on long-term care to another 327.000 people. They visited 79% of all nursing homes and 46% of all assisted living and similar homes and conducted 7,257 training sessions in facilities on such topics as residents' rights. They also provided 128,400 individual consultations to long-term care facility managers and staff and participated in 21,000 resident council and 4,900 family council meetings.

Special Projects

· Civic Engagement

AoA's long-range vision is to highlight the important role that volunteers, including older volunteers, play within the Aging Network and to provide them with innovative ways of using their skills and experience. The OAA Amendments of 2006 highlight the role of volunteers as a strategy to support and enhance OAA programs. The amendments:

New initiative, 2010 funding is unclear

- Provide guidelines for the use of volunteers at all levels in OAA programs;
- Provide for multigenerational and civic engagement demonstration grants that encourage community capacity-building involving older individuals; and
- Call for collaboration between the AoA and the Corporation for National and Community Service to help modernize the way public and private non- profit organizations, such as community and faithbased organizations, utilize older adults as volunteers.

AoA is also funding a three year project with the National Council on Aging to provide technical assistance and other support to local programs that can become national multi-generational and civic engagement models for using older volunteers in meaningful direct services. Projects will focus on three target populations: 1) older relatives caring for grandchildren; 2) families caring for children with special needs; and 3) caregivers of frail elderly.

Snapshot of LGBT Nonprofits That Work in Aging or on Aging Issues

This appendix briefly describes LGBT aging work undertaken by LGBT nonprofits. The appendix does not cover LGBT-specific work by mainstream aging organizations (e.g., AARP, American Society on Aging).²⁴⁴ The appendix groups relevant LGBT organizations in four categories:

- LGBT organizations that focus entirely on LGBT aging
- National LGBT organizations that do some substantive LGBT aging work
- State and local LGBT organizations that do some substantive LGBT aging work
- Umbrella/coordinating organizations that focus on LGBT aging

LGBT Organizations that Focus Entirely on LGBT Aging

Services & Advocacy for GLBT Elders (SAGE) www.sageusa.org	SAGE is a national organization that improves the overall quality of life for LGBT older adults; supports and advocates for the rights of LGBT older people; fosters a greater understanding of aging in all communities; and promotes positive images of LGBT life in the later years. SAGE is the world's oldest and largest nonprofit addressing the needs of LGBT elders. Major programs include clinical and social services programs, community services, caregiver services, HIV services, cultural competency training curricula, advocacy and policy work, and services and technical assistance to SAGE affiliates. SAGE is also currently developing the National Technical Assistance Resource Center for LGBT Elders.
SAGE Affiliates	SAGE affiliates serve local LGBT communities. They are financially and legally independent of SAGE but coordinate activities with SAGE and across the SAGE affiliate network through SAGENet. SAGE affiliates include: SAGE affiliates include: SAGE at the Center on Halsted (Chicago). www.centeronhalsted.org SAGE of the Hudson Valley (at Hudson Valley LGBTQ Community Center). www.lgbtqcenter.org SAGE Long Island. www.sageli.org SAGE Metro D.C. http://www.thedccenter.org SAGE of Metro St. Louis. www.sagemilwaukee.org SAGE/Milwaukee. www.sagemilwaukee.org SAGE at Rainbow Bridge Connection (Hampton Roads, VA). http://rbcnlmcc.org/home SAGE Palm Springs. www.goldenrainbowseniorcenter.org SAGE Philadelphia (at William Way Gay & Lesbian Community Center). www.waygay.org SAGE Queens (at Queens Community House in NY). www.queenscommunityhouse.org Rainbow SAGE of the Genessee Valley (Rochester, NY). www.queenscommunityhouse.org SAGE South Florida. www.sagewebsite.org SAGE Upstate (Central NY). www.sageupstate.org SAGE Upstate (Central NY). www.sageupstate.org
	SAGE Utah (at Utah Pride Center). www.utahpride.org
Aging As Ourselves (San Diego) www.agingasourselves. org	Aging As Ourselves is a community-based collaboration of six mainstream and LGBT health and social service providers working together to ensure that comprehensive elder services are delivered in an LGBT culturally sensitive manner and that LGBT providers address specific health issues facing this hidden population.

²⁴⁴ To identify LGBT organizations for inclusion in this appendix, MAP surveyed about 200 LGBT organizations that work with MAP or SAGE. Nearly 70 respondents said they do some elder-specific work, however, we excluded respondents who have general programming that happens to touch on LGBT elders, but do not do aging-specific work. MAP also scanned documents and websites for additional organizations missed in the survey. We apologize to any organizations whose aging work we accidently missed.

LGBT Aging Issues Network (LAIN) http://www.asaging. org/networks/index. cfm?cg=LAIN Azteca Project (San Diego) www.aztecaproject.org	LAIN is a national American Society on Aging constituent group that works to raise awareness about the concerns of LGBT elders and about the unique barriers they encounter in gaining access to housing, health care, long-term care and other needed services. LAIN seeks to foster professional development, multidisciplinary research and wide-ranging dialogue on LGBT issues through publications, conferences, and cosponsored events. The Azteca Project provides vital support and referral services in both English and Spanish to LGBT Latinos/ Latinas 50+. Information is provided on social services, available discounts for medications, living assistance, housing, legal, income tax assistance, transportation, employment meals delivered to homes, home repairs, and discounted utilities.
Gay & Lesbian Elder Housing (Los Angeles) www.gleh.org	Gay & Lesbian Elder Housing builds and operates high-quality affordable, multicultural housing developments which include a community space used to provide social and recreational services. As an affordable housing developer, GLEH provides housing retention programs, aging in place programs and health and wellness programs.
GLBT Generations (Twin Cities area , MN) http://glbtgenerations.grg	GLBT Generations is a membership-based organization that works on raising the visibility of GLBT elders, provides information about them, sponsors drop-in events, and has conducted a Twin Cities area GLBT needs assessment survey
GRIOT Circle www.griotcircle.org	GRIOT Circle is an intergenerational, culturally diverse community-based organization serving the needs of the community of LGBT elders of color over age 50. Programs include friendly visitor, caring callers, computer classes, health and fitness, HIV 50+ support group, and interest groups (e.g., books, art)
Lavender Seniors of the East Bay (Alameda & Contra Costa counties of CA) www.lavenderseniors. org	Lavender Seniors of the East Bay improves the quality of life of older LGBT residents through outreach, advocacy, and education. Services include friendly visitors, telephone support, speaker panels (cultural competency training for agencies and providers), LGBT elder awareness, periodic informative and social gatherings, and information and referrals.
LGBT Aging Project (MA) www.lgbtagingproject. org	The LGBT Aging Project helps ensure that LGBT elders have equal access to the life-prolonging benefits, protections, services and institutions. Services and programs include education and technical assistance (the Open Door Task Force), community and policymaker education and advocacy and social activities for LGBT elders, their caregivers and friends.
New England Association on HIV Over Fifty www.hovoverfifty.org	New England Association on HIV Over Fifty hosts an annual conference on HIV and aging.
Old Lesbians Organizing For Change (OLOC) www.oloc.org	OLOC is a national network of Old Lesbians over age 60 working to make life better for Old Lesbians and to confront ageism using education and public discourse as primary tools. During biennial national gatherings hundreds come together to share experiences and ideas. Long-term projects include collecting the herstories of lesbians 70 years and older and memorializing old lesbian friends and mentors who have died.
openhouse (San Francisco) www.openhouse-sf.org	openhouse builds critically-needed housing, services and community programs to support the health and well-being of LGBT older adults, and changes the culture of long-term care by training service providers to create welcoming, safe and secure environments for the LGBT clients they serve.
Primetimers Worldwide (international) www.primetimersww. org	Prime Timers Worldwide is a social organization that provides older gay & bisexual men the opportunity to enrich their lives. The organization has grown to over 60 chapters located throughout North America, Europe and Australia. Individual chapters welcome the chance to meet visitors from other chapters.

Rainbow Seniors of Western New York (Rochester, Finger Lakes Region, Southern Tier, and Buffalo) http://www.rainbowseniorswny.org	RSWNY offers social and life-enriching programs, events, and networking; strives to promote positive images of growing older; and advocates for the rights of the older GBLT individuals in both the gay and non-gay communities.
SPRY – Seniors Preparing for their Rainbow Years (Houston) www.spryhouston.org	SPRY strives to shine a light on the lives of LGBT seniors (age 60+) for them to be able to experience prideful, bold and bright rainbow years. Services include counseling, case management, groups and socials.
Stonewall Communities (New England) www. stonewallcommunities. org	Stonewall Communities is a community-based organization that serves older LGBT people via educational, social, residential, and support opportunities. Programs include a Lifelong Learning Institute at Wheelock College, as well as residential (Audubon Circle) and support (Aging in Community) programs.
Transgender Aging Network (National) www.Forge-forward.org/ TAN	The Transgender Aging Network improves the lives of current and future trans and allied elders by identifying, promoting communication among, and enhancing the work of researchers, service providers, educators, advocates, elders and others; promoting awareness of the issues and realities of trans aging; advocating for policy changes; and providing communication channels through which trans elders can give and receive support and information (including ElderTG, an on-online support group).

National LGBT Organizaions That Do Some Aging Work

ACLU LGBT Rights Project www.aclu.org/lgbt- rights	The ACLU LGBT Rights Project advocates on issues such as defined pensions, Medicaid/Medicare, and partner benefits. It does not have a dedicated elder law program area.
AIDS Community Research Initiative of America (ACRIA) www.acria.org	ACRIA's Center on HIV & Aging investigates, defines, and seeks to address the unique needs and challenges that older adults of diverse populations living with HIV face as they age.
American Veterans For Equal Rights www.aver.us	AVER is a chapter-based association of active, reserve and veteran servicemembers that advocates for recognition, respect and equal treatment/benefits to military veterans who are LGBT. AVER works to engage the Veterans' Administration and VA hospitals to advance LGBT culturally competent care.
CenterLink www.lgbtcenters.org	CenterLink is a member-based coalition to support the development of strong, sustainable LGBT community centers. Centerlink is working with SAGE to build community centers' capacity in aging services and advocacy. It is also collaborating with SAGE on creating the National Technical Assistance Resource Center for LGBT Elders.
Human Rights Campaign (HRC) www.hrc.org	HRC is the largest civil rights group working to achieve equality for LGBT Americans. HRC's website provides information on LGBT elder issues including estate, inheritance and end-of-life decision planning. HRC's Healthcare Equality Index (in collaboration with the Gay & Lesbian Medical Association) rates healthcare facilities on their policies and practices related to the LGBT community. The HRC Foundation participates in Divided We Fail, a coalition with AARP and others to find common-sense solutions to health care and financial security for America's seniors.
Lambda Legal www.lambdalegal.org	Lambda provides legal services and referrals specific to LGBT elders (e.g., estate, inheritance and medical decision-making documents) and undertakes litigation and advocacy in areas such as disability rights; Social Security benefits; Medicare/Medicaid benefits; inheritance rights and nursing home regulations.
National Center For Lesbian Rights www.nclrights.org	NCLR's Elder Law Project litigates impact cases challenging discrimination; promotes policies requiring equal treatment in benefits, housing, assisted care and other services; collaborates with mainstream aging advocacy organizations to assure their programs are LGBT culturally competent; and educates LGBT elders about their rights including via NCLR and SAGE's publication <i>Planning with Purpose: Legal Basics for LGBT Elders (2009)</i> .
National Center for Transgender Equality (NCTE) www.nctequality.org	NCTE is a social justice organization dedicated to advancing the equality of transgender people through advocacy, collaboration and empowerment. NCTE advocates for the federal Administration on Aging to collect data on transgender elders and take into account that transgender elders face particular hurdles.
National Gay and Lesbian Task Force www.thetaskforce.org	The Task Force builds the grassroots power of the LGBT community as part of a broader social justice movement. It has a formal collaboration with SAGE and, in 2009, released <i>Outing Age 2010: Public Policy Issues Affecting LGBT Elders</i> , an update to the groundbreaking Outing Age report issued in 2000. In 2010 the Task Force, together with the Los Angeles Gay & Lesbian Center, is sponsoring Rock for Equality, a campaign focusing on discrimination against LGBT seniors in Social Security.
Williams Institute www.law.ucla.edu/ williamsinstitute	A national think tank at UCLA Law, the Williams Institute advances sexual orientation law and public policy through rigorous, independent research and scholarship. A number of recent publications by Williams Institute scholars have addressed policy issues affecting LGBT elders, including Federal Estate Tax Disadvantages for Same-Sex Couples (November 2009); The Impact of Inequality for Same-Sex Partners in Employer-Sponsored Retirement Plans (May 2009); and Tax Implications for Same-Sex Couples (April 2009).

State and Local LGBT Organizations that Do Some Substantive Aging Work

This list includes only LGBT community centers and state advocacy groups known to have extensive elder programs or program work. While not included here, note that many LGBT community centers have discussion and/or social groups for LGBT seniors while many statewide LGBT advocacy organizations do general policy/legislative work that benefits LGBT elders as well as other groups.²

Equality California (EQCA) www.eqca.org	EQCA, California's statewide LGBT civil rights and advocacy organization, has worked to ensure the rights of LGBT seniors in retirement communities and state services and programs—and safeguard their homes and assets after the death of one partner. EQCA-sponsored legislation includes: Fair and Equal Taxation for Surviving Partners Act, which reduces inequitable property tax increases levied on some domestic partners; Older Californians Equality and Protection Act, under which LGBT seniors receive protections from discrimination in state-funded programs; Domestic Partners Intestate Succession, under which widowed domestic partners receive legal recognition in the distribution of the deceased partner's estate and protections; and Domestic Partnership Limited Rights and Responsibilities, providing registered domestic partners with new rights and benefits.
Howard Brown Health Center (Chicago) www.howardbrown.org	Howard Brown Health Center is one of the nation's largest LGBT healthcare organizations. Howard Brown's comprehensive health program for LGBT older adults, "AGING AS WE ARE: It's Our Time," aims to create a new model of care for LGBT older adults. It offers a geriatric physician specialist, onsite pharmacy, mental health services, HIV/STD services, caregiver support, legal assistance and recreational events.
L.A. Gay & Lesbian Community Center (Los Angeles) www.lagaycenter.org	The L.A. Gay & Lesbian Center's Seniors Services Department enriches the lives of LGBT people 50+ through educational, social and cultural events and activities; counseling; support groups; HIV testing and medical care; legal services; self-enrichment courses; the Internet cyber center and more. In 2010 the L.A. Gay & Lesbian Center is sponsoring Rock for Equality, a campaign focused on discrimination against LGBT seniors in Social Security.
New Leaf: Services for Our Community (San Francisco Bay area) www.newleafservices. org	New Leaf is the multi-purpose counseling center. New Leaf Outreach to Elders provides LGBT seniors age 60+ with a wide range of social services designed to encourage independent living and improve quality of life including outreach and support services, social-recreational activities, and counseling and psychosocial assessments.
New York City LGBT Community Center www.gaycenter.org	In addition to operating a variety of senior programs, the New York City LGBT Community Center participates in Ask the Experts, an online forum for LGBT older people presented by SAGE.

² See <u>www.lgbtcenters.org</u> for a nationwide directory of LGBT community centers and <u>www.equalityfederation.org</u> for a nationwide director of LGBT state advocacy organizations.

Umbrella/coordinating Organizations that Focus on LGBT Aging

National LGBT Aging Roundtable

http://sageusa. org/uploads/ December_roundtable_ report_2009.pdf The National LGBT Aging Roundtable: 1) improves the overall quality of life for LGBT seniors, 2) reduces discrimination against LGBT older adults, and 3) provides an opportunity for people engaged in this work to share best practices and raise issues of concern. Member organizations are:

- AIDS Community Research Initiative of America
- Aging as Ourselves
- · ASA/LAIN
- Azteca Project
- American Veterans for Equal Rights
- Chicago Task Force
- Family Equality Council
- Gay and Gray In The West
- Gay & Lesbian Elder Housing
- GLBT Generations
- Gay Men's Health Crisis
- GRIOT Circle
- Howard Brown Health Center
- · LGBT Aging Project
- Lambda Legal
- Lavender Seniors of the East Bay
- L.A. Gay & Lesbian Community Center
- New England Association On HIV Over 50
- National Center For Lesbian Rights
- National Center for Transgender Equality

- National Gay & Lesbian Task Force
- National Coalition for LGBT Health
- New Leaf Services
- Old Lesbians Organizing For Change
- openhouse
- Primetimers
- SAGE
- CenterSAGE
- SAGE Long Island
- SAGE/Queens
- SAGE Upstate
- SAGE Utah
- SAGE Center On Halsted
- · Sage Metro St. Louis
- SAGE Milwaukee
- SAGE South Florida
- SAGE of The Rockies/GLBT Center of Colorado
- Sunshine Social Services
- Stonewall Communities
- Transgender Aging Network

SageConnect

<u>http://sageconnect.net/</u> intranet/ Sponsored by SAGE, SageConnect is a collaborative on-line community for organizations and individual advocates who work on LGBT aging issues. Its focus is sharing lessons learned in creating programs for LGBT older people and engaging in advocacy around LGBT aging.

National Technical Assistance Resource Center for LGBT Elders

Currently under development by SAGE, The Resource Center will provide information, assistance and resources for mainstream aging organizations, LGBT organizations and LGBT individuals. Among other tools, SAGE plans to develop a comprehensive, web-based clearinghouse that includes diverse resources, social networking tools, an "Ask the Experts" service, web-based trainings and other features.

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