

# DISRUPTING DISPARITIES

CHALLENGES AND SOLUTIONS FOR 50+ LGBTQ ILLINOISANS







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## PARTNERS

### SAGE

As the world's largest and oldest organization dedicated to improving the lives of LGBTQ older adults, SAGE is proud to stand with AARP in improving the lives of older LGBTQ Illinoisans and their families. This report could not have come at a more important time, as COVID-19 continues to exacerbate disparities that long predated the current public health and economic crisis.

Founded in New York City in 1978, SAGE has provided comprehensive social services and programs to LGBTQ older adults for more than four decades and currently operates five SAGE centers across New York City and supports our dozens of affiliates in over 20 states across the country, including in Puerto Rico. Our SAGE Centers and affiliates collectively welcome thousands of LGBTQ older adults each year, offering health and wellness programming, lifelong learning opportunities, case management support, and congregated meals, among other programs.

### AARP OF ILLINOIS

AARP of Illinois is the state office for the nation's largest nonprofit, nonpartisan organization dedicated to empowering people 50 and older to choose how they live as they age. With 1.7 million members in Illinois, AARP strengthens communities and advocates for what matters most to families: health security, financial stability and personal fulfillment.

Equity for LGBTQ older Illinoisans is of paramount importance for AARP of Illinois. As a partner in *Disrupting Disparities: Challenges and Solutions for 50+ LGBTQ Illinoisans*, we hope the policy successes that will be achieved in Illinois for LGBTQ older adults can be used as best practices in other states.

### WORKING GROUP

AARP of Illinois and SAGE want to thank the following organizations for their thoughts, input, and guidance in the creation of this important research report:

Center on Halsted

Equality Illinois

Pride Action Tank, a project of AIDS Foundation Chicago

RRF Foundation for Aging

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## EXECUTIVE SUMMARY

People over the age of 50 are a key demographic in Illinois, making up a third of the state's overall population. Older Illinoisans are also well-represented among Illinois' lesbian, gay, bisexual, transgender, and/or queer (LGBTQ) community. Of the estimated 506,000 LGBTQ adults in Illinois, about one-quarter (24%) are over the age of 50. These older LGBTQ Illinoisans contribute to the state's diversity. LGBTQ older adults live in urban and rural communities across the state, and are part of every racial and ethnic group, are veterans, are immigrants, and are living with disabilities. And the population of LGBTQ older Illinoisans is only expected to grow as the state's population ages: by 2030, an estimated 3.6 million Illinoisans—about 24% of the state's population—will be over age 60.

The face of aging is really growing much more diverse - at a faster rate than anybody realizes. LGBTQ+ older adults are often invisible in aging service demographics, resulting in an inability to evaluate the effectiveness of existing services, and inefficient planning for future programmatic expansions. In addition, LGBTQ+ older adults have often lived through discrimination, social stigma, and the effects of prejudice, resulting in poor health outcomes and greater risk for chronic illnesses and mental illnesses."

*Director Paula A. Basta  
Illinois Department on Aging*

Although a key part of Illinois' rapidly growing elder population, LGBTQ older adults remain largely invisible. Yet LGBTQ older adults are strong and resilient. This pioneering generation paved the way for the progress we now see on LGBTQ equality and created and sustained a movement in the face of danger and adversity. We need their

wisdom, knowledge, creativity, and spirit now more than ever to build a better future. While LGBTQ older adults have long had to come together to support one another through decades of hard work and struggle, now is the time to ensure that LGBTQ elders have the support they need to age safely and with dignity and respect.

Though resilient, LGBTQ older adults face significant disparities that are rooted in discrimination based on sexual orientation and gender identity, racism, a lack of legal and social recognition, a reliance on chosen family, reduced access to inclusive services, and other social determinants of health and well-being. Disparities are often compounded and thus even greater for the estimated 1 in 5 LGBTQ older adults of color. Prior analysis from AARP shows that older Illinoisans of color face significant disparities in economic security, health, and connectivity. The disparities that most impact older African American/Black, Hispanic/Latino, and Asian American/Pacific Islander older adults in Illinois were documented in [Disrupt Disparities: Challenges & Solutions for 50+ Illinoisans of Color](#) in 2021. The recommendations made in this report are equally critical for 50-plus LGBTQ Illinoisans, many of whom are older adults of color.



"My partner of 14 years and I got married right as she was becoming very ill. We had a great plan to retire together and move to a milder climate than Chicago. When she passed away suddenly, not only did I suffer the loss of my best friend, but I suffered financially having to cover the entire mortgage, while also caring for my elderly mother. It's difficult being an African American gay woman without children, as I often find myself without the social and financial support I need. I've always been a very independent person, but I worry about being able to support myself as I get older without those traditional networks that other communities may have."

– Phyllis Johnson

Phyllis uses she/ her pronouns

The barriers noted above can and have led to severe negative health, economic, and social implications for LGBTQ older adults that policymakers must address. These challenges have made it difficult for many LGBTQ older adults to acquire a well-paying job with benefits like a retirement savings plan, leading to lower Social Security and retirement income in older age. Estrangement from family and legal barriers to marriage, adoption, caregiving, and social services have caused many to be more isolated and disconnected from services than non-LGBTQ people. Legal and social structures, which limited the ability of many LGBTQ older adults to build a family, have meant that LGBTQ older adults are far more likely to live alone than non-LGBTQ individuals and far less likely to have adult children or other family members to rely upon for informal caregiving.

Illinois has made progress in addressing the challenges faced by LGBTQ older adults. However, state policymakers can do more to ensure that this community has the tools and resources needed to thrive and age successfully. Given the unique challenges faced by LGBTQ older adults, AARP of Illinois commissioned this report to 1) identify the disparities faced by Illinois' 50-plus LGBTQ population; and 2) develop concrete policy solutions to address these disparities. This report includes both but notes that the lack of comprehensive LGBTQ data remains a major limitation. While this report discusses available information, additional data is needed to fully understand and respond to LGBTQ-specific disparities in Illinois' 50-plus population.

The report includes a series of policy recommendations on the need for a comprehensive strategy to support LGBTQ older adults; equal access to inclusive programs and services; and LGBTQ-inclusive data collection. Action is particularly important to address the discriminatory legal, societal, and cultural conditions that have enabled even greater disparities faced by LGBTQ older adults of color and transgender older adults. This report builds upon the important recommendations made by AARP of Illinois and partners in the prior report, [Disrupt Disparities: Challenges & Solutions for 50+ Illinoisans of Color](#). By closing the serious gaps identified in the report, LGBTQ older Illinoisans will have more choices as to how and where they live as they age.

## WHAT THE DATA SAYS: DISPARITIES FACED BY 50-PLUS LGBTQ ILLINOISANS

Although comprehensive data is unavailable, nearly one-quarter of Illinois' LGBTQ population is estimated to be over age 50. Many LGBTQ older adults have encountered unique and long-standing systemic discrimination and barriers as they age, leading to widespread disparities in health, economic security, caregiving, and social connections. Because these barriers are often combined with or contribute to racism, white supremacy, and transphobia, disparities are often particularly pronounced for LGBTQ older adults of color and transgender older adults. LGBTQ older adults living in rural areas may face additional





“When I found out I was HIV+ in 1990, I thought I would die within five years. Many of my friends had died from AIDS within five years and I thought that would happen to me too. At first, I didn’t know where to go for help, but after a few years, I found a great doctor who was knowledgeable about HIV and became an incredible advocate for me, getting me into an HIV clinical study which would fund my medications. After the study ended, a doctor referred me to an HIV caseworker who helped me apply for an AIDS Drug Assistance Program. Without the assistance I receive through this program, my medications would cost me \$4000 per month. I can’t stress enough how important it is to advocate for yourself and to find the right people within systems who will get you the help you need.”

– Adrian George Garcia

*George uses he/him pronouns*

barriers in accessing affirming services. These and other disparities, as well as the reasons why these disparities exist, are discussed in greater detail in the full report.

- **Health and Well-Being.** LGBTQ older adults experience mental and physical health disparities due to the lack of competent, inclusive health care, lifelong experiences of discrimination, and social isolation. Those that have faced discrimination have a higher likelihood of poor health outcomes, and many LGBTQ older adults have received inferior care or have been denied care altogether.

These disparities are exacerbated for LGBTQ older adults of color who face additional social determinants of health—such as poverty, unemployment, and racism—that further limit access to care and healthy living. LGBTQ older adults of color, especially Black and Latino people, report even greater vulnerability about accessing health care (relative to white LGBTQ older adults) given concerns that they will face discrimination based on race and ethnicity as well as sexual orientation and gender identity. This discrimination—coupled with a historic lack of access to health care—also contributes to the significant health disparities faced by LGBTQ people.

This discrimination contributes to a range of disparities faced by LGBTQ older adults relative to non-LGBTQ older adults, including increased rates of disability, poor physical and mental health, alcohol and tobacco use, and HIV. Many of these disparities put LGBTQ older adults at an increased risk of experiencing COVID-19 more acutely.

LGBTQ older Illinoisans need improved access to culturally and clinically competent health care and relief from high health care costs. Over half of LGBTQ survey respondents of all ages in Chicago noted an aspect of health insurance, physical health, or mental/emotional health as a core issue that needed to be addressed. Many also cited the need for quality and culturally competent mental health care, better quality and lower-cost medical services, and better access to LGBTQ-friendly health care services.

- **Economic Security.** Older LGBTQ adults have fewer financial resources and are more likely to be low-income relative to non-LGBTQ older adults. Nearly one-third of LGBTQ older adults live at or below 200% of the federal poverty level, compared to a quarter of non-LGBTQ people. Poverty rates are even higher for LGBTQ older adults of color, those aged 80 and older, bisexual older adults, and transgender older adults.

Economic instability is due in large part to a lifetime of employment discrimination that LGBTQ older adults have faced, resulting in lower earning



"As an LGBTQ+ older adult, I am also an advocate for health-care providers about building culturally competent systems for the LGBTQ+ community. Some of the things that LGBTQ+ older adults struggle with are social isolation from losing their lifelong associates like friends and family, the ageism and paternalism that can be very triggering as society tends to perceive older adults as weak, and the experience of going back into the closet as they try to secure social services such as housing that may not be LGBTQ+-friendly. It is so important that we create and promote systems that make our LGBTQ+ older adults feel included, empowered and in control of their own lives."

– Don Bell

*Don uses he/him pronouns*

power and lower payments or income from Social Security, retirement, or pensions. Further, LGBTQ older adults whose spouse or partner died or retired before the freedom to marry may be unable to access Social Security survivor benefits or their partner's benefits or assets. As a result, 44% of LGBTQ older adults report being concerned about having to work well beyond retirement age (compared to 26% of non-LGBTQ people).

This economic instability is, for many, exacerbated by the HIV/AIDS pandemic. Stigma caused additional discrimination, leading to the loss of job opportunities and insurance discrimination. These lost opportunities and higher costs had long-term consequences, limiting the ability of many LGBTQ older adults to save and secure financial stability. Many LGBTQ older adults are currently living with HIV, lost partners and other loved ones to the crisis, and/or served as caregivers even with fewer financial resources.

Housing options are also limited for LGBTQ older adults who are more likely to be low-income, face housing discrimination in senior living communities, and may have a history of housing insecurity or homelessness. To avoid discrimination, many—34% of LGBTQ older adults and 54% of transgender and gender nonconforming older adults—fear having to re-closet themselves when seeking elder housing. This is likely why 90% of LGBTQ older adults are extremely, very, or somewhat interested in LGBTQ-welcoming older adult housing developments.

Lack of access to affordable housing is exacerbated by the current real estate and eviction crisis, which itself has been magnified by the disparate impact of COVID-19 on elders' safety, support networks, and economic stability. Transgender elders are facing compounded barriers, exacerbated by recent attempts to rollback federal Fair Housing Act protections, implement religious exemptions, and eliminate explicit federal housing and homeless shelter protections for transgender people. And most continuing care retirement communities are religiously affiliated organizations, which can jeopardize the safety and security of LGBTQ older adults when they are most vulnerable.

- **Caregiving and Social Connections.** Older LGBTQ adults are often isolated, disconnected from services, and have thin support networks. These disparities persist because many LGBTQ older adults have been estranged from family and historically faced legal barriers to marriage, adoption, caregiving, and social services. As a result, LGBTQ older adults are far more likely to live alone than non-LGBTQ individuals and far less likely to have adult children or other family members to rely upon for informal caregiving. Three out of four LGBTQ people age 45 and older are concerned about having enough support from family and friends as they age, and LGBTQ people are more likely than non-LGBTQ people to report being lonely.



"We have a strong, proud, and active LGBTQ population in Southern Illinois in part because of Southern Illinois University in Carbondale. Living in the red part of the blue state is tough and it is long past due for our downstate legislatures to show up, listen, and stop hiding behind the notion that it's the will of their constituents."

– Billy Rogers, 66,  
DuQuoin

Co-Chair of Golden  
Rainbows of Illinois  
South

Social isolation can be difficult to overcome because there are fewer opportunities to socialize in age-friendly and LGBTQ-inclusive environments. In some communities, LGBTQ community centers try to fill these gaps. However, these entities often lack crucial resources and dedicated support for programs for LGBTQ older adults. This is especially true for LGBTQ older adults in less welcoming environments. Fewer than half (48%) of LGBTQ older residents in big cities and as few as 10% of rural and small town residents reported access to LGBTQ-inclusive elder services in their community.

Although the networks that LGBTQ older adults have built are strong and resilient, thinner support networks mean that many LGBTQ older adults rely on other LGBTQ people, such as friends and family of choice, as caregivers. LGBTQ older adults become caregivers more often than non-LGBTQ counterparts. An estimated 21% of LGBTQ older adults have provided care to friends (compared to only 6% of non-LGBTQ peers). Because this support often goes unrecognized, many LGBTQ caregivers do not avail themselves of the resources that are available to caregivers even though LGBTQ caregivers are more likely to be providing care in isolation and tend to have poorer mental and physical health.

Thinner support networks, in turn, make LGBTQ older adults more reliant on community service providers. Yet, many LGBTQ people experience or fear mistreatment from service providers and in long-term care facilities. These concerns stem from a long history of discrimination—rooted in homophobia, transphobia, racism, and bias—that LGBTQ older adults have faced when accessing health and social services. Majorities of LGBTQ people age 45 and older have concerns about long-term care, including concerns about neglect (67%), abuse (62%), verbal or physical harassment (61%), refusals or limits on services (61%), and being forced to hide or deny their identity (52%). These rates are even higher for gender expansive older adults: 70% of older transgender and gender expansive people reported concern that they may have to hide or deny their identity to receive long-term care. Given these concerns, it is unsurprising that more than eight in 10 LGBTQ older adults would feel more comfortable with providers who are trained in LGBTQ patient needs, have some LGBTQ staff, or otherwise create an LGBTQ-welcoming environment.

## **A COMPREHENSIVE STRATEGY TO SUPPORT LGBTQ OLDER ADULTS**

The disparities faced by LGBTQ older adults, especially LGBTQ older adults of color and transgender people, underscore the need for Illinois policymakers to adopt a comprehensive strategy that helps 50-plus LGBTQ people thrive. Policymakers should:



"Healthcare providers know very little about LGBTQ folks, and especially trans folks. They don't understand the importance of using our correct pronouns, which is huge. They don't understand our particular anxieties about our bodies, and there are also people in the healthcare world that display some animosity toward specifically transgender folks.

The hospital system is just not set up for that, and I'm talking about in all respects. I know how it could actually be done and it starts at the moment the hospital or healthcare place meets the respective patient.

I need to know, as a trans woman, that when I go to a hospital I don't have to explain myself, to explain what it means to be trans. I need them to advocate for me. We have a long way to go."

– Danie Flora Muriello,  
69, Chicago

- **Fully implement inclusive greatest social need.** Ensure that legislation designating older LGBTQ Illinoisans and older Illinoisans living with HIV as populations of greatest social need under the Older Americans Act is fully implemented and enforced, including through publication of an annual report on progress made in addressing the needs of these communities.
- **Establish an LGBTQ Aging Commission.** Establish a standing Commission on LGBTQ Aging to identify challenges, share best practices, and develop expert recommendations on ways to improve the quality of life of 50-plus LGBTQ Illinoisans, with an emphasis on addressing the needs of the most marginalized community members.
- **Make Illinois Council on Aging LGBTQ inclusive.** Establish membership criteria to ensure that the Illinois Council on Aging reflects the diversity of older Illinoisans, including LGBTQ Illinoisans, transgender Illinoisans, and racially diverse LGBTQ people.
- **Include LGBTQ measurables in State and Area Plans on Aging.** Adopt additional measurable LGBTQ-specific goals, objectives, strategies, and metrics in State and Area Plans on Aging and develop these metrics using existing data, community needs assessments, and input from LGBTQ older adults.
- **Host a series of convenings.** Host a series of convenings to bring awareness to the unique challenges faced by LGBTQ older adults, enhance information sharing, and promote statewide community engagement (including in rural areas).
- **Create inclusive area agency advisory councils.** Require area agency advisory councils and long-term care councils to include racially diverse LGBTQ people.
- **Include LGBTQ organizations in state and area planning processes.** Seek input from, and partner with, LGBTQ organizations to inform state and area planning processes.

## EQUAL ACCESS TO INCLUSIVE PROGRAMS AND SERVICES

Older LGBTQ Illinoisans should have access to the affirming supports and services they need to age successfully. Research shows that stronger social supports and social networks are vitally important to improving health outcomes among LGBTQ older adults. To make these supports and services a reality, policymakers should:

- **Protect LGBTQ older adults from discrimination by:**
  - Implementing and enforcing comprehensive nondiscrimination protections in employment, housing, assisted living and long-term care, public accommodations, health care and health insurance, and credit and lending.
  - Creating an LGBTQ ombudsperson to advocate for LGBTQ older adults who experience barriers to accessing and utilizing services.
- **Authorize a state tax credit to support caregivers.** Illinois should authorize a state tax credit that reflects the diversity of families—including, but not limited to, LGBTQ families and caregivers—and recognizes the significant contributions that caregivers make that reduce the demand for state-funded services.
- **Adopt an LGBTQ long-term care residents’ bill of rights.** Illinois should adopt a comprehensive long-term care bill of rights for LGBTQ older adults and issue guidance to long-term care facilities and other social service providers on how to provide respectful, appropriate care to LGBTQ older adults.
- **Mandate LGBTQ cultural competency training for state-funded providers.** Illinois should require all staff, subcontractors, subgrantees, and volunteers of state-funded aging services, long-term support services, home and community-based services, and housing services to receive a minimum level of training in LGBTQ cultural competency from organizations with expertise in LGBTQ aging.
- **Fund services that address the root causes of inequality and help remedy discrimination based on sexual orientation, gender identity, race, and ethnicity.** Illinois should fund affirming and affordable housing initiatives, access to affordable health care, workforce development and job readiness programs, programs for individuals living with HIV, and access to services for veterans. Illinois should also ensure that existing programs reflect, and are inclusive of, the unique needs of LGBTQ older adults, especially LGBTQ people of color, including those living in rural areas and undocumented LGBTQ people.

“In terms of the issues facing LGBTQ+ older adults in Illinois, the biggest hurdle is them being able to access services like getting a homemaker, meals on wheels, and/or going to their local senior center, since some people might be anti-LGBTQ+. ... It is incredible to see the trajectory since Stonewall 50 years ago to where we are today, but there is still so much work to do.”

*Director Paula A. Basta  
Illinois Department on Aging*

- **Expand LGBTQ programming and targeted outreach to LGBTQ older adults.** State officials in Illinois should ensure that existing programming is LGBTQ-competent; survey partners to assess current LGBTQ programming, partnership,



and outreach; conduct targeted outreach so LGBTQ clients, caregivers, community leaders, and partners are aware of available programs and services; and continue to promote LGBTQ-inclusive resources. These efforts are especially important for older LGBTQ Illinoisans living in rural areas and LGBTQ older adults of color.

## **LGBTQ-INCLUSIVE DATA COLLECTION**

The needs of older LGBTQ Illinoisans will remain invisible until Illinois enhances its current efforts to collect, analyze, and report LGBTQ-inclusive data. Ongoing collection of demographic data is especially important to understanding racial inequities among older Illinoisans and the intersectionality of race and ethnicity with other factors, such as sexual orientation, gender identity, disability, and income. Policymakers should:

- **Implement data collection requirements.** Implement recent legislation requiring increased collection of data on age, sexual orientation, gender identity, disability status, and primary or preferred language and ensure that COVID-19 surveillance efforts and patient records capture sexual orientation and gender identity as part of routine demographic information.
- **Create LGBTQ-inclusive data collection strategic plan.** Issue a strategic plan and timeline to expand LGBTQ-inclusive data collection to Illinois data systems, intake forms, survey instruments, and needs assessments. This plan should include guidance for state employees and third-party entities, training in how to communicate about LGBTQ-inclusive data collection, and close partnership with state and local organizations that serve LGBTQ Illinoisans.
- **Aggregate and report on existing LGBTQ-inclusive data.** Aggregate and report on existing LGBTQ-inclusive data to better understand the disparities facing LGBTQ older adults, especially LGBTQ older adults of color, and then use this data to design targeted programs and services that meet these needs.
- **Conduct LGBTQ older adult assessments.** Conduct regular assessments of the needs of older LGBTQ Illinoisans (through surveys, focus groups, informant interviews, and other tools) and ensure that LGBTQ older adults are represented in broader community needs assessments.
- **Utilize community-generated data.** Utilize community-generated data (such as survey data and community-based needs assessments) to inform policymaking and resource allocation while increasing government-wide data collection.



## **CONCLUSION**

The time to act is now to disrupt these disparities. We encourage policymakers, elected officials, and community leaders to adopt and implement the policy changes necessary to address the disparities faced by 50-plus LGBTQ Illinoisans.



## What The Data Says: Disparities Faced by 50+ LGBTQ Illinoisans

The nearly 3 million LGBTQ people over age 50 in the United States have shown incredible strength and resiliency in the face of adversity. But these challenges and a history of discrimination have taken a toll, leading to widespread disparities in areas that include health care, economic security, and caregiving and social connections.<sup>1</sup> These disparities are driven by a multitude of interacting factors, including the cumulative effect of racism, stigma, and living with discriminatory laws, policies, and systems for much of their lives.

LGBTQ older adults face unique challenges as they age. The disparities are rooted in discrimination based on sexual orientation and gender identity, racism, a lack of legal and social recognition, a reliance on chosen family, reduced access to inclusive services, and other social determinants of health and

well-being. These systemic barriers have hindered the ability of many LGBTQ older adults to acquire a well-paying job, save for retirement, secure stable housing, create a legally recognized family, access high-quality health care, or access needed social supports needed to age with dignity.

For instance, LGBTQ older adults are twice as likely to be single and live alone, four times less likely to have children, and far more likely to have faced discrimination and social stigma.<sup>2</sup> LGBTQ older adults are also more likely to face poverty and homelessness and to have poor health.<sup>3</sup> Disparities are often even worse for LGBTQ older adults of color and older transgender people. African American and Hispanic older

LGBTQ adults report lower levels of household income, educational attainment, identity affirmation, and social support.<sup>4</sup>

Many of these nationally observed disparities appear to exist in Illinois as well. The estimated 500,000 LGBTQ adults in Illinois are more likely than non-LGBTQ Illinoisans to be uninsured, low-income, and food insecure.<sup>5</sup> Even in areas of the state with sizeable LGBTQ populations (such as Chicagoland), LGBTQ Illinoisans continue to face significant challenges in access to health care, affordable housing, and public benefits.<sup>6</sup> Many of these disparities are likely

### Who Are LGBTQ Older People?

#### Nationwide

- **2.7 million** LGBTQ people are 50 and older, with **1.1 million** who are 65 and older
- **1 in 5** LGBTQ older people are people of color
- **1 in 3** LGBTQ older people live at or below 200% FPL

#### Illinois

- **24%** of Illinois' LGBTQ population is 50 and older
- An estimated **4.3%** of all adults in Illinois identify as LGBTQ
- An estimated **38%** of Chicago's 146,000 LGBTQ adults is 45 and older

Sources: Movement Advancement Project and SAGE, [Understanding Issues Facing LGBT Older Adults](#) (2017). Williams Institute, [LGBT Demographic Data Interactive: Illinois](#), (2019). Illinois Department of Human Services, [Illinois Census 2020](#); Chicago Department of Public Health, [Healthy Chicago Databook: Lesbian, Gay, Bisexual & Transgender Health](#) (2018).

exacerbated for 50-plus LGBTQ Illinoisans who comprise nearly one-quarter (24%) of Illinois' LGBTQ population. And a prior AARP report documented widespread disparities that persist among 50-plus Illinoisans of color in the areas of economic security, health, and connectivity.<sup>7</sup> These disparities—and their root causes—limit opportunity, perpetuate inequality, and hinder successful aging.

This section of the report summarizes available data on key indicators and the disparities faced by LGBTQ older adults, both nationally and in Illinois, in the areas of health, economic security, and caregiving and social connections. The data presented is limited to older adults who identify as LGBTQ and thus does not capture the many more who may experience same-sex sexual behavior or attraction, but do not identify as LGBTQ perhaps due to stigma.

While some data is available, the lack of comprehensive LGBTQ data remains a major limitation. In some instances, data is presented for the entire LGBTQ community in Illinois, rather than LGBTQ older adults, because specific data on the needs of LGBTQ older adults is not available. In other instances, data is not available on a statewide basis and is limited to, for instance, surveys of LGBTQ adults in Chicagoland. There is also a dearth of data on the needs of LGBTQ older adults of color (though studies show persistently greater disparities among LGBTQ people of color relative to white LGBTQ people). As outlined elsewhere in this report, efforts to advance LGBTQ-inclusive data collection should be a priority for state policymakers.

## HEALTH AND WELL-BEING

LGBTQ older adults experience mental and physical health disparities in part due to the lack of a competent, inclusive, and affordable health care system and lifelong experiences of discrimination and social isolation. These disparities are exacerbated for LGBTQ older adults of color who face additional social determinants of health—such as poverty, unemployment, and racism—that further limit access to health care and healthy living. Those that have faced discrimination have a higher likelihood of poor health outcomes, and many LGBTQ older adults have received inferior care or been denied care altogether. This section summarizes some of the health disparities and challenges faced by LGBTQ older adults.

**LGBTQ Older Adults Face Mental and Physical Health Disparities.** LGBTQ older adults experience a range of disparities rooted in discriminatory policies and systems relative to non-LGBTQ older adults, including increased rates of disability, poor physical and mental health, alcohol and tobacco use, and HIV.<sup>8</sup> About 10% of LGBTQ older adults in Chicagoland reported that physical health services were fair or poor while 15% describe access to mental health services this way.<sup>9</sup> And 33% of transgender Illinoisans of all ages reported mistreatment

by health care providers; others delayed or avoided care because of fear of mistreatment (24%) or because they could not afford care (29%).<sup>10</sup> Systemic racism and reduced access to health care contribute to worse health outcomes for older adults of color, including presumably LGBTQ older adults of color, who are at greater risk for chronic health issues like diabetes, hypertension, and heart disease.<sup>11</sup> Researchers have long pointed to the need for tailored interventions to address these health disparities and the unique needs of LGBTQ older communities.

- **Depression.** Discrimination and social isolation are linked to depression and higher rates of poor mental health for LGBTQ older adults relative to non-LGBTQ older adults.<sup>12</sup> Survey data from Chicago confirms similar disparities among some segments of the LGBTQ community: lesbian and bisexual women over age 45 in Chicagoland are more likely to report psychological distress, including depression, relative to straight peers.<sup>13</sup> Separate data from Chicago shows that the rates of behavioral health hospitalizations among older adults were highest among older adults of color.<sup>14</sup>
- **Chronic Disease.** Older LGBTQ adults have a significantly higher likelihood of a range of chronic health conditions and face disparities regarding high blood pressure, cholesterol, diabetes, and heart disease.<sup>15</sup> Disparities exist within the LGBTQ community.<sup>16</sup> For instance, lesbian and bisexual older women are more likely than straight older women to report strokes, heart attacks, arthritis, or multiple chronic conditions.<sup>17</sup> Gay and bisexual older men are more likely to report heart disease and cancer compared to straight men.<sup>18</sup> LGBTQ people are also more likely than non-LGBTQ people to be told they have cancer and less likely to have received certain preventive screenings.<sup>19</sup>

People of color, and particularly African American/Black people and Hispanic/Latino people, are at greater risk for hypertension, diabetes and other chronic health issues because being of color in the United States exposes them to a legacy of racism, and social, economic, and residential segregation that negatively impacts their health and well-being.<sup>20</sup> For instance, 75% of older African American/Black people and 64% of older Hispanic/Latino people in Chicago are diagnosed with hypertension compared to 56% of older white adults in Chicago.<sup>21</sup>

- **HIV/AIDS.** In 2018, more than half of people living with HIV were age 50 and older.<sup>22</sup> About 1 in 6 HIV diagnoses in 2018 were among people age 50 and older, and older adults of color—particularly Black/African American people and Hispanic/Latino people—are disproportionately affected.<sup>23</sup> Transgender people are also disproportionately affected: among respondents to the U.S. Trans Survey, 3.3% of transgender respondents ages 45 to 64 reported living with HIV while 1.6% of transgender respondents ages 65 and over reported living with HIV (compared to 1.4% of all respondents and 0.3% of the population as a whole).<sup>24</sup> Older LGBTQ adults with HIV are more likely than

HIV-negative peers to report discrimination, poorer overall social support, a higher likelihood of living alone, and an increased likelihood of mental health issues.<sup>25</sup>

- **Tobacco and Substance Use.** LGBTQ people smoke cigarettes at rates 68% higher than the general population.<sup>26</sup> Elevated risks of smoking and excessive drinking are a major concern among LGBTQ older adults, in part because intervention strategies are often targeted primarily to young people.<sup>27</sup> Tobacco use was a noted disparity among LGBTQ older adults in Chicagoland: older LGBTQ adults were more likely to smoke and less likely to have tried to quit smoking in the past year.<sup>28</sup> These disparities may be even greater for LGBTQ older adults of color since older African American/Black people in Chicago are significantly more likely to smoke compared to older white adults.<sup>29</sup> LGBTQ older adults are significantly more likely to consume excessive alcohol than straight older adults.<sup>30</sup> An estimated 10% of LGBTQ older adults reported excessive drinking and 12% used drugs that were not prescribed.<sup>31</sup>
- **Disabilities.** LGBTQ people have an elevated risk of disability, which researchers believe is tied to lifetime experiences of victimization and the impact of chronic stress on health.<sup>32</sup> 41% of all LGBTQ older adults report having a disability, compared to 35% of non-LGBTQ older adults.<sup>33</sup> This is compared to the estimated 36% of all Chicago older adults who report a disability.<sup>34</sup> Certain populations within the LGBTQ older adult community—including older lesbian and bisexual women and older transgender people—have higher rates of disability.<sup>35</sup>
- **Wellness.** Self-care is frequently more difficult for LGBTQ older adults because they are much more likely to live on their own, have fewer financial resources, and do not necessarily trust their health care providers. Lesbian and bisexual women, for instance, are less likely than straight women to have received certain preventive screenings.<sup>36</sup> Older lesbian and bisexual women in Chicagoland, for instance, were less likely than straight peers to receive mammograms as recommended.<sup>37</sup> And nearly 10% of all older adults in Chicagoland report that it is difficult to access fresh fruits and vegetables; this rate is highest amongst Latinx and African American/Black older adults.<sup>38</sup>

### **LGBTQ Older Adults Face Challenges in Accessing Affirming Health Care.**

LGBTQ older adults have long faced significant challenges in accessing health care, from legal restrictions on visitation to overt discrimination by health care providers. In a 2010 study, about 11% of LGBTQ people reported that a doctor or other health care provider used harsh or abusive language while treating them; among transgender and gender nonconforming people, the number was 21%.<sup>39</sup> Far too little has changed over time. In 2018, over half of LGBTQ survey respondents of all ages in Chicago noted an aspect of health insurance, physical

## COVID-19 and LGBTQ Older People

The COVID-19 crisis has exacerbated many of the nation's underlying health disparities—and LGBTQ older people are no exception. LGBTQ older people, and especially LGBTQ older people of color, are at an increased risk of experiencing COVID-19 more acutely and are affected by the pandemic in unique ways.

- LGBTQ people experience higher rates of chronic conditions (such as HIV and cancer) that could make them more at risk for serious complications from COVID-19.
- Many LGBTQ older people live in congregate care facilities, such as nursing homes and long-term care facilities, which have been heavily affected by the pandemic.
- LGBTQ older people are more likely to live alone and be socially isolated, making it more challenging to receive help when sheltering in place (such as picking up groceries or prescriptions) or connect socially.
- Even in a crisis, LGBTQ older people are less likely to reach out to health and aging providers (such as senior centers and meal programs) because they fear discrimination and harassment.
- LGBTQ older people have faced a long history of health care discrimination which leads to a reluctance to seek medical care unless doing so is urgent.

Source: Movement Advancement Project, SAGE, and Center for American Progress, [LGBTQ Older People & COVID-19](#) (2020).

health, or mental/emotional health as a core issue that needed to be addressed.<sup>40</sup>

**The Health Care Closet.** Given past experiences of discrimination, many LGBTQ older adults are afraid to disclose their sexual orientation and gender identity to their health care provider. An estimated 40% of LGBTQ older respondents in their 60s and 70s reported that their provider did not know about their sexual orientation.<sup>41</sup>

LGBTQ older adults of color are even less likely to disclose their LGBTQ status.<sup>42</sup> Many elders of color are even more concerned about how their age or race or ethnicity could result in poor health care, in addition to concerns about treatment based on their sexual orientation or gender identity.<sup>43</sup> The potential for discrimination across a range of factors means LGBTQ older adults of color feel uniquely vulnerable in the health care system. These concerns may be even further

exacerbated for those with limited English proficiency: close to one quarter of older adults in Chicago have difficulty speaking English while the vast majority of physicians practice medicine only in English.<sup>44</sup>

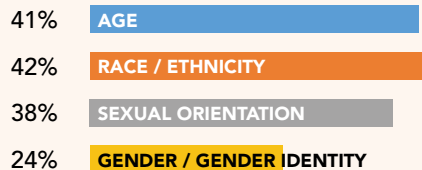
**The Need for Culturally and Clinically Competent Health Care.** The lack of access to culturally and clinically appropriate health care services is another significant barrier, especially for transgender people. In a national survey, 65% of older transgender respondents felt there would be limited access to care as they aged and over half (55%) feared they would be denied medical treatment.<sup>45</sup>

These concerns exist in Illinois as well. About 10% of LGBTQ survey respondents of all ages in Chicago reported that they can rarely or never safely access health insurance or physical health services.<sup>46</sup> Even more respondents (15%) reported similar barriers to safe access to mental health services.<sup>47</sup> Survey results and focus group data underscored the need for high-quality, affordable, culturally responsive and comprehensive health care, with many LGBTQ Chicagoans citing the need for quality and culturally competent mental health care, better quality and lower-cost medical services, and better access to LGBTQ-friendly health care services.<sup>48</sup> The lack of health professionals trained in LGBTQ issues places unique burdens on transgender Illinoisans, about 33% of whom reported at

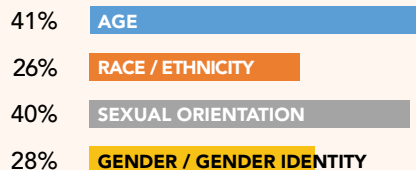
As you get older, how concerned are you that the quality of care you receive by healthcare professionals and staff will be adversely impacted based on your ...

% Very or Somewhat Concerned

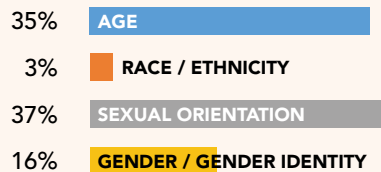
BLACK / AA



LATINO



WHITE



Source: Maintaining Dignity: Insights on Concerns and Preferences of Mid-Life and Older LGBT Adults.

least one negative health care experience in the prior year (including having to teach their medical providers about transgender health care needs).<sup>49</sup>

**Insurance Improvements But High Health Care Costs.**

High uninsured rates and discriminatory coverage policies have historically exacerbated health disparities for LGBTQ older adults. Previously, health insurance was typically only available through an employer or a spouse’s employer. This led to gaps for LGBTQ people who worked in lower-income jobs that did not offer health insurance or whose employer did not offer same-sex benefits, including health insurance.

Significant coverage gains have been made under the Affordable Care Act and through the Medicare and Medicaid programs,<sup>50</sup> but gaps remain, particularly for older adults of color. In Illinois, only 6.1% of whites aged 50 to 64 lacked health insurance while rates were much higher for older adults of color aged 50 to 64, including uninsured rates of 11.5% for Asian Americans/Pacific Islanders, 11.7% for African Americans/Blacks, and 22.1% for Hispanics/Latinos.<sup>51</sup> Accessing health care services in Illinois is also significantly harder

for older African American/Blacks, Hispanic/Latinos, and Asian American/Pacific Islanders than older whites.<sup>52</sup> In urban areas, health care providers and pharmacies are concentrated in white neighborhoods; across Illinois, whites are three times more likely to have access to a car—the highest of any racial or ethnic group.<sup>53</sup>

In a 2018 survey, older LGBTQ Illinoisans in Chicagoland identified health insurance and access to physical health services and care among their top priorities for local officials over the next year.<sup>54</sup> A separate survey found that more than one-quarter (28%) of transgender Illinoisans had an insurance problem related to their transgender status and 29% did not see a doctor because they could not afford it.<sup>55</sup> And high costs are especially a barrier for accessing medications. Older African American, Hispanic, and Native American LGBTQ people are more likely to face economic barriers when trying to access needed medications relative to older white LGBTQ adults.<sup>56</sup>

## Expanding Health Insurance to Older Undocumented LGBTQ Illinoisans

The rates of insurance coverage in Illinois change dramatically for those 65 and older, with 99 percent of older adult residents covered by insurance - most of whom are covered through Medicare. However, there are some glaring exceptions – namely, Hispanic/Latino (6.75%) and Asian American/Pacific Islander (5.1%) older adults experience more lack of coverage than African American/Black (just less than 1%) and white older adults (less than 0.4%). As a result, older Hispanic/Latinos and Asian American/Pacific Islanders in this age range are 18 times and 13 times more likely, respectively, not to have health insurance coverage.

This disparity in coverage may be explained by the recent immigration status of the older adults and the prevalence of undocumented immigrants within the Hispanic/Latino and Asian American/ Pacific Islander older adult populations. Illinois reports that the state has a significant immigrant population, with a very high portion of the Hispanic/Latino and Asian American/Pacific Islander population being foreign-born. In an unpublished study by Rush University Medical Center, Illinois is projected to experience an increase in older immigrant populations with mixed status over the next decade. By the year 2030, there may be over 55,000 undocumented older adult immigrants in the state.

Most of these older adult immigrants came to the United States in the 1980s while in their late 20s to 40s and are reaching retirement age. With chronic health issues impacting older adults, insurance coverage is a particular focus of the state. In order to address this projected increase in health care needs, Illinois recently passed legislation providing Medicaid access to non-citizens over the age of 65 for whom income is at or below the federal poverty level.

Source: AARP of Illinois et al., [Disrupt Disparities: Challenges & Solutions for 50+ Illinoisans of Color](#) (2020).

## ECONOMIC SECURITY

Older LGBTQ adults have fewer financial resources and are more likely to be low-income relative to non-LGBTQ older adults. Several variables—including gender, generation, race and ethnicity, and marital status—can make financial decisions especially challenging for LGBTQ older adults. Ongoing legal discrimination, compounded with economic disparities that accumulate across the life course, make it harder for LGBTQ older adults to be financially secure and result in significant wealth differences at retirement age. This section summarizes some of the existing data on the challenges faced by LGBTQ older adults that lead to economic insecurity and higher rates of poverty.

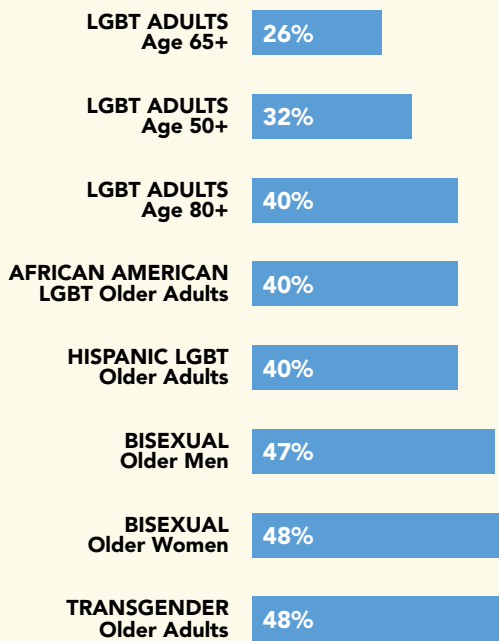
Economic insecurity is even greater for LGBTQ older adults of color given racial disparities in education opportunities and attainment, employment rates, wages, and the resulting personal income. Wealth differences are also caused by lack of access to banking and credit in communities of color, which decrease access to mortgages and home ownership, as well as lack of access to retirement savings, pensions and 401k plans. These barriers have caused significant wealth differences at retirement age between whites and African American/Blacks, Hispanic/ Latinos, and Asian American/Pacific Islanders, especially in the areas of Social Security benefits, employment pensions and retirement plans and personal savings.<sup>57</sup>

**One-Third of LGBTQ Older Adults Are Very Low-Income.** Nearly one-third of LGBTQ older adults age 65 and older (32%) live at or below 200% of the federal poverty level, compared to a quarter of non-LGBTQ older adults.<sup>58</sup> Poverty rates are even higher for those aged 80 and older, bisexual older adults, transgender older adults, and LGBTQ older adults of color.<sup>59</sup> The latter findings are consistent with a prior AARP report that found that older African Americans/Black people in Illinois are three times more likely to live in poverty than white older adults in Illinois; poverty rates were 1.7 times higher for Hispanics/Latinos in Illinois and

1.2 times higher for Asian American/Pacific Islanders.<sup>60</sup> Poverty rates are higher among LGBTQ older adults because of the cumulative impact of discrimination over the course of a lifespan and because LGBTQ older adults are much more likely to live alone. Nationwide, 27% of LGBTQ people reported food insecurity at least once in the past year, with even higher rates of food insecurity reported for African American, Hispanic or Latino, American Indian, and Pacific Islander LGBTQ people.<sup>61</sup> In Chicagoland, slightly more than half (53%) of older LGBTQ adults reported earning a living wage.<sup>62</sup>

### LGBTQ Older Adults are More Likely to Live in Poverty

Percentage of Older Adults Who Live At/Or Below 200% of the Federal Poverty Level, by Population



Source: Maintaining Dignity: Insights on Concerns and Preferences of Mid-Life and Older LGBT Adults

### LGBTQ Older Adults Have Faced Significant Employment Discrimination, Leading to Lower Earning Power.

Many LGBTQ older adults have faced a lifetime of employment discrimination, which contributes to lower earning power. For instance, LGBTQ older adults report not being hired (27%), not being promoted (26%), or being fired (18%) because of their sexual orientation or gender identity.<sup>63</sup> Employment discrimination may be even greater for LGBTQ older adults of color and those living with HIV or AIDS who

additionally faced racism, bias, and stigma because of their race or ethnicity and/or health status or perceived health status, leading to income loss and lower savings over time. Job discrimination is also significant for transgender older adults: 51% of transgender women reported not being hired for a job because of their perceived identity.<sup>64</sup>

Discrimination in employment remains a reality for many LGBTQ Illinoisans, with significant implications for future generations of LGBTQ older adults. Among respondents to the U.S. Trans Survey, 11% of transgender Illinoisans reported being unemployed in 2015 (compared to 5% unemployment nationwide in 2015).<sup>65</sup>



### **Lower Earning Power and Lack of Legal Recognition Means Lower Income During Old Age.**

Lower earning power from a lifetime of discrimination means lower payments from Social Security and lower income from retirement and pensions. More than 8 in 10 (83%) of LGBTQ older adults report relying mostly on Social Security to fund their retirement years, with a majority concerned that cuts to Social Security would impact their future financial security.<sup>66</sup> LGBTQ older adults whose spouse or partner died or retired before the freedom to marry may be unable to access Social Security survivor benefits, their partner's retirement or pension benefits, or their partner's assets.<sup>67</sup>

This economic instability is, for many, exacerbated by the HIV/AIDS pandemic. Stigma caused additional discrimination, leading to the loss of job opportunities and health (and other) insurance discrimination. These lost opportunities and higher costs have long-term consequences, limiting the ability of many LGBTQ older adults to save and secure financial stability. Many LGBTQ older adults are currently living with HIV, lost partners and other loved ones, and/or served as caregivers even with fewer financial resources.

Given these barriers, it is unsurprising that 44% of LGBTQ older adults report being concerned that they will have to work well beyond retirement age to have enough money to live compared to 26% of non-LGBTQ people.<sup>68</sup> This may be particularly true for LGBTQ older adults living with HIV who may not have

### **Census Bureau Confirms that LGBTQ People Have Been Disproportionately Affected by the Economic Impact of the COVID-19 Pandemic**

For the first time ever, U.S. Census Bureau released survey data in August 2021 confirming the disparities faced by LGBTQ people of all ages. Analysis of this data shows significant disparities between LGBTQ people aged 49 and older and non-LGBTQ peers of the same age. Key findings include:

- More LGBT older adults (5.8%) lived in a household that experienced **food insecurity** in the past seven days, compared to non-LGBT older adults (3.7%).
- More LGBT older adults (40.5%) lived in a household that had **difficulty paying for usual household expenses** in the previous seven days, compared to non-LGBT older adults (34.8%).
- More LGBT older adults (13.9%) lived in a household with **lost employment income** in the past four weeks, compared to non-LGBT older adults (10.1%).
- More LGBT older adults (48.1%) said they **felt down, depressed, or hopeless** in the past two weeks, compared to non-LGBT older adults (35.1%).

This data confirmed what many researchers expected to be true: that the COVID-19 pandemic would disproportionately impact LGBTQ people, people of color, women, and groups living at the intersections of those identities. This is because these communities are historically disproportionately affected by unemployment during—and long after—economic downturns such as the COVID-19 crisis

Sources: Analysis of Household Pulse Survey data (2021); Thom File & Joey Marshall, [Household Pulse Survey Shows LGBT Adults More Likely to Report Living in Households with Food and Economic Insecurity Than Non-LGBT Respondents](#), U.S. Census Bureau (2021); Sharita Gruberg & Michael Madowitz, [Same-Sex Couples Experience Higher Unemployment Rates Throughout an Economic Recovery](#), Center for American Progress (2020).



expected to live into retirement but now are living well past retirement age due to anti-retroviral therapy and finding themselves with inadequate savings. LGBTQ older adults of color likely also face similar earnings disparities. Data from a prior AARP report shows that African American/Black, Hispanic/Latino, and Asian American/Pacific Islander older adults in Illinois are more likely to work past the age of 64 than their white peers, and are significantly more likely to have lower income levels.<sup>69</sup>

**Housing Discrimination Limits Options for LGBTQ Older Adults.** Affordable housing is a challenge for many older adults, with significant disparities in home ownership in Illinois based on race and ethnicity. While the majority (68.2%) of Illinoisans own their own homes, these numbers vary significantly between whites (77.9%), African American/Blacks (41.8%), Asian American/Pacific Islanders (66.6%), and Hispanic/Latinos (56.1%).<sup>70</sup> Beyond home ownership alone, there are large and growing differences in the value of property that people own. In Chicagoland, for example, homes in predominantly African American/Black communities appreciate in value at slower rates and have lower peak values than homes in majority-white neighborhoods. And those living in these homes are less likely to accumulate comparable levels of equity over time. While there are many reasons for these disparities, the ability to access mortgage credit is critical.

Access to affordable housing is especially challenging in Chicago where more than half of LGBTQ older adults reported that the cost of housing was a very serious or serious issue in their neighborhood.<sup>71</sup> But accessing rental or elder housing can be even more challenging for LGBTQ older adults who are more likely to be low-income and face housing discrimination in elder living communities.

Housing discrimination—whether based on sexual orientation, gender identity, race, ethnicity, disability, or another factor—can occur at the hands of property managers, staff, and other residents or service providers. A study of older same-sex couples applying for housing in 10 states showed that 48% experienced overt discrimination in the application process relative to different-sex couples.<sup>72</sup> Surveys confirm this experience: 13% of LGBTQ older adults reported housing discrimination based on sexual orientation and 25% of transgender people reported discrimination based on gender identity.<sup>73</sup> This does not reflect the additional discrimination that an LGBTQ older adult of color, or an LGBTQ older adult living with a disability, might face in accessing affordable housing services.

Older LGBTQ Americans in LGBTQ-unfriendly communities were seven times more likely to report recent housing discrimination (14% vs. 2% in LGBTQ-friendly communities).<sup>74</sup> In light of discrimination, 34% of LGBTQ older adults

and 54% of transgender and gender nonconforming older adults were at least somewhat worried about having to re-closet themselves to seek housing.<sup>75</sup> This may be why 90% of older LGBTQ survey respondents were extremely, very, or somewhat interested in LGBTQ-welcoming older adult housing developments.<sup>76</sup>

Lack of access to affordable housing is exacerbated by the current real estate and eviction crisis, which itself has been magnified by the disparate impact of COVID-19 on elders' safety, support networks, and economic stability. Transgender elders are facing compounded barriers, exacerbated by recent attempts to rollback federal Fair Housing Act protections, implement religious exemptions, and eliminate explicit federal housing and homeless shelter protections for transgender people. And most continuing care retirement communities are religiously affiliated organizations, which can jeopardize the safety and security of LGBTQ older adults when they are most vulnerable.<sup>77</sup>

## CAREGIVING AND SOCIAL CONNECTIONS

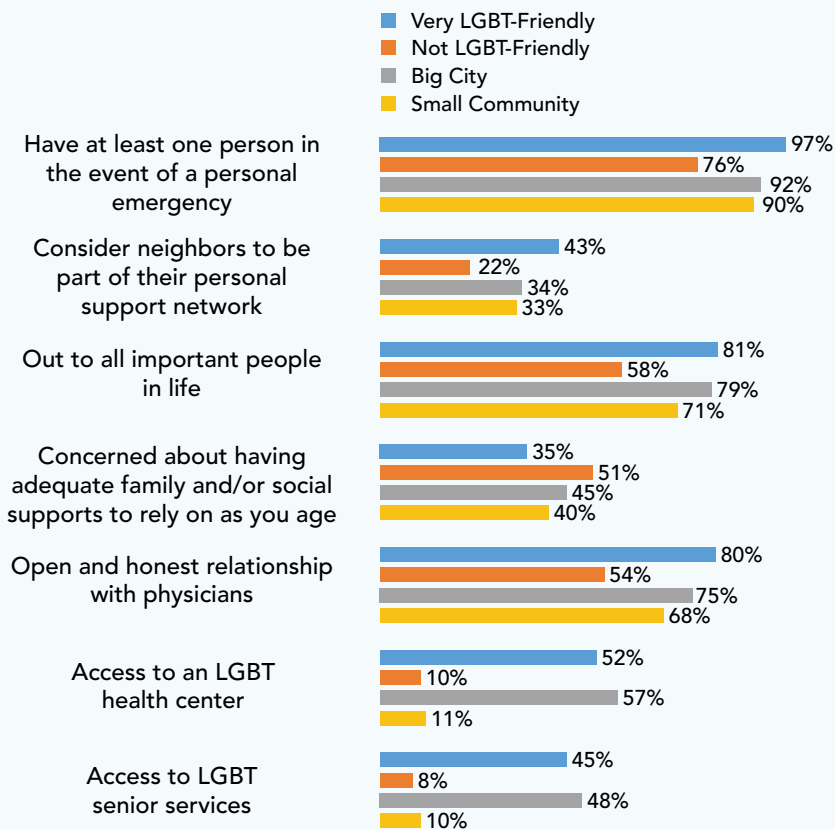
Estrangement from family and legal barriers to marriage, adoption, caregiving, and social services have caused many LGBTQ older adults to be more isolated and disconnected from services than non-LGBTQ people. Many were shunned by their families and, as a result, are less likely to have close relatives to turn to for support. Legal and social structures, which limited the ability of many LGBTQ older adults to build a family, have meant that LGBTQ older adults are far more likely to live alone than non-LGBTQ individuals and far less likely to have adult children or other family members to rely upon for informal caregiving.

As a result, LGBTQ older adults are often disconnected from services and have thin support networks. Although the networks that LGBTQ older adults have built are strong and resilient, a lack of legal family ties can worsen care and social isolation. Friend networks often age at the same time, and friends or families of choice are often not recognized under the law. This results in unique barriers to caregiving and prevents loved ones from being able to fully support the LGBTQ older adults in their care. Thinner support networks, in turn, make LGBTQ older adults more reliant on community service providers, even though LGBTQ older adults are more likely to face discrimination from those providers. This section summarizes some of the current data including research supported by AARP Foundation and AARP on the challenges faced by LGBTQ older adults with respect to caregiving and social connections.

**Thin Support Networks Exacerbate Social Isolation.** According to the AARP's Maintaining Dignity study, three out of four LGBTQ people age 45 and older are concerned about having enough support from family and friends as they age.<sup>78</sup> This is because LGBTQ older adults are more likely to live alone than non-LGBTQ individuals and less likely to rely on adult children or other family

## Support and Quality of Life by LGBT-Friendliness and Size of Community

among LGBT adults age 45 and older



Source: Maintaining Dignity: Insights on Concerns and Preferences of Mid-Life and older LGBT Adults

they consider gay or straight friends, family, or neighbors part of their personal support network.<sup>85</sup>

Social isolation can be difficult to overcome because there are fewer opportunities to socialize in age-friendly and LGBTQ-inclusive environments. It can also be challenging to find LGBTQ-inclusive programming or events. This is especially true for LGBTQ older adults of color and those in less welcoming environments or rural settings where there are fewer LGBTQ-inclusive businesses or services. Fewer than half (48%) of big city residents surveyed and as few as 10% of rural and small-town residents reported access to LGBTQ-inclusive elder services in their community.<sup>86</sup> Access to inclusive services is particularly important in rural areas since up to 20% of the total LGBTQ population lives in rural areas across the country.<sup>87</sup>

members for informal caregiving.<sup>79</sup> And LGBTQ people are more likely than non-LGBTQ people to report being lonely.<sup>80</sup>

This isolation contributes to the physical and mental health disparities noted above. Nearly 60% of LGBTQ older adults report feeling a lack of companionship, with over 50% reporting feeling isolated from others.<sup>81</sup> LGBTQ older adults are also more likely to report fear of dying alone and in pain.<sup>82</sup> The limited data that exists suggests that LGBTQ older adults may face high rates of elder abuse due to their isolation, vulnerability, and reliance on others.<sup>83</sup>

Disparities exist even within the LGBTQ community, putting certain segments of the community at greater risk of isolation. Gay men, for instance, report being less connected in a range of relationships relative to lesbians.<sup>84</sup> Although 53% have children or grandchildren, transgender or gender expansive people were the least likely to say

**LGBTQ Older Adults Often Serve as Caregivers.** Although the networks that LGBTQ older adults have built are strong and resilient, thinner support networks mean that many LGBTQ older adults rely on other LGBTQ people, such as friends and family of choice, as caregivers. LGBTQ older adults become caregivers more often than their non-LGBTQ counterparts.<sup>88</sup> An estimated 21% of LGBTQ older adults have provided care to friends (compared to only 6% of non-LGBTQ peers) even as LGBTQ caregivers are more likely to be providing care in isolation and tend to have poorer mental and physical health.<sup>89</sup> In one study of LGB older adults in New York City and Los Angeles, 65% of respondents had provided care to another LGB older adult in the last five years.<sup>90</sup> Survey data suggests that at least 4% of LGBTQ adults in Chicago are caring for an older adult or adults and 5% are caring for a person or people with disabilities.<sup>91</sup> Among LGBTQ older adults in Chicagoland, 29% described themselves as being a caregiver to children, other adults, or people with disabilities.<sup>92</sup>

LGBTQ caregivers face unique obstacles, from laws that privilege biological families to a lack of resources for LGBTQ-specific needs. Yet because this support often goes unrecognized, many LGBTQ caregivers do not avail themselves of the resources that are available to caregivers. Given that caregivers tend to have poorer mental and physical health than non-caregivers, LGBTQ older adults who serve as caregivers could face even more serious health disparities. Many LGBTQ people were caregivers for loved ones during the AIDS crisis, meaning that caregiving anew can bring up difficult memories and contribute to mental health disparities. Beyond its physical and mental toll, caregiving can bring financial risks for LGBTQ caregivers. Since many LGBTQ older adults do not have the financial means to fully support themselves should they need long-term medical care, LGBTQ caregivers may see their own financial resources strained or face economic insecurity while caring for a loved one. And legal documents (such as advance directives) are even more important for LGBTQ older adults whose primary caregiver is not a legal next of kin.

### **Many LGBTQ Older Adults Fear Discrimination By Aging Services**

**Providers.** LGBTQ older adults have lived through discrimination, social stigma, and family rejection. About two-thirds of LGBTQ older adults have experienced victimization at least three times in their lives, with higher rates of discrimination for LGBTQ older adults of color and transgender older adults.<sup>93</sup> This includes discrimination in long-term care facilities.<sup>94</sup>

Given a lifetime of discrimination—which is rooted in homophobia, transphobia, racism, and bias—many older LGBTQ Illinoisans are understandably concerned about continued discrimination by service provider staff and peers. Continued fear of discrimination in care settings forces many LGBTQ older adults to go back into the “closet” to preserve their safety and dignity.<sup>95</sup> Indeed, majorities of LGBTQ people age 45 and older have concerns about long-term care, including concerns about neglect (67%), abuse (62%), verbal or physical harassment (61%), refusals or limits on services (61%), and being forced to hide or deny their

## LGBTQ Older Adults Face Discrimination and Harassment in Care Facilities

% of respondents who had experienced ...

Experiences Related to Resident's Real or Perceived Sexual Orientation and/or Gender Identity	Percent of All Instances
Verbal or Physical Harassment from Other Residents	23%
Refused Admission or Re-admission, Attempted or Abrupt Discharge	20%
Verbal or Physical Harassment from Staff	14%
Staff Refused to Accept Medical Power of Attorney from Resident's Spouse or Partner	11%
Restriction of Visitors	11%
Staff Refused to Refer to Transgender Resident by Preferred Name or Pronoun	9%
Staff Refused to Provide Basic Services or Care	6%
Staff Denied Medical Treatment	6%

Source: The National Senior Citizens Law Center et al, "LGBT Older Adults in Long-Term Care Facilities: Stories from the Field" accessed May 11, 2017, [https://www.lgbtagingcenter.org/resources/pdfs/NSCLC\\_LGBT\\_report.pdf](https://www.lgbtagingcenter.org/resources/pdfs/NSCLC_LGBT_report.pdf)

identity (52%).<sup>96</sup> These rates are even higher for gender expansive older adults: 70% of older transgender and gender expansive people reported concern that they may have to hide or deny their identity to receive long-term care.

To avoid having to go back into the closet, LGBTQ older adults want long-term care providers who understand the specific needs of LGBTQ older adults. Most LGBTQ older adults would feel more comfortable with providers who are trained in LGBTQ patient needs (88%), use advertising to promote LGBTQ-friendly services (86%), have some LGBTQ staff members (85%), or display LGBTQ-welcoming signs or symbols (82%).<sup>97</sup>

In some communities, LGBTQ community centers try to fill these gaps by providing competent care for LGBTQ older adults. However, these centers often lack crucial resources with very little grant support dedicated to programs for LGBTQ older adults. Funding disparities persist even though LGBTQ community centers typically serve a high proportion of LGBTQ older adults: on average, 26% of center clientele is over the age of 50, with some centers reporting that 50% or more of their clientele are over the age of 50.<sup>98</sup>

Survey data from Chicago confirms that LGBTQ health and human service providers play a key role in the lives of older LGBTQ Illinoisans in need of health and social services. Overall, 82% of older LGBTQ adults in Chicagoland cited safe and supportive groups, programs, institutions, and social services providers such as Howard Brown, Center on Halsted, Affinity Community Services, and Chicago House.<sup>99</sup>

## A Comprehensive Strategy to Support LGBTQ Older Adults

The disparities faced by LGBTQ older adults mean that Illinois must adopt a comprehensive strategy that helps ensure that LGBTQ 50-plus people thrive. Doing so will build on the leadership that Illinois has already shown in understanding and addressing the needs of LGBTQ older adults. A comprehensive strategy is consistent with long-standing efforts of Illinois policymakers, including the Illinois Department on Aging (IDoA), to better serve and foster the inclusion of LGBTQ older adults.<sup>100</sup> This section identifies policy recommendations to further improve the lives of LGBTQ older adults.

### Implement the Designation for Populations of Greatest Social Need

Illinois has already shown strong leadership by designating LGBTQ older adults and older adults living with HIV as populations of greatest social need for inclusion in aging programming under the Older Americans Act.<sup>101</sup> The Older Americans Act is the nation's leading vehicle for funding and delivering services to older adults nationwide with the goal of ensuring that older adults can live independently and remain in their communities. It funds programs including home and congregate meals (like Meals on Wheels), chore assistance, transportation assistance, legal assistance, and a suite of wrap-around services and supports to enable people to age in place.

The Older Americans Act provides funds to the Administration for Community Living (ACL) which, in turn, funds state units on aging and local AAAs across the country. Services must be made available to all individuals aged 60 or older, but Congress and ACL recognized that individuals in certain subpopulations (often those belonging to communities that have been marginalized) were not





receiving services for which they were eligible. As a result, the Older Americans Act requires aging network providers to target programs and services to distinct marginalized and underserved populations, including those with greatest social need. Congress reinforced the importance of being inclusive of LGBTQ older adults in 2020, by requiring the aging network to engage in outreach to LGBTQ older adults, collect data on the needs of LGBTQ older adults, and collect data on whether they are meeting the needs of LGBTQ older adults.<sup>102</sup>

Recognizing that LGBTQ older adults fit squarely within the Older Americans Act's definition of "greatest social need," Illinois designated LGBTQ older adults as a group of greatest social need in 2019.<sup>103</sup> In the same law, Illinois became the first state to additionally identify older adults living with HIV as a population of greatest social need. With this designation, aging network providers must identify and provide services specific to LGBTQ older adults and older adults living with HIV; collect data on the geographic distribution of LGBTQ older adults and older adults living with HIV; target services and supports to these communities; and provide technical assistance and training to service providers.

This designation is already informing IDoA's approach to services and inclusion and establishes a strong foundation for ensuring that LGBTQ-specific disparities in Illinois do not go unaddressed. However, Illinois policymakers can do more to make sure that this designation is fully implemented and enforced. One important way to do so is through the publication of an annual report on progress made in addressing the needs of older LGBTQ adults and older adults living with HIV. Regular public reporting would promote transparency and accountability, help guide state leaders in policy adoption and resource allocation, and complement efforts to increase the collection of LGBTQ-inclusive data collection (which is critical to assess the progress made in meeting the needs of these communities). Another way to ensure effective implementation is to strengthen and incentivize more meaningful partnership between AAAs, AIDS service organizations, LGBTQ equality organizations, and other core partners that already serve LGBTQ older adults in Illinois.

### **Establish A Statewide Commission on LGBTQ Aging**

Given the unique needs of LGBTQ older adults, Illinois should establish a standing commission on the needs of LGBTQ older adults. The commission could include state officials, representatives from the AAAs, service providers, LGBTQ community organizations, LGBTQ older adults and advocates for older adults, among other stakeholders.

Several states have already established similar commissions or initiatives. Massachusetts established a first-in-the-nation statewide LGBT Aging Commission to address the unique concerns and needs of older LGBTQ adults. The Commission is charged with 1) investigating, analyzing, and studying the health, housing, financial, psychosocial, and long-term care needs of older LGBTQ adults and their caregivers and 2) making recommendations to

improve access to benefits and services where appropriate and necessary. The Commission issued a report in 2015 with overarching recommendations and specific recommendations on long-term services and supports, public health, housing, senior centers and community engagement, and legal considerations.<sup>104</sup>

Illinois should establish a similar standing commission to inform its efforts to advance equality and provide affirming services to 50-plus LGBTQ Illinoisans. This commission would provide an ongoing forum to identify challenges and best practices related to serving LGBTQ older adults in Illinois, ensure a sustained focus on meeting the needs of LGBTQ older adults of color, and solicit expert recommendations on improving the quality of life of 50-plus LGBTQ Illinoisans. This forum could also facilitate communication on a statewide basis and help ensure that AAAs and service providers are not duplicating efforts or operating in isolation when developing new materials, training programs, or service initiatives.

Other states have established statewide task forces or initiatives. The Missouri Department of Health and Senior Services developed an LGBT Aging Alliance. This collaborative effort helps inform communities and service providers about inclusive practices to ensure that LGBT older adults feel welcome and supported across the state.<sup>105</sup> And AAAs in Michigan participated in a statewide LGBT and Aging Initiative to help identify LGBT-friendly community services, update policies and practices, and develop materials on best practices for cultural competency.<sup>106</sup>

### The Massachusetts LGBTQ Aging Commission

In 2013, Governor Deval Patrick signed [legislation](#) to establish a 20-member LGBTQ Aging Commission. The Commission was charged with:

- Examining the impact of state policies and regulations on LGBTQ older adults and making recommendations to ensure equality of access, treatment, care, and benefits;
- Examining strategies to increase provider awareness of the needs of LGBTQ older adults and caregivers and improve cultural competency and access to treatment, services, and care;
- Assessing the funding and programming needed to enhance services to the growing population of LGBTQ older adults;
- Examining best practices for increasing access, reducing isolation, preventing abuse and exploitation, promoting independence and self-determination, strengthening caregiving, eliminating disparities, and improving quality of life;
- Examining whether certain policies and practices promote the premature admission of LGBTQ older adults to institutional care;
- Recommending lower cost and culturally appropriate home and community-based alternatives to institutional care;
- Examining the feasibility of developing statewide training curricula to improve provider competency in delivering health, housing, and long-term support services to older LGBTQ adults; and
- Examining outreach protocols to reduce apprehension among LGBTQ older people about utilizing mainstream providers.

The Commission was directed to consider best policies and practices from other states and held listening sessions, solicited written comments, and requested expert presentations. The Commission—now known as the Commission on LGBTQ Aging—continues its work and held a series of renewed listening sessions in 2019.

In addition to establishing a statewide commission on LGBTQ aging, Illinois should update the membership criteria for the existing Illinois Council on Aging to ensure ongoing representation of older LGBTQ adults. This step is key to ensuring that the Council continues to reflect the diversity of all older Illinoisans, including LGBTQ Illinoisans, transgender Illinoisans, and racially diverse LGBTQ people.


IDoA could also host a series of events to bring awareness to the unique challenges faced by LGBTQ older adults, to share best practices among providers, and to take questions from attendees. These types of convenings may be especially important to promoting statewide community engagement, especially in rural areas of the state. As just one example, the Pennsylvania Department of Aging hosted such an event in 2018. The Pennsylvania LGBTQ Aging Summit featured the former federal Assistant Secretary of Aging, senior state officials, LGBTQ older adults, the national LGBTQ liaison for the AARP, the chief executive officer of SAGE, and local service providers.<sup>107</sup> The Summit helped highlight the barriers faced by LGBTQ elders and promoted regional planning sessions with tangible community outcomes. IDoA could model its convenings after similar efforts by SAGE and Pride Action Tank to engage the Illinois aging network and raise awareness of the new designation of populations of greatest social need under the Older Americans Act.

### **Create LGBTQ-Inclusive State and Area Plans on Aging**

As the number of LGBTQ older adults continues to climb, the needs of LGBTQ people should be considered during Illinois' process of designing, implementing, and evaluating its aging services and programs. Building an inclusive planning process may require building new partnerships with LGBTQ-focused organizations, ensuring that community assessments reflect the needs and concerns of LGBTQ constituents, and including LGBTQ-specific goals, objectives, strategies, and outcomes.<sup>108</sup>

Illinois' State Plan on Aging is among its most important tools for advancing LGBTQ inclusion and equality. With specific goals and objectives, this document guides how Older Americans Act-funded services are delivered and how policy is developed throughout the state. The Plan also serves as a benchmark to measure effectiveness and efficacy.

Recognizing the importance of LGBTQ inclusion, IDoA's draft State Plan on Aging for 2021 to 2023 includes an objective on expanding awareness and enhancing understanding of serving LGBTQ older adults in Illinois.<sup>109</sup> Strategies to achieve this objective would include SAGE trainings for IDoA staff and provider agencies, AAAs, and other aging network providers; ongoing training to Senior HelpLine staff; LGBTQ-affirming outreach and communication



materials (with a specific focus on reducing social isolation and reaching people with dementia); the inclusion of LGBTQ older adults or those who represent them on IDoA advisory councils; development of a needs assessment with SAGE to help improve service delivery; and encouraging LGBTQ older Illinoisans to plan for long-term care and end of life options through education and counseling. IDoA would measure success based on the extent of annual LGBTQ cultural competency trainings, whether there is a 20% increase in LGBTQ older adults being engaged in or served by the aging network, and the degree of sharing demographic information collected by the Senior HelpLine with service providers. Other parts of the draft State Plan on Aging also note the need to be inclusive in Illinois' approach to aging services and supports.

These specific objectives and references to LGBTQ needs are critical to serving LGBTQ older adults, promoting accountability, and helping ensure true inclusion by partners. In Michigan, for instance, aging officials included LGBTQ older adults in a statewide needs assessment to help inform its State Plan on Aging. As a result of the assessment, Michigan's Plan included an outcome to increase outreach to and services for LGBTQ older adults.<sup>110</sup> IDoA should also partner with organizations such as the AIDS Foundation of Chicago's OUTAging Committee to inform the planning process and help identify partners. Area Plans on Aging should similarly incorporate measurable, time specific, and attainable goals for promoting LGBTQ inclusion.

## Equal Access to Inclusive Programs and Services

LGBTQ older adults face unique barriers when seeking home and community-based services, social services, and long-term care. Key challenges include a lifetime of discrimination, racism, a lack of legal and social recognition, a reliance on chosen family, and a lack of competent, inclusive health care. Fear of discrimination can also cause LGBTQ older adults to delay seeking necessary care and lead to premature institutionalization in nursing homes and long-term care facilities due to fear of hostile in-home care providers. Many of these concerns are exacerbated for those living with HIV who face additional stigma and privacy concerns.

Social isolation is arguably the greatest issue that LGBTQ older adults face as they age. Due to discriminatory and hostile social systems and structures, many older LGBTQ adults lack access to social institutions that provide critical security in later life, such as marriage, family, faith communities, and employment. This leads many LGBTQ older adults to more greatly rely on friends, family of choice, or formal caregivers to assist with daily living. Social isolation can be even more difficult to overcome because of fewer opportunities to socialize in age-friendly and LGBTQ-inclusive environments and less LGBTQ-inclusive programming.

While these challenges require a range of responses, policymakers can do more to ensure that LGBTQ older adults have access to the affirming supports and services they need to age successfully. These policies make a difference. Research shows that LGBTQ older adults who receive culturally competent health and support services in their community report higher physical and emotional quality of life scores and better overall health.<sup>111</sup>

### **Implement and Enforce Comprehensive Nondiscrimination Protections**

Explicit nondiscrimination protections remain crucial to ensuring that LGBTQ people—across the lifespan—can achieve income security, find and maintain stable housing, access affirming health care, and otherwise be treated with dignity and respect in their daily lives. Comprehensive nondiscrimination protections are especially critical for older LGBTQ adults who can face multiple sources of discrimination, such as age discrimination, racism, and discrimination based on their LGBTQ status.

The Illinois Human Rights Act bans discrimination based on sexual orientation and gender identity in employment, housing, public accommodations, and credit.<sup>112</sup> To promote compliance with state law, state officials should issue more detailed guidance on LGBTQ-specific nondiscrimination and the respectful

treatment of older transgender Illinoisans. Such a policy should advise AAAs and aging network providers on transgender-specific nondiscrimination protections, such as referring to older transgender people by their chosen name and otherwise treating older LGBTQ adults in a respectful manner that is consistent with their gender identity or expression.

State officials should further ensure that nondiscrimination policies are known by the aging network, LGBTQ older adults, and the public by including nondiscrimination information on state websites, fact sheets, and other public-facing documents. Illinois should also establish an LGBTQ ombudsperson to ensure the integration of LGBTQ concerns into the state's aging and human services networks and to advocate for LGBTQ older adults who experience barriers to accessing and utilizing services. An LGBTQ ombudsperson should work directly with LGBTQ equality organizations that already serve LGBTQ older adults; this is the most efficient way to ensure that such an office could assist those in need, market its services, and receive and resolve complaints about mistreatment.

### **Adopt an LGBTQ Long-Term Care Residents' Bill of Rights**

Illinois should ensure that LGBTQ older adults are fully protected while in long-term care. Because many LGBTQ older adults lack traditional support systems, many rely on nursing homes or other institutions providing long-term care. Illinois prohibited discrimination against LGBTQ residents of assisted living and shared housing facilities in legislation enacted in 2019.<sup>113</sup> These critical protections notwithstanding, more can be done to ensure that LGBTQ older adults and older adults living with HIV are treated with respect in nursing homes and other long-term care facilities.

### **California Adopts LGBTQ Long-Term Care Facility Residents' Bill of Rights**

California Governor Jerry Brown signed [legislation](#) to establish an LGBTQ Long-Term Care Facility Residents' Bill of Rights. The Bill of Rights strengthens protections for LGBTQ elders in long-term care facilities, which include skilled nursing facilities, intermediate care facilities, and residential care facilities for the older people.

The Bill of Rights requires facilities and staff to refer to residents by their chosen name or pronoun and prohibits facilities from denying admission, involuntarily discharging, evicting or transferring a resident within a facility or to another facility based on anti-LGBTQ attitudes of other residents or a person's actual or perceived sexual orientation, gender, gender identity, gender expression or HIV status. Facilities must post a notice regarding LGBTQ discrimination.

Survey data from LGBTQ older adults, providers, and support systems shows that LGBTQ older adults continue to face discrimination and mistreatment while in long-term care settings.<sup>114</sup> This abuse can take many forms, including being turned away or evicted from a long-term care facility based on sexual orientation or gender identity. After a lifetime of bullying by and bias from schoolmates, coworkers, and society at large, some LGBTQ older adults are forced to share a room with homophobic, transphobic, or racist companions. Same-sex couples are sometimes separated.

Concerns within the LGBTQ community about long-term care are significant. A prior AARP survey of LGBTQ adults age 45 and older showed that majorities are concerned about neglect, abuse, service refusals, and harassment.<sup>115</sup> The possibility of being forced back into the closet in order to receive care was a concern for about half of LGB respondents and for 70% of transgender and gender expansive respondents.<sup>116</sup>

While Illinois-specific data are not available, there have been documented cases of anti-LGBTQ discrimination in long-term care facilities in Illinois. In one case that went on to be a major federal court case, Marsha Wetzel faced harassment from fellow residents at her long-term care facility in

Niles, Illinois because she is a lesbian.<sup>117</sup>

Marsha filed a lawsuit, claiming the long-term care facility failed to protect her from this discrimination. In 2018, the Seventh Circuit Court of Appeals ruled that a landlord may be held liable under the Fair Housing Act for failing to protect an LGB tenant from known, discriminatory harassment at the hands of other tenants.<sup>118</sup> This case underscores that discrimination and harassment still takes place against LGBTQ older adults in long-term care facilities.

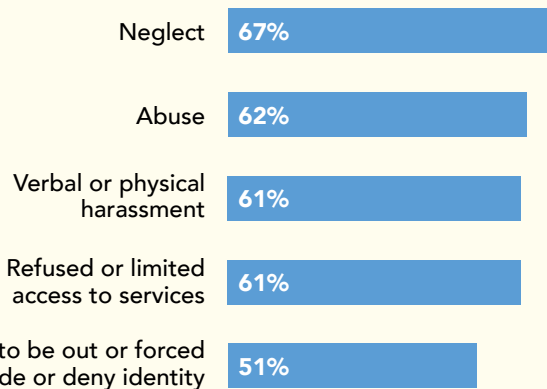
Some states, such as California and New Jersey, have already taken action to recognize and address the need for specific LGBTQ and HIV protections in long-term care settings. California adopted an LGBT Long-Term Care Facility Residents' Bill of Rights in 2017 to protect people from discrimination on the basis of their actual or perceived sexual

orientation, gender identity, gender expression, or HIV status. The goal of the legislation was to help protect LGBT older adults and older adults living with HIV when they are at the most vulnerable and ensure that facilities provide culturally competent services and care. New Jersey's law was informed by statewide engagement of older LGBT New Jersey residents to ensure that the nine elements included in the law would truly serve and protect older LGBT people based on sexual orientation, gender identity and expression, intersex status, and HIV status.<sup>119</sup>

Illinois should update state law to include a comprehensive long-term care bill of rights for LGBTQ older adults and older adults living with HIV. The bill of rights would help ensure that long-term care residents fully understand their legal rights and responsibilities—and would serve as both an educational and empowerment tool. In implementing the bill of rights, IDoA and other agencies should issue guidance on how to provide respectful, appropriate care to LGBTQ older adults and older adults living with HIV, including standards for maintaining privacy, ensuring safety, preventing

**As an LGBT community member, if you or your spouse/partner ever needed long-term care, such as in-home assistance, assisted living or nursing home care, how concerned would you be about the following?**

Percentage Very or Somewhat Concerned among LGBT Adults Age 45 and Older



Source: Maintaining Dignity: Insights on Concerns and Preferences of Mid-Life and Older LGBT Adults

harassment, allowing for individual gender expression, and providing LGBTQ affirming mental health services and other community resources. The bill of rights legislation should include explicit requirements for training and disseminating this information to providers as well as long-term care residents and their families.

### **Mandate Cultural Competency Training for State-Funded Providers**

LGBTQ clients (like all clients) need individualized care for successful aging, and providers must have the training needed to provide care that reflects the social, cultural, and legal needs of LGBTQ older adults. Without this competency, LGBTQ older adults may feel misunderstood or unwelcome and avoid assistance altogether.

Indeed, most LGBTQ older adults have lived through discrimination, social stigma, racism, and prejudice. For some, this fear and social stigma has disrupted their lives, their connections with family, their lifetime earnings, and their opportunities to save for retirement. It has also made many wary of health care professionals and service providers, leading LGBTQ older adults to be less likely than non-LGBTQ peers to access aging network services and providers, senior centers, and meal programs. Some may access services but choose to remain closeted while others resist accessing these services altogether, seeking help only for emergencies.

IDoA has recognized the need for training in LGBTQ cultural competency and held a mandatory webinar for IDoA staff and the aging network.<sup>120</sup> More than 25% of staff at provider agencies—and all IDoA staff—participated in this webinar, earning a SAGECare Bronze credential. As noted above, IDoA's draft State Plan on Aging will further incentivize training of all provider agencies, AAAs, other aging network providers, and IDoA staff.

To better meet the unique needs of LGBTQ older Illinoisans, aging network providers—including staff, subcontractors, subgrantees, and volunteers of state-funded aging services, long-term support services, home and community-based services, and housing services—should be required to receive a minimum level of training in LGBTQ cultural competency. Training should cover LGBTQ-specific terminology, disparities, the unique needs of LGBTQ older adults and caregivers, best practices, and issues such as privacy, health care needs, and familial status. Training requirements should extend to state-funded aging services, long-term support services, and housing services.



Mandatory training will ensure that IDoA-funded services are delivered in a professional manner by staff that feels both prepared and empowered to meet the needs of LGBTQ older adults. Illinois would not be alone in doing so. California and the District of Columbia require LGBTQ cultural competency training in the certification of long-term care institutions, and Massachusetts extends its requirements for LGBTQ cultural competency training to all state-funded or licensed aging providers.

### Fund Services That Support LGBTQ Older Adults

Given the disparities faced by LGBTQ older adults, Illinois should support programs and initiatives that address many of the root causes of inequality and help remedy discrimination based on sexual orientation, gender identity, race, and ethnicity. This includes addressing many social determinants of health for LGBTQ older Illinoisans by increasing access to affordable housing initiatives, affordable health care, economic and employment opportunities, programs for individuals living with HIV, and services for veterans.

In New York, for instance, the legislature funded the SAGEVets program to respond to the swelling need among LGBTQ veterans and to identify, support, and provide access to care for LGBTQ veterans statewide. This type of program remains critical in light of enactment of the federal Restoration of Honor Act of 2019, which restores the rights of LGBTQ veterans who were denied an honorable discharge because of their sexual orientation or gender identity, and the fact that there are an estimated 134,000 transgender veterans nationwide.<sup>121</sup>

### Inclusive Caregiving Benefits

States should fully recognize the needs and realities of the diversity of today's families, including LGBTQ individuals and caregivers, in caregiving protections, such as family or medical leave policies. Because of estrangement from biological family members, LGBTQ older adults may have unique caregiving arrangements and rely on a close friend, an ex-partner, or a younger relative as a primary caregiver. But these relationships often go unrecognized legally and socially, which makes it difficult for someone to be identified as a caregiver or perform tasks or access services on their loved one's behalf.

Illinois should recognize the contributions of caregivers, including LGBTQ caregivers, by authorizing a caregiver state tax credit. This tax credit should be available in a way that reflects the diversity of families—including, but not limited to, LGBTQ families—and defines a caregiver to include spouses, domestic partners, other biological relatives, and non-biological individuals that have a close association that is the equivalent of a family relationship. A broad view of family inclusion is also needed to protect those living at the intersections of marginalized identities: immigrants and people of color are more likely than white people to be living in households with extended family members.

Additional support is needed for elder housing, health care services, and employment support (such as workforce development and job readiness programs) for older LGBTQ Illinoisans. For instance, Illinois should promote the development of LGBTQ-affirming housing options and ensure that all senior living communities have the training, credentialing, and tools they need to support LGBTQ older adults. There is also a critical need to ensure that human services programs that are most relevant to the needs of older LGBTQ adults—including substance use, behavioral health, suicide

prevention, domestic violence, and emergency shelter—understand the unique needs of LGBTQ older adults, especially LGBTQ older adults of color and older transgender people.

### **Expand LGBTQ-Specific Programming and Targeted Outreach to LGBTQ Older Adults**

One way to combat social isolation and promote inclusion is to offer and publicize LGBTQ-specific programming (including virtual programming) for older adults and ensure that existing programming is LGBTQ-competent. Service providers can, for instance, partner with LGBTQ community organizations to offer the use of physical gathering spaces for LGBTQ clients. Providers can also ensure that regular programming (such as services from attorneys or financial advisors) is LGBTQ-competent (i.e., programming reflects inclusive language and knowledge about issues faced by LGBTQ families).

To assess opportunities for LGBTQ-inclusive programming, IDoA could survey its partners to assess the degree to which they currently offer LGBTQ-specific programming, whether they advertise programming directly to the LGBTQ community, the level of partnership and communication they have with local LGBTQ partners, and the barriers they face in conducting any of these activities. IDoA could then consider ways to support partners in offering this type of programming by issuing guidance on best practices, spotlighting successful partnerships, and regularly communicating about the importance of inclusive programming. Doing so would help ensure that aging network partners have the tools they need to identify and offer high-quality LGBTQ-specific programming—and partner with organizations that can.

IDoA can also help ensure that LGBTQ people, caregivers, community leaders, and partner organizations are aware of available programs and services. IDoA already prominently displays the SAGECare certification badge on its website and links to LGBTQ-specific resources such as the SAGE LGBT Elder Hotline and the National Resource Center on LGBT Aging. This type of prominent display is critical because of the long history of discrimination faced by LGBTQ older adults. Unless informed otherwise, many LGBTQ older adults may assume that programming and services are not LGBTQ-inclusive or welcoming. As a result, there is a significant need for culturally competent outreach (including digital outreach) that ensures that LGBTQ older adults are accessing the services they need and are entitled to, such as veterans services.

IDoA, partner agencies, and service providers should also conduct outreach on topics that disproportionately or uniquely impact LGBTQ older adults. For instance, state officials could develop a public outreach campaign that promotes advance planning and addresses the unique circumstances of LGBTQ people.

Other outreach efforts that would benefit from LGBTQ-specific messaging include public health issues (such as HIV prevention and substance use), elder abuse and neglect, and the needs of LGBTQ veterans.

## LGBTQ-Inclusive Data Collection

Many LGBTQ-specific disparities persist due in part to a lack of systemic LGBTQ-inclusive data collection that would help inform new policies and programs to address these disparities. LGBTQ older adults are often invisible in aging service demographics, program planning, needs assessments, and other types of agency- and provider-level data collection. From the federal to local levels, the identities of LGBTQ older adults are rarely included in research studies, needs assessments, service intake forms, or client notes. This lack of data collection across the spectrum of aging policy and programs exacerbates the unique challenges facing LGBTQ older adults.

The data gap means policymakers and providers lack the information they need to better understand and serve LGBTQ older adults and to target resources appropriately. Ongoing collection of demographic data is especially important to understanding racial inequities among older Illinoisans and the intersectionality of race and ethnicity with factors such as sexual orientation, gender identity, disability, and income. For instance, studies have noted a shortage of evidence on the impact of loneliness initiatives on LGBTQ older adults due to a lack of data collection and analysis to understand what approaches might work best.<sup>122</sup> Further, the broader research field is left with little data to study questions related to health and well-being among older LGBTQ populations.<sup>123</sup> In a 2020 report, the National Academies of Sciences, Engineering, and Medicine noted “a dearth of research on illness, caregiving, and end-of-life issues” among older LGBTQ populations, with further study needed to assess what types of social and economic support would improve outcomes for this community.<sup>124</sup>

For these reasons, data collection remains a critical priority to ensure that the needs of LGBTQ individuals are understood and met. By collecting, analyzing, and reporting data on the experiences of LGBTQ older adults, Illinois can better understand the needs of this community and use accurate data to enhance and improve services throughout the state.

Illinois passed new legislation in 2021 to try to address these data gaps and disparities. Under the new law, hospital systems and Illinois agencies (including IDoA) must begin collecting demographic data on the age, sex,



disability status, sexual orientation, gender identity, and primary or preferred language—in addition to other data that is already collected such as data on race and ethnicity—of the individuals they serve.<sup>125</sup> Doing so is critical to tracking disparities in health care access and outcomes, understanding the impact of the COVID-19 pandemic on LGBTQ and other communities, underscoring the need to fund programs and services that specifically target LGBTQ older Illinoisans, and helping track progress in advancing equity across state programs.

Even before the legislation, IDoA had taken important steps to enhance LGBTQ-inclusive data collection by incorporating demographic questions on sexual orientation and gender identity in referral and intake processes.<sup>126</sup> Thus, when an individual calls the IDoA Senior HelpLine and completes the referral and intake process for services under the Community Care Program, they are asked optional demographic questions about sexual orientation and gender identity. Data collected through these programs assists service providers in developing person-centered care plans.

### **LGBTQ-Inclusive Data Collection As Standard Practice Across Agencies**

The inclusion of questions on sexual orientation and gender identity on referral and intake forms is a critical step towards addressing a lack of LGBTQ data in Illinois. However, much more can be done on a government-wide basis to ensure that the collection of voluntary and confidential data on sexual orientation, gender identity, gender expression, and relationship status (“LGBTQ-inclusive data”) is treated as a standard practice by all agencies and included in tools designed specifically for older Illinoisans (such as individual assessments, program monitoring data systems, participant satisfaction surveys, and program evaluation). As examples of this data gap, LGBTQ older adults are mentioned only once (in the context of suicide prevention) in each of the IDoA’s annual Serving Minority Seniors reports from fiscal years 2016 to 2019. And the Illinois Department of Public Health previously released data on how HIV affects members of the LGBTQ community, but these resources are not current and reflect outdated data.<sup>127</sup>

Consistent with the 2021 legislation noted above, it is time to expand on Illinois’ current data collection efforts to collect additional data and publicly report on that data and the needs of LGBTQ older adults. LGBTQ-inclusive questions should be asked routinely on every form where other demographics, such as age and race, are asked. Doing so would also be consistent with the 2020 reauthorization of the Older Americans Act, which requires state units on aging and AAAs to collect data on services needed by older populations, including LGBTQ older adults, and whether they are meeting those needs.

It is not enough to simply collect data on LGBTQ older adults. Even if data is being collected, the failure to report out or use this data means that LGBTQ older adults remain an invisible population. When LGBTQ-inclusive data is collected, aggregated, and reported, it can yield powerful, data-driven insights about the profound disparities facing LGBTQ older adults. In turn, it helps government officials and the public understand the importance of funding programs and services that support LGBTQ clients.

“The goal was to learn if LGBT people are satisfied with case management, if their families, however defined, receive caregiver support, and if they need help in the morning getting out of bed. That’s all. The agenda is that simple. LGBT older people exist. They have needs.”

*Fmr. U.S. Asst. Secretary for Aging Kathy Greenlee on the importance of LGBT-inclusive data collection under the Older Americans Act*

With its new legislation, Illinois is following in the footsteps of other states that already expanded their efforts to collect LGBTQ-inclusive data. California, for instance, enacted the LGBT Disparities Reduction Act in 2015 to require its Department of Aging, alongside

other state agencies, to collect voluntary self-identification information pertaining to sexual orientation and gender identity in the course of collecting other demographic data.<sup>128</sup> This data is to be used for demographic analysis, coordination of care, quality improvement, approved research, reporting requirements, and policy or funding decisions. Beyond collecting this demographic data, the Department of Aging must publicly report the data collected except where doing so would reveal personal identifying information or result in statistical unreliability.

In implementing new data collection requirements, Illinois should develop a strategic plan and timeline for expanding LGBTQ-inclusive data collection, including to all IDoA data systems, intake forms, survey instruments, and needs assessments. This should be accompanied by a publicly available report or fact sheet to memorialize IDoA’s efforts, in particular, to improve LGBTQ-inclusive data collection. A public-facing resource is critical to highlighting the importance of LGBTQ-inclusive data collection, promoting best practices and coordination across agencies, and ensuring accountability for future data collection efforts.

As part of these implementation efforts and strategic plan, Illinois should:

- **Ensure that state forms collect LGBTQ-inclusive data and add questions to forms or in databases as needed.** Questions should be integrated into the general demographics section on all forms, rather than in a separate section for sexual orientation and gender identity (which may reinforce feelings of stigma and discrimination in LGBTQ older adults). Forms should also be gender-neutral using words such as “partner,” “spouse,” “primary caregiver,” “domestic partner,” and “parent.”

- **Develop appropriate guidance for state employees and third-party entities on LGBTQ-inclusive data collection.** Guidance should address the collection, analysis, and reporting of voluntary demographic questions on LGBTQ-inclusive data collection, how data may be used, best practices for asking LGBTQ-inclusive questions, ways to ensure a welcoming and inclusive environment, and privacy and confidentiality policies.
- **Ensure that relevant personnel are trained in how to communicate about LGBTQ-inclusive data collection in an effective way.** Training also helps staff members be comfortable with asking questions about sexual orientation and gender identity. Cultural competency trainings should be a mandatory component of staff training and should be conducted in partnership with state and local organizations that serve LGBTQ Illinoisans.
- **Prohibit the reporting of demographic data that would permit the identification of individuals or result in statistical unreliability.** Due to the sensitive nature of data relating to sexual orientation and gender identity and the need to protect the safety and privacy of those who would voluntarily provide this information, demographic reports that include information on sexual orientation and gender identity should be aggregated at the state, county, city, census tract, or zip code level to facilitate comparisons and identify disparities but should prevent the identification of individuals.
- **Identify reports where LGBTQ-inclusive data collection will be reflected and issue LGBTQ-specific reports, fact sheets, and other materials using that data.** All agencies, including IDoA, should include data on LGBTQ older adults alongside any reporting of other demographic information, such as age and race. State agencies would also be able to develop LGBTQ-specific reports, such as annual assessments of service delivery for LGBTQ older adults for Pride month in June and transgender older adults for Transgender Awareness Month in November.

Even as agencies work to increase LGBTQ-inclusive data collection, state leaders should utilize community-generated data to inform policymaking and resource allocation. This includes surveys and community-based needs assessments, such as the Chicago LGBTQ Community Needs Assessment which was most recently issued in 2019, and forthcoming data by partners such as the Center for Applied Transgender Studies.<sup>129</sup> This data can help inform the allocation of resources and the design and implementation of programs to meet LGBTQ health and human service needs and address disparities that most impact LGBTQ communities. This is true even if the data is not fully representative of the entire LGBTQ older population.

### **Conduct Regular LGBTQ-Specific Statewide Needs Assessments**

As a complement to expanded data collection, IDoA should conduct regular assessments of the needs of 50-plus LGBTQ Illinoisans. This could be done through surveys, focus groups, key informant interviews, and other tools that solicit feedback from LGBTQ older adults, LGBTQ community leaders, and service providers. Given a dearth of data on LGBTQ older adults, needs assessments are an important tool to assess the social, economic, housing, public health, and long-term support service needs of LGBTQ older adults and caregivers. IDoA should also ensure that LGBTQ older adults are fully included in broader (non-LGBTQ-specific) needs assessments. This can be done through outreach to, and partnership with, LGBTQ older adults, LGBTQ community leaders, and service providers.

## **Conclusion**

LGBTQ older adults face widespread and persistent disparities in the areas of health, economic security, and caregiving and social connections. With its growing LGBTQ population age 50 and older, Illinois faces a significant challenge to address and reduce these disparities in the years ahead. This report makes several recommendations that state policymakers can adopt and that have the potential to improve the lives of Illinois's older LGBTQ communities. We welcome and encourage policymakers, elected officials, and community leaders to adopt and implement the changes necessary to address the disparities faced by 50-plus LGBTQ Illinoisans.



## End Notes

- <sup>1</sup> Movement Advancement Project & SAGE, [Understanding Issues Facing LGBT Older Adults](#) (2017).
- <sup>2</sup> SAGE, [The Facts on LGBT Aging](#) (2018); Movement Advancement Project et al., [Improving the Lives of LGBT Older Adults](#) (2010).
- <sup>3</sup> SAGE, supra note 2.
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