



ISSUES BRIEF:

LGBT AND DEMENTIA



Currently the population of adults aged 65 years or older is estimated at 47.8 million (AOA, 2012). In 2030, when the last baby boomer turns 65, one out of every five Americans — about 72 million people — will be an older adult (CDC, 2013). Activists from many different communities have worked hard to highlight the diversity of the older adult population and the unique challenges faced by those who are aging and who are also members of one or more minority communities.

This is crucial work because the demographic landscape of our nation is changing quickly. By 2050, Latino, Black, Asian and Pacific Islander, and American Indian and Alaska Native people will comprise more than 42 percent of the elder population (Chop, 2013). Additionally, the U.S. older adult population includes millions of lesbian, gay, bisexual and transgender (LGBT) people. Researchers estimate that there are 2.7 million LGBT people over the age of 50, and that number is increasing rapidly as the baby boomers age and more people self-identify as LGBT (MAP: Understanding Issues Facing LGBT Older Adults). It is important to note that while we need to speak of LGBT older adults as a discrete community because many share the same challenges, LGBT people are found within every community and the LGBT older adult population is one of tremendous racial, ethnic, cultural and religious diversity. For example, one in five (20 percent) of LGBT older adults are people of color (MAP and SAGE: Understanding Issues Facing LGBT Older Adults).

An aging population presents many challenges and among them is caring for people living with Alzheimer's or other dementias. An estimated 5.5 million Americans of all ages are living with Alzheimer's dementia in 2017. This number includes an estimated 5.3 million people age 65 and older and approximately 200,000 individuals under age 65. By 2050 this number could rise as high as 16 million (Alzheimer's Association, *2017 Facts and Figures*). At some point in their lives, one in three older Americans will deal with dementia in some capacity.

“ With the growing prevalence of Alzheimer's disease and the swelling population of LGBT older adults, we place a high priority on examining the intersections of Alzheimer's disease, sexual orientation, and gender identity and expression. ”

– Sam Fazio, PhD,
Alzheimer's Association
Director of Quality Care and Psychosocial Research.

LGBT older people who receive a dementia diagnosis face a particularly challenging set of circumstances. As discussed below, LGBT older adults exhibit several health disparities, such as diabetes and high blood pressure, which increase the risk of developing Alzheimer's and other dementias. LGBT older adults are also more likely to exhibit particular vulnerabilities that can exacerbate how Alzheimer's disease manifests and its impact, such as disproportionately high levels of social isolation and stigmatization as they age, making it difficult to find support.

¹ Throughout this document, Alzheimer's disease and dementia are used interchangeably and are intended to represent all related dementias.

LGBT-identified caregivers face similar challenges. Adult children who are LGBT, who often do not have children of their own may be seen by siblings as the natural choice to care for a parent. However, LGBT people often have fewer financial resources and other support networks to help them when providing care. They may also be caring for a parent who does not accept their identity, relationship or gender expression, adding to the psychological burden of providing care.

With the rising ubiquity of Alzheimer’s disease and the growing population of LGBT older adults, we must examine the intersections of Alzheimer’s disease, sexual orientation, and gender identity and expression. A more thorough and thoughtful understanding of this intersection will allow us as advocates and care providers to better meet the needs of LGBT elders and their caregivers who are faced with dementia.

“ *I think there needs to be more training of people in the dementia field ... the LGBT community has unique needs ... many of us don’t have biological families or children ... people in my generation are dying of HIV or aging and can’t help me ... people are isolated and won’t always seek services.* ”

– LGBT person living with dementia

This paper is divided into three sections. First, we present a general overview of the situation faced by LGBT older adults, people living with Alzheimer’s or another dementia, and caregivers. Next, we look at seven areas where LGBT identities intersect with Alzheimer’s disease: stigma, social isolation, poverty, health disparities, sexuality and sexual expression, barriers to utilizing existing services and living with HIV/AIDS. Finally, we conclude with recommendations in the areas of practice and research, recognizing that all changes to organization practice require a shift in policy and procedure.

LGBT HISTORY

In 1953 President Eisenhower calls for the dismissal of homosexuals from government service.

In 1963 Bayard Rustin, notable civil rights and gay rights activist, organizes the March on Washington but is forced to play a “behind the scenes” role due to his sexual orientation.

In 1969 the Stonewall Riots in New York City mark the unofficial beginning of the LGBT rights movement.

In 1973 American Psychiatric Association declares homosexuality is not a mental disorder. Today, transgender people continue to be diagnosed with Gender Dysphoria.

In 1979 the first National March on Washington for Gay and Lesbian rights protest was held in D.C.

The 1980s saw the first reported cases of HIV/AIDS.

In 1996 Congress passes DOMA (Defense of Marriage Act), prohibiting the federal government from recognizing same-sex marriages.

In 2011 “Don’t Ask Don’t Tell” was repealed.

In 2015 the United States Supreme Court extends marriage equality to all 50 states.

Overview

LGBT AGING ISSUES

LGBT older adults are resilient and strong people who have, in many cases, lived through a history of persecution and discrimination. Many came of age when President Eisenhower's administration was systemically purging homosexuals from government positions. Homosexuality was a diagnosable psychological disorder until 1973, and today, transgender people are still diagnosed with a condition known as Gender Dysphoria. Consensual same-sex sexual activity was illegal in some states until 2003, and LGBT people still face high rates of hate crime victimization. While we have seen recent advances in LGBT rights, such as the 2015 Supreme Court decision extending marriage equality to all 50 states, LGBT older adults are often marginalized and face discrimination. They are resilient and have created strong bonds of mutual support, but also are more likely than other older Americans to live in poverty and be socially isolated or only "out" to a small group of friends. They have unique health disparities and they remain underserved by a national aging network that is ill-prepared to engage them (MAP and SAGE: Understanding Issues Facing LGBT Older Adults).

As noted above, the LGBT older adult population is growing quickly, and compared to non-LGBT counterparts they have limited social networks to support them as they age. LGBT older adults are more likely to age without a spouse or partner, more likely to live alone and less likely to have children to support them (MAP & SAGE, 2010). According to a recent survey, one-third (34 percent) of LGBT older people live alone and 40 percent report that their support networks have become smaller over time (SAGE, 2014).

This is also a geographically diverse population. We know that LGBT-identified people live in every state (with percentages ranging from 8.6 percent of the population of the District of Columbia and 5.3 percent of Vermont on the highest ends, and 2.0 percent of the South Dakota population on the lowest (Gates, 2017). LGBT older adults live in urban, suburban and rural communities. Most health care providers already work with, or will soon meet, LGBT older adults.

As discussed below, LGBT older adults have a greater amount of health disparities when compared to their non-LGBT peers, and LGBT elders of color face greater health disparities than their white LGBT counterparts. For older LGBT people of color, the consequences of inadequate care include higher rates of numerous chronic diseases such as HIV/AIDS, diabetes and cardiovascular disease (SAGE, 2013). Many of these health conditions have been linked to an increased risk of Alzheimer's and vascular dementias.

These disparities mean that this population needs supportive services, but many LGBT elders experience barriers to accessing help, including discrimination, heterosexist attitudes and a lack of cultural competence on the part of providers (Brennan-Ing, Seidel, Larson, and Karpiak, 2014). LGBT older adults have distinct aging experiences and require specific, targeted outreach to overcome service barriers and attendant mistrust of providers.

This report outlines these disparities in health, wealth, isolation and trust that make reaching LGBT older adults with Alzheimer's disease particularly challenging, while also highlighting their tremendous resilience and ability to thrive when provided with appropriate resources and supports.

Dementia

Alzheimer's is the sixth-leading cause of death in the United States. Alzheimer's is a progressive disease — dementia symptoms gradually worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years, depending on age and other health conditions. On average, a person with Alzheimer's disease will spend more years (40 percent of the total number of years with Alzheimer's) in the most severe stage of the disease than in any other stage. Much of this time may be spent in a nursing home, as nursing home admission by age 80 is expected for 75 percent of people with Alzheimer's compared with only 4 percent of the general population (Alzheimer's Association, *2017 Facts and Figures*).

Clinicians who suspect dementia often do not disclose or document a formal diagnosis. As a result, approximately 50 percent of persons with dementia have no documentation of diagnosis in their medical record (Alzheimer's Association, *2017 Facts and Figures*).

The impact of Alzheimer's is deeply impacted by gender. Almost two-thirds of American older adults living with Alzheimer's are women. Of the 5.3 million people age 65 and older with Alzheimer's in the United States, 3.3 million are women and 2 million are men. Not only are women more likely to have Alzheimer's, they are also more likely to be caregivers of those with Alzheimer's. The 2015 Behavioral Risk Factor Surveillance System (BRFSS) survey found that of all dementia caregivers who spent more than 40 hours per week providing care, 69 percent were women (Alzheimer's Association, *2017 Facts and Figures*).

Race also has a substantial influence on the impact of Alzheimer's. It is estimated that older African-Americans are about twice as likely than older whites to have Alzheimer's disease and other dementias, but less likely to receive a diagnosis. Older Hispanics are estimated to be at least one and one half times more likely than older whites to have Alzheimer's and other dementias (Alzheimer's Association, *2017 Facts and Figures*).

ALZHEIMER'S ASSOCIATION 2017 FACTS AND FIGURES

Alzheimer's disease is the **6th leading cause of death** in the United States.

More than **5 million Americans** are living with Alzheimer's.

Every 66 seconds, someone in the United States develops the disease.

More than 15 million Americans provide unpaid care for people with Alzheimer's or other dementias.

In 2016, these caregivers provided and estimated **18.2 billion hours** of care valued at over **\$230 billion**.

In 2017, Alzheimer's and other dementias will cost the nation **\$250 billion**. By 2050, these costs could rise as high as **\$1.1 trillion**.

35% of caregivers for people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities, compared to **19% of caregivers** for older people without dementia.

One in three seniors dies with Alzheimer's or another dementia.

Alzheimer's kills more people than breast cancer and prostate cancer combined.

Since 2000, deaths from heart disease have **decreased by 14%**, while deaths from Alzheimer's disease have **increased by 89%**.

Because Alzheimer’s disease is complex, current approaches in treatment and research focus on several different aspects, including helping people maintain mental function, managing behavioral symptoms and delaying the symptoms of disease. Currently there is no prevention, cure or way to slow the progression of Alzheimer’s disease, so early detection and planning is crucial to maintaining a high quality of life for the person living with the disease as well as their caregivers.

Caregiving

It is estimated that 34.2 million Americans have provided unpaid care to an adult age 50 or older in the last 12 months. (AARP and National Alliance for Caregiving, 2015). More than 15 million Americans provide 18.2 billion hours of unpaid care for people with Alzheimer’s and other dementias — care valued at \$230 billion (Alzheimer’s Association, 2017 *Facts and Figures*). Caregivers of people with Alzheimer’s and other dementias provide care for a longer time, on average, than do caregivers of older adults with other conditions. 35 percent of caregivers for people with Alzheimer’s or another dementia report that their health has gotten worse due to care responsibilities compared to 19 percent of caregivers for older people without dementia. (Alzheimer’s Association, 2017 *Facts and Figures*). Additionally, LGBT people become caregivers at a higher rate than the general population (one in five vs. one in six) (AARP and National Alliance for Caregiving, 2015).

Many LGBT older adults may not have a relationship with their legal or biological families, and are instead supported by their families of choice. As LGBT people age, these chosen family members, friends and community members often serve as caregivers; since LGBT elders are less likely to have children to assist

them and more likely to be single, adult children and partners often are not part of the caregiving mix (MAP & SAGE, 2010). As a result, caregivers of LGBT older adults may be age contemporaries of the person for whom they are caring.

The Alzheimer’s Association conducted interviews with LGBT people living with or caring for someone with dementia. A woman who lost her female partner when she was 63 shared that she and her partner were friends with 15-20 couples that were LGBT or accepting, but when they told them of the Alzheimer’s diagnosis, all of these people abandoned them and simply disappeared. Care networks take many forms, and it’s important that LGBT older adults feel safe reaching out.

While more data is needed from U.S. studies about LGBT older adults living with dementia and the experiences of their caregivers, a qualitative study undertaken in England, explored the experiences of 21 gay men and lesbian women who care or cared for a person with dementia. Respondents’ narratives reflected a range of pervasive anxieties about the future, including fears about stigma, lack of health and/or social care and support, and the need for specialized services for LGBT older people

(Price, 2012). Caregiving is difficult work for anyone, and because LGBT people find themselves in unique social networks and support structures, providers need to know how to identify, reach and support LGBT caregivers.

LGBT Older Adults and Dementia

STIGMA

Stigma is an attribute, behavior or reputation that is socially discrediting in a particular way. It causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normative one (Alzheimer's Disease International, 2012). Today, more and more people do not see LGBT identities as undesirable or stigmatized, but that is far from universally true. Within the U.S., social acceptance of LGBT identities varies significantly by region; the same is true across the globe. Recent data suggests that increases in social acceptance of LGBT people in the U.S. may have plateaued and may even be reversing course (GLAAD, 2018). Moreover, we must remember the long history of discrimination faced by LGBT people. Historical discrimination and years of codified discrimination have shaped the experiences of LGBT older adults, and the stigma that many LGBT older people face across their lifespan continues into their later years.

Many LGBT older adults reside in settings where LGBT bias and discrimination is legal, even today. For example, many states have no law prohibiting discrimination against LGBT people. A lack of legal protections and experiences of discrimination means that many LGBT older adults harbor a deep distrust of mainstream institutions. When LGBT older adults do access services, their history of stigmatization can negatively impact their willingness to “come out” or disclose their LGBT identity, thereby delaying appropriate care until their health deteriorates and crisis hits. The available data indicates that these fears of discrimination on the part of LGBT older people are justified (Justice in Aging, 2015). Forty percent of LGBT older people in their 60s and 70s say their health care providers don't know their sexual orientations (SAGE, 2014).

For transgender elders, the reality is especially stark. Transgender people face particular barriers as they access health services, and often cannot selectively hide or disclose their transgender status, especially when seeking medical care or assistance with tasks such as bathing and dressing. This has real implications for their health care: Two-thirds of transgender adults (65 percent) feel that there will be limited access to health care as they grow older (SAGE, 2014). A 2015 survey by the National Center for Transgender Equality (NCTE) found that 50 percent of respondents experienced rejection from an immediate family member, 33 percent reported a negative interaction with a medical provider during the past year and 23 percent did not see a doctor when they needed to or seek out medical care for fear of being mistreated. This leads many transgender people to avoid service providers or delay care (NCTE, 2015).

Severe societal stigma also accompanies dementia. It's common to stereotype all people with dementia as falling into one undifferentiated category (Alzheimer's Disease International, 2012). While Alzheimer's is the most common form, dementia is a general term for a decline in mental ability severe enough to interfere with daily life and therefore may be a symptom of many diseases with different treatments. This basic lack of understanding about dementia may impact the person with a dementia diagnosis, as well as those providing care.

In the early stage of dementia, stereotyping can lead to devaluing the potential contribution of the person with dementia in conversation and care planning, which results in less interaction and an eroding of relationships between the person with dementia, family members and friends. In all stages, the stigma associated with dementia often leads to a focus on the individual's impairments and deficits rather than on his or her remaining strengths and ability to enjoy many activities and interactions with other people. The person with dementia is often deprived of the companionship of family and friends; the resulting isolation and lack of stimulation causes disability beyond that caused by the illness itself (Alzheimer's Disease International, 2012).

Stigma is especially salient in preventing caregivers from seeking services that could potentially reduce caregiver burden. The personal burdens associated with caring for a person with Alzheimer's are exacerbated by the stigma associated with the illness; caregivers often are deeply and negatively affected by what others think about their loved one with the disease. This includes stigma resulting from poorly-trained and ill-informed physicians (Werner et al., 2012).

Taken in combination, an LGBT person may not reach out for services and support because they face or fear poor treatment because of their LGBT identity, because they fear the stigma of being diagnosed with dementia, or both. LGBT caregivers may fear unequal treatment for themselves or their loved ones, feel unable to integrate their personal support network into care planning for fear of outing themselves, or may have internalized stigma surrounding the disease.

Social isolation

Research shows that diminished social and caregiving supports have been correlated with a wide range of health problems that can have serious consequences for older people, including premature institutionalization and early death (Holt-Lunstad et al., 2015). A 2015 meta-analysis demonstrated that isolation and loneliness has been associated with an increased risk of early mortality (Holt-Lunstad et al., 2015).

LGBT older adults are more likely to put off care, to be self-reliant and to be protective of their home as a safe space — three dynamics that impact willingness to seek help. Many LGBT elders access essential services, including visiting nurses, food stamps, senior centers and meal plans much less frequently than the general aging population — despite the fact that they would benefit greatly from these services. A recent survey found that one in three (32 percent) LGBT older people are very or extremely concerned about “being lonely and growing old alone,” as compared to 19 percent of non-LGBT people (SAGE, 2014).

Loneliness and social isolation are also common among persons living with Alzheimer's and dementia. It can be estimated that 800,000 (15 percent of 5.4 million) people in the U.S. have Alzheimer's and live alone in the community. On average, people with dementia who live alone in the community tend to be older, female and less cognitively impaired than people with dementia who live in the community but do not live alone. Those living alone are also more likely to live in poverty, to have had dementia for a shorter period and to have fewer impairments in performing daily activities. Yet, people with dementia who live alone are at increased risk of inadequate self-care and wandering, which can result in falls and injuries. (Alzheimer's Association, 2012 *Facts and Figures*). People with dementia tend to withdraw from situations

“ **It’s important to be able to feel safe and be yourself in order to get the support you need.** ”

– LGBT Caregiver

that provide social support, such as working, volunteering and community activities, exacerbating social isolation and loneliness (Alzheimer’s Association, *2012 Facts and Figures*). Immobility, transportation difficulties and poor health also contribute to their social isolation.

Alzheimer’s disease and a fear of mistreatment can cause someone to be more isolated and not reach out for help. This isolation may be the result of factors like poor transportation or access to community centers, which are structural problems — meaning that our villages, towns and cities are often not designed to support aging in place. Isolation may also be caused by stigma, which manifests as a fear of people with the disease or a desire to avoid LGBT-identified people.

Poverty

Until recently, LGBT people did not have access to institutions like marriage, and many faced unfair tax burdens. Combined with a lifetime of employment discrimination, LGBT people, particularly LGBT older people and people of color, are at increased risk for poverty. One in two (51 percent) LGBT older people report being very or extremely concerned about “having enough money to live on” as compared to 36 percent of non-LGBT people (SAGE, 2014). Alzheimer’s is the most expensive disease in the nation (*The New England Journal of Medicine*, April 4, 2013). Total payments in 2017 (in 2017 dollars) for all individuals with Alzheimer’s or other dementias are estimated at \$259 billion. Medicare and Medicaid are expected to cover \$175 billion, or 67 percent, of the total health care and long-term care payments for people with Alzheimer’s or other dementias. Out-of-pocket spending is expected to be \$56 billion, or 22 percent of total payments (Alzheimer’s Association, *2017 Facts and Figures*).

Nationally, same-sex partnered older adults lag behind different-sex married households in income, assets and home ownership; elder same-sex partnered households have 37.4 percent less income from retirement savings than elder heterosexual married couples (Knauer, 2011). Forty-two percent of LGBT older people surveyed in 2014 reported being very or extremely concerned that they will outlive the money they have saved for retirement, as compared to 25 percent of non-LGBT people, and 44 percent of LGBT older people are very or extremely concerned that they will have to work well beyond retirement age in order to have enough money to live, as compared to 26 percent of non-LGBT people (SAGE, 2014).

This means that LGBT older adults may have a greater need for social supports and services, but, as discussed below, they are also fearful of accessing these services. The combined impact of increased economic insecurity and the cost of Alzheimer’s care may make people less likely to recognize the symptoms, less able to provide in-home care and avoid institutionalization, and generally increase the precarious state of the situation facing LGBT people living with Alzheimer’s or caring for someone the disease.

Health disparities

LGBT older adults experience health disparities across many areas. The Institute of Medicine of the National Academies (IOM) identified the following pressing health issues for LGBT people: lower rates of accessing care (up to 30 percent); increased rates of depression; higher rates of obesity in the lesbian population; higher rates of alcohol and tobacco use; lower rates of preventive screenings including pap tests, mammograms and prostate exams; higher risk factors of cardiovascular disease for lesbians; and higher incidents of HIV/AIDS for gay and bisexual men (Brennan-Ing, Seidel, Larson, and Karpiak, 2014). Risk factors for vascular disease (problems with blood circulation) — like diabetes, tobacco use, high blood pressure and high cholesterol — may also be risk factors for Alzheimer’s disease and stroke-related dementia.

Those disparities are particular to LGBT populations, but we must remember that LGBT people are members of all other racial and ethnic minorities. Several studies suggest that certain racial, ethnic and socioeconomic groups may be at greater risk than others for cognitive decline and dementia, and that different groups are vulnerable to different risk factors. It is estimated that older African-Americans are about twice as likely to have Alzheimer’s or other dementias as older whites, and Hispanics are about one and one-half times as likely to have Alzheimer’s or other dementias as older whites (Alzheimer’s Association, *2017 Facts and Figures*). Currently, there is not enough evidence from population-based cohort studies in which everyone is tested for dementia to estimate the national prevalence of Alzheimer’s and other dementias in other racial and ethnic groups (Alzheimer’s Association, *2017 Facts and Figures*).

Two other health disparities involved with Alzheimer’s and other dementias have been identified, both around the issue of diagnosis. First, while undiagnosed Alzheimer’s is a problem across all racial and ethnic groups, Medicare data show that African-Americans are less likely than whites to be diagnosed, given the estimated prevalence rates in the United States. Second, when they are diagnosed, African-Americans and Hispanics — possibly due to barriers to accessing health care — are typically diagnosed in later stages of the disease, resulting in higher use of health care services and substantially higher costs. Average per-person Medicare payments are 45 percent higher for African-Americans with a dementia diagnosis and 37 percent higher for Hispanics compared with whites who have dementia (Alzheimer’s Association, *2013 Race, Ethnicity & Alzheimer’s Disease*).

Cognitive health is linked to overall health, so access to health care, and in particular, preventative care, is an important way to reduce health disparities that may result in an increased risk of developing Alzheimer’s or other vascular dementias. Encouraging people to access health care services, make lifestyle changes and support their overall health can have a positive impact on both LGBT and non-LGBT communities. Additionally, effective outreach to LGBT communities that is sensitive to racial, ethnic and cultural differences could result in earlier diagnosis, which has been linked to better outcomes.

Sexuality and gender expression

Our society desexualizes older adults and often does not recognize that many people remain sexually active across the lifespan. Research shows that heterosexual and LGBT older adults are sexually active well into their mid-80s, with a 2007 national study showing 53 percent of adults age 65-74 and 26 percent of adults age 75-85 as sexually active with one or more partners (Lindau et al., 2007).

People with dementia may also have the need to be sexual and intimate. As they experience changes in cognition and judgment, the expression of their sexuality may result in behaviors that are challenging for others. A person with dementia may experience reduced sexual interest, increased sexual interest,

“ People living with dementia may start to explore or express parts of their identities or desires that are a surprise to their loved ones. For people already grappling with the diagnosis and disease this may feel like too much to handle, but well-trained and open-minded staff can help ensure that the person with dementia is given the space to express themselves, and help family members understand these changes. ”

– Tim R. Johnston, director of national projects, SAGE

inappropriate sexual behavior, changes in level of inhibition and even the formation of new relationships. Spouses and partners often struggle with decisions about appropriateness, obligations, needs and unfaithfulness, and may need to adjust their attitudes and actions to maintain physical and emotional intimacy. Gay, lesbian and bisexual older adults face the additional barrier of providers who do not recognize that many older adults are attracted to people of their same gender, or who harbor negative opinions about same-sex sexual contact. Care providers need to examine their own beliefs and prejudices, as well as organizational policies. This issue may become even more complex when it comes to same-sex relations, which may trigger the family’s or caregiver’s biases toward or about the LGBT community.

Even in environments that recognize and affirm everyone’s right to sexual expression, older gay, lesbian and bisexual people may face considerable barriers in the need for sexual expression, especially those living in care homes (Benbow and Beston,

2012). In skilled nursing facilities with little LGBT cultural competence, there have been instances where care staff are uncomfortable with same-sex contact and more quickly assume that it is abusive and not consensual. Conversations about sexuality and sexual expression are often fraught and difficult for staff, family and loved ones. It is important to note that these conversations may be even more complicated or emotional when the sexual activity is between two people of the same gender.

Sexual contact between people where one or more participants is living with Alzheimer’s or another dementia requires a team-based approach based on person-directed care. LGBT people should be given the same opportunities to experience healthy and safe sexual contact as their heterosexual peers. Attitudes and beliefs toward sexuality and aging are strongly influenced by stereotypes and myths, not only among the general public, but also among those working in health and social care. It is important that staff training and onboarding include discussion on sexuality, aging and dementia in training curricula.

At the same time, we all express our gender identity in different ways through — speech, mannerisms, clothing, personal grooming and style. Like people of all ages and health statuses, people living with dementia may express a desire to wear clothing associated with the opposite gender, may request help with new personal grooming regimes, or change the name and pronoun they use to describe themselves. While this can be new or confusing for family, friends and caregivers, these choices should be respected, and staff need to be trained to respond to the wishes as they are expressed.

Aging network/service utilization and preparedness

The aging network is differentially prepared to identify, engage and serve LGBT older adults. Many LGBT older adults distrust aging providers because those providers assume that they are heterosexual or not-transgender, and often fail to recognize same-sex partners or families of choice. Research has shown that LGBT older adults face barriers due to lack of cultural competency, the reality and fear of discrimination or of not receiving optimal care (Brennan-Ing, Seidel, Larson, and Karpiak, 2014).

LGBT older adults have many of the same needs as other older adults, including senior housing, transportation, legal services, social events and support groups. Yet, when it comes to actual services for LGBT older adults, a 2010 nationwide survey of 320 area and state units on aging found that less than 8 percent offered services targeted to LGBT older adults and only 12 percent reported outreach

efforts to this population (Knochel et al., 2010).

That same survey found that a majority of respondents believed that LGB (75.6 percent) and T (71.9 percent) older adults would be welcomed by local aging service providers. However, only a minority of agencies had received a recent request to help an LGBT older adult.

“ *I wanted to see a therapist and they referred me to an ‘LGBT-sensitive therapist.’ Several months into our conversations, I used the term “LGBT” and the therapist asked what it meant. She had no idea what it was!* ”

– LGBT man living with dementia

This suggests that despite providers’ perspectives, LGBT older adults are not reaching out for help. The available research shows that most aging agencies and facilities do not offer cultural competency trainings to their staff. Yet there is a direct correlation between cultural competence

trainings on LGBT issues and engagement by the LGBT community. Area Agencies on Aging with staff trained on LGBT cultural competence were three times more likely to receive a request to assist a transgender person and twice as likely to have received a request for help for a lesbian, gay or bisexual person (Knochel et al., 2010).

When it comes to dementia, caregivers may not fully utilize community services, and professional provider networks are not always trained to deal with the unique needs of a person with dementia. Empirical studies have suggested that use of formal services can offset the negative effects of care recipients’ impairment on the psychosocial well-being of caregivers (Bass, Noelker, and Rechlin, 1996) and delay the need for institutional care of older persons with dementia (Shapiro and Taylor, 2002; Gaugler, Kane, Kane, and Newcomer, 2005). Even when services are available and affordable, research findings consistently indicate low rates of formal service use among community dwelling older people and their familial caregivers

(Bookwala, et al., 2004; Pedlar and Biegel, 1999). Those living in rural areas may also face unique challenges. Krout and Bull (2006) pointed out that factors such as lack of public transportation, limited knowledge about available services, financial constraints and doubtful attitudes toward public services may contribute to low service use among rural older people. The use of respite has shown improvement in emotional and physical health, as well improvements for the person with dementia, yet barriers including cost, availability and caregiver guilt prevent widespread use.

Many people may not reach out for help if they feel their local resources are not prepared to meet their needs. An LGBT-affirming environment, complete with strong visual indicators of LGBT acceptance and staff trained on LGBT cultural competency and dementia care, can improve care for LGBT people with dementia.

HIV/AIDS and dementia

The advent of HIV medications has allowed many people to survive and age with HIV —a first for this generation. In 2014, 45 percent of Americans living with HIV/AIDS were 50 and older (CDC, 2018). Data shows that gay and bisexual men are more likely to contract HIV than other men, and this is particularly true for gay and bisexual African American men (CDC, 2017). Globally, transgender people are 49 times more likely to be living with HIV than the general population (UNAIDS, 2016).

Despite HIV/AIDS being a chronic condition that can be managed, it still carries a stigma borne of the HIV/AIDS crisis. The stigma associated with HIV/AIDS may prevent many from seeking social supports or intimate relationships, as they may internalize the stigma and feel that they lack social worth and that no one will want to be with them.

HIV can bring about cognitive impairment. Approximately 50 percent of individuals with HIV experience cognitive problems. A sample of 1,555 adults with HIV from six sites within the United States found that 52 percent of those surveyed exhibit cognitive problems, 33 percent expressed asymptomatic cognitive impairments, 12 percent mild cognitive disorder and 2 percent HIV-related dementia (Heaten et al., 2010).

Given the connection between HIV/AIDS and cognition, as people with HIV age, there is growing concern that they will be at increased risk of developing cognitive problems that may have an impact on their everyday functioning (e.g., medication adherence) and quality of life (Vance, 2002). Further, given that comorbidities such as diabetes, hypercholesterolemia, hypertension, and renal and liver diseases are more prevalent with increasing age in this population (Vance et al., 2011), studies suggest that these may also contribute to poorer cognitive function.

Some cognitive impairments associated with HIV are more severe. HIV-associated dementia (HAD) occurs in approximately 10-15 percent of all individuals with HIV/AIDS and is more common in later stages of infection. No specific treatment guidelines for HAD are available (MacArthur and Brew, 2010). HIV associated neurocognitive disorder (HAND) describes the full spectrum of cognitive impairment (Singh, 2012). This type of dementia can be pervasive: Less severe forms of HAND occur in 30-60 percent of people infected with HIV depending on the stage (MacArthur and Brew, 2010). Social isolation can further diminish cognitive functioning, so it is important for providers to consider ways to promote social engagement, as this may help improve or protect mood and cognitive functioning of their patients,

and ways to improve or protect cognitive functioning and mitigate cognitive loss must be sought in the service of helping older adults living with HIV/AIDS (Vance, Fazeli, Moneyham, et al., 2013).

Aging service providers should prepare for an increase in the number of older adults living with HIV/AIDS by learning about the health needs of people living with HIV/AIDS and the particular stigma experienced by this population. Similarly, providers caring for a person living with both dementia and HIV/AIDS need to ensure correct adherence to medical regimes, as well as have an understanding of the history of the epidemic and the impact that can have on the person's identity. Creating a supportive atmosphere where an older adult feels comfortable disclosing their HIV status can also ensure that the cognitive impacts of living with HIV/AIDS are not misdiagnosed as Alzheimer's or another dementia.

Conclusions

RECOMMENDATIONS FOR ORGANIZATIONAL PRACTICE AND POLICY

LGBT older adults and their caregivers face some unique challenges when facing Alzheimer's disease. While it is necessary to take a sober and realistic view of these challenges, it is also important to recognize their strength, resilience and ability to create community in the face of adversity. As researchers, providers, advocates, caregivers and people living with the disease there are things we can all do to create a world where LGBT people with Alzheimer's disease can get the respectful and competent care they deserve.

The following are suggested recommendations for working with LGBT people living with Alzheimer's or other dementias, as well as supporting LGBT-identified caregivers for people living with dementia. We have divided the suggestions into two categories. First, suggestions for aging and dementia care organizations to be inclusive of LGBT people and caregivers. Second, recommendations for LGBT service providers to include people living with dementia and their caregivers.

INCLUDING LGBT PEOPLE IN DEMENTIA-RELATED SERVICES

- 1. Expand your definition of family:** Often when people say the word "family" they mean the nuclear family —or biological and legal relatives. Many LGBT people either do not have a relationship with their family of origin, or they may have strained relationships. Many do not have children or a partner. LGBT people may have a chosen family, or family of choice, who provide them with care and support. When discussing family members or other supports, consider using terms like "network of support," "chosen family" or "loved ones" and make it clear that family does not necessarily mean family of origin or children or partner.
- 2. Use LGBT-affirming language:** Don't be shy to use the term LGBT or the words lesbian, gay, bisexual and transgender. Publicize your commitment to welcoming people of diverse sexual orientations and gender identities. Note, the word transgender is an adjective, not a noun. Please say "transgender man / woman / person" and not "transgenders" or "transgendered."
- 3. Engage in LGBT-specific outreach:** Consider participating in your local LGBT Pride Parade or Fair. Pride events are usually held in the month of June to recognize LGBT Pride Month, but may vary regionally.

- 4. Incorporate LGBT people into your marketing materials:** Adding images of LGBT people and families to your website, promotional materials and brochures sends the message that LGBT people are already accessing your services, and that your organization cares enough to recognize these people and families.
- 5. Educate your staff on LGBT cultural competency:** Professional development is essential to person-directed care, and it is important that you equip your staff with the information they need to provide culturally competent care to LGBT older adults and LGBT caregivers. Training content often includes key terminology, the history of the LGBT experience, and case studies or recommendations to help reinforce the content. SAGE offers cultural competency training and credentials through the SAGECare program (www.sageusa.care).
- 6. Find or create support groups specifically for LGBT caregivers and LGBT people living with dementia:** There is value to having specific groups for people who identify as LGBT or who are caring for an LGBT person. If these are not available in your community, consider starting LGBT-friendly support groups, perhaps in areas of town with a higher concentration of LGBT people, or in partnership with an LGBT community center. That said, it is also important to ensure that LGBT people feel welcome at all of your support groups. The Alzheimer's Association hosts an online support for people with the disease and caregivers, including a message board for the LGBT community and allies (www.alzconnected.org).
- 7. Partner with local LGBT community groups and political organizations:** Building a relationship with leaders in your local LGBT community is a great way to begin to develop trust. Many LGBT people turn to one another for recommendations for providers and supports. These relationships are an important way to reach LGBT older adults and caregivers through word of mouth.
- 8. Advocate for non-discrimination protections:** It is still legal to discriminate against LGBT people in many parts of the country. Your organization can take a public stand to demand that local leaders work to protect LGBT people.
- 9. Collect information on sexual orientation and gender identity:** Collecting demographic information on sexual orientation and gender identity helps you to know if you are reaching the LGBT community, and can aid advocates in understanding the specific needs of LGBT people. For more information see *A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity* from the National Resource Center on LGBT Aging (lgbtagingcenter.org).

ENHANCING DEMENTIA AND CAREGIVING SERVICES IN LGBT ORGANIZATIONS

- 1. Recognize the role of ageism in LGBT communities:** Many LGBT communities are more centered on youth than they are on older community members. Internalized ageism may exacerbate the stigma of Alzheimer's or other dementias and make it more difficult for an LGBT older adult to seek a diagnosis or support. Discuss aging and ageism with your staff and constituents.
- 2. Encourage education around early detection and diagnosis of Alzheimer's disease:** Partner with your local Alzheimer's Association chapter to offer community education on topics such as the warning signs of Alzheimer's disease, the basics of Alzheimer's disease, the importance of early detection and more.
- 3. Help plan for the future:** Make sure that LGBT people and their families and loved ones have completed advanced directives and are empowered to choose who will make decisions on their behalf as the disease progresses. Providing legal clinics staffed by lawyers who have experience working with LGBT people can help provide protection for the future.
- 4. Locate caregiver respite or support groups, making sure existing groups are welcoming to LGBT people:** Contact aging services providers for resources and supports. If you run a care-giver respite or support group, be sure to train facilitators and staff on LGBT cultural competency and communicate that your group is open to everyone.
- 5. Partner with local organizations:** Invite aging network providers to visit with your community, attend Pride functions and build relationships with your constituents. Creating these relationships now will be important for moments when your constituents need to locate and access affirming services.
- 6. Include older adults in your Pride planning:** Make sure that your Pride activities are age friendly. Provide seating out of the sun, make sure event spaces are ADA accessible and include older adults in your promotional materials.
- 7. Connect outside of social media:** Social media is a powerful tool to share information and events, but many older adults prefer printed calendars or phone calls. Start a phone tree, mailing list and bulletin board to get the word out about your activities and events.

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