

DISRUPTING DISPARITIES

SOLUTIONS FOR LGBTQ NEW YORKERS AGE 50+







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INTRODUCTION

New York State ranks among the top 10 states in terms of the percentage of its population that is lesbian, gay, bisexual, and/or transgender (LGBTQ). Of the estimated 800,000 LGBTQ adults in New York State, nearly one-third (28%) are over the age of 50. These older LGBTQ New Yorkers contribute to the diversity of New York State. LGBTQ older people live in urban and rural communities across the state, are part of every racial and ethnic group, are veterans, are immigrants, and are living with disabilities. And the population of LGBTQ older New Yorkers is only expected to grow as the population ages: by 2030, 1 in 5 New Yorkers are expected to be over age 60.

Although a key part of New York State's rapidly growing elder population, LGBTQ older people remain largely invisible. Many are isolated and disconnected from services in part because LGBTQ older people are far more likely to live alone than non-LGBTQ individuals and far less likely to rely on adult children or other family members for informal caregiving. AARP Foundation-supported research found that half of LGBTQ adults age 45 and older are lonely, and intersecting identities only exacerbate the prevalence of loneliness. According to the AARP's *Maintaining Dignity* study, three out of four LGBTQ people age 45 and older were concerned about having enough support from family and friends as they age. Thin support networks mean that LGBTQ older people are more likely to rely on community service providers as they age, even though many are distrustful of providers due to the fact that LGBTQ older people face discrimination when accessing health and social services.

Fear of discrimination can lead LGBTQ older people to delay seeking needed care and can lead to premature institutionalization in nursing homes and long-term care facilities due to fear of hostile in-home care providers. The *Maintaining Dignity* study found that 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%). LGBTQ older people also experience significant health disparities that include reduced access to health care, mental health concerns, and chronic physical conditions. Many of these concerns are compounded for LGBTQ older people of color who face even greater disparities and those living with HIV who face additional stigma and privacy concerns. Disparities for LGBTQ older people of color have long existed but have been laid bare at a time of renewed focus on systemic racism in response to the murders of George Floyd, Breonna Taylor, Ahmaud Arbery, Tony McDade, and countless others.

Given the unique challenges faced by LGBTQ older people, AARP commissioned this report to 1) identify the disparities faced by New York State's 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 New York's 50-plus population.

"The New York State Office for the Aging is committed to fostering the inclusion of LGBTQ older adults in person-centered programs and services that help older adults maintain their independence in the community."

Acting Director Greg Olsen

New York State Office for the Aging

The report includes a series of policy recommendations on the need for a comprehensive strategy, including a coordinated interagency response, to support LGBTQ older people; equal access to inclusive programs and services; and comprehensive, LGBTQ-inclusive data collection. Many of these recommendations are even more important in light of the COVID-19 pandemic and its effect on older people in New York, including LGBTQ people and especially LGBTQ people of color. By closing the serious gaps identified in the report, LGBTQ older people will have more choices as to how and where they live as they age.

PARTNER REMARKS

SAGE

As the world's largest and oldest organization dedicated to improving the lives of LGBTQ older people, SAGE is proud to stand with AARP in improving the lives of older LGBTQ New Yorkers and their families. New York is our home, and those we serve confront the challenges outlined in this report each and every day. This report could not have come at a more important time, as COVID-19 exacerbates 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 people for more than four decades and currently operates a network of 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 people each year, offering health and wellness programming, lifelong learning opportunities, case management support, and congregate meals, among other programs. SAGE partnered with leading developers to create New York City's first LGBTQ-welcoming elder housing developments: Stonewall House in Brooklyn and Crotona Pride House in The Bronx; the first building to open, Stonewall House, is the largest LGBTQ-friendly elder housing development in the country.

AARP FOUNDATION

AARP Foundation works to end senior poverty by helping vulnerable older adults build economic opportunity and social connectedness. Bolstered by vigorous legal advocacy, we spark bold, innovative solutions that foster resilience, strengthen communities and restore hope. Our approach seeks to diminish systemic barriers, disparities and other biases in programs and policies that disproportionately affect low-income older adults and perpetuate conditions of poverty and economic instability.

Equality for LGBTQ older adults across the nation is of paramount importance for AARP Foundation. Among our efforts, AARP Foundation's litigation team has fought LGBTQ discrimination to increase access to housing and health care and we support the Long-Term Care Equality Index developed by SAGE and the Human Rights Campaign Foundation. Inclusive of our nationwide approach, we know change also occurs on a local and state level. As a partner in *Disrupting Disparities: Solutions for LGBTQ New Yorkers Age 50+*, we hope the policy successes that will be achieved in New York for LGBTQ older adults can be used as best practices in other states.



EXECUTIVE SUMMARY

AARP's purpose is to empower people to choose how to live as they age. Through a societal movement called Disrupt Aging, AARP and AARP Foundation encourages all to challenge outdated beliefs and spark new solutions to facilitate people's choices. As the country's largest and oldest organization dedicated to improving the lives of LGBTQ older people, SAGE is proud to stand with AARP in improving the lives of older LGBTQ New Yorkers and their families. New York is our home, and those we serve confront the challenges outlined in this report each and every day.

This report could not have come at a more important time, as COVID-19 exacerbates disparities that long predated the current public health and economic crisis. Key disparities among 50-plus LGBTQ New Yorkers create inequalities that can limit or even impede their choices. Many of these disparities are rooted in discrimination against LGBTQ people, 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.

This history has made it challenging for many in New York State's LGBTQ community to acquire a well-paying job with benefits like a retirement savings plan, leading to lower Social Security and retirement income in older age. LGBTQ older people are also twice as likely to be single, four times less likely to have children, and far more likely to have faced discrimination and stigma across their lifespan. While older LGBTQ people are resilient, these and other unique challenges have severe negative health, economic, and social implications that must be addressed.

Disparities are often compounded and thus even greater for the estimated 1 in 5 LGBTQ older people of color. Prior analysis from AARP shows that older New Yorkers of color face significant disparities in health, economic security, and livable communities. For instance, only one out of five homeowners in New York State is a person of color (even though people of color comprise one-third of New York's overall population), and 50-plus African American/Black, Asian American and Pacific Islander, and Hispanic/Latino people are twice as likely to be paying over half their income on housing. Inexcusably, 50-plus New Yorkers of color have less access to safe, affordable housing and mobility options compared to white New Yorkers. These and other disparities were documented in [Disrupting Racial and Ethnic Disparities: Solutions for New Yorkers Age 50+ in 2018](#), [Racial and Ethnic Disparities in Rent-Regulated Housing for 50-Plus New Yorkers in 2019](#), and [Disrupting Racial and Ethnic Disparities 2.0 in 2020](#). The recommendations made in these reports are equally critical for 50-plus LGBTQ New Yorkers, many of whom are older people of color.

To illustrate the scope of the disparities, this report highlights existing data and other key indicators about the experiences of LGBTQ older New Yorkers, as well as the concrete policy recommendations that our leaders can take—starting immediately—to remedy the disadvantages faced by 50-plus LGBTQ New Yorkers and their families. The recommendations made here complement those included in AARP's series of *Disrupting Racial and Ethnic Disparities* reports on improving the lives of older New Yorkers of color.



"As a Black lesbian, it's always been a struggle to deal with the misogyny, racism, and homophobia that is embedded in our world. I never thought they would affect my finances. Back then, I only thought about budgeting in terms of making sure I had what I needed to succeed in the moment, not necessarily in the long run."

— Donna Sue Johnson

Donna Sue uses she/her pronouns

WHAT THE DATA SAYS: DISPARITIES FACED BY 50-PLUS LGBTQ NEW YORKERS

Although comprehensive data is unavailable, nearly one-third of New York State's LGBTQ population is estimated to be over age 50. Many LGBTQ older people face unique challenges as they age, leading to widespread disparities in health, economic security, caregiving, and social connections. These disparities are often particularly pronounced for LGBTQ older people of color and transgender older people.

Health and Well-Being. LGBTQ older people 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 people have received inferior care or been denied care altogether. These disparities are exacerbated for LGBTQ older people 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.

LGBTQ older people experience a range of disparities relative to non-LGBTQ older people, including increased rates of disability, poor physical and mental health, alcohol and tobacco use, and HIV. LGBTQ New Yorkers over age 50 report frequent mental distress (17%), probable depression (13%), and frequent poor physical health (14%). And transgender New Yorkers of all ages are nearly 50% more likely to report being in fair or poor health when compared to non-transgender respondents, even when controlling for age and education. In 2017, more than half of people living with HIV in New York State were age 50 and older. Many of these disparities put LGBTQ older people at an increased risk of experiencing COVID-19 more acutely.

LGBTQ older New Yorkers need improved access to culturally and clinically competent health care and relief from high health care costs. LGBTQ New Yorkers of all ages cite a lack of personal financial resources (37%) and inadequate insurance coverage (23%) as the most significant structural barriers to health care. While only 7% of LGBTQ New Yorkers reported being uninsured in 2015, about 22% were unable to see a health care provider because of cost. High costs are especially a barrier for accessing medications, such as pre-exposure prophylaxis (PrEP), a daily medication used to prevent HIV.

Economic Security. Older LGBTQ people have fewer financial resources and are more likely to be low-income relative to non-LGBTQ older people. Nearly one-third of LGBTQ older people 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 people of color, those aged 80 and older, bisexual older people, and transgender older people. These trends are consistent with known data in New York State: for instance, 35% of SAGE's New York City clients are Medicaid-eligible, with annual pre-tax incomes below \$10,000, while an additional 35% subsist on annual pre-tax incomes of \$20,000 or less.



"I always wanted to be in a gay-friendly environment without discrimination, and the glares and looks you can get from people. Stonewall House is a great community and area. I have been an advocate for the LGBTQ community even back when we were illegal, so it's great to finally live somewhere I can be myself. I can smile more and be happy, be safe, and to meet new friends."

– Diedra Nottingham

Diedra uses she/her pronouns

Economic instability is due in large part to a lifetime of employment discrimination that LGBTQ older people have faced, resulting in lower earning power and lower payments or income from Social Security, retirement, or pensions. Further, LGBTQ older people 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 people report being concerned about having to work well beyond retirement age (compared to 26% of non-LGBTQ people).

Housing options are also limited for LGBTQ older people 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 people and 54% of transgender and gender nonconforming older people—fear having to re-closet themselves when seeking elder housing. This may be why 90% of LGBTQ older people 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 attempts to roll back federal Fair Housing Act protections, implement religious exemptions, and eliminate explicit federal housing and homeless shelter protections for transgender people.

Caregiving and Social Connections. Older LGBTQ people are often isolated, disconnected from services, and have thin support networks. This is because LGBTQ older people are far more likely to live alone than non-LGBTQ individuals and far less likely to rely on adult children or other family members 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.

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 people. This is especially true for LGBTQ older people 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 people have built are strong and resilient, thinner support networks mean that many LGBTQ older people rely on other LGBTQ people, such as friends and family of choice, as caregivers. LGBTQ older people become caregivers more often than non-LGBTQ counterparts. An estimated 21% of LGBTQ older people 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.



"Life was really hard, I was homeless from the age of 13 up until my 50s – back then, you're doing everything you can to survive on the streets. Today my life is a lot different. SAGE has been a lifesaver for me. When I became homeless again, I got ahold of them and they got me a case manager and she helped me get doctors because I was sick, look for housing, and she calls me to check up on me, make sure I'm alright. Walking in those doors and not having to worry about someone putting me down was a completely different experience for me. I could be myself."

– Jay Toole

Jay uses she/her and he/him pronouns

Thinner support networks, in turn, make LGBTQ older people more reliant on community service providers. Yet, many LGBTQ people experience or fear mistreatment from service providers and in long-term care facilities. This makes LGBTQ older people understandably concerned about discrimination from the staff of traditional senior centers, long-term care and social services, and by their peers. More than eight in 10 LGBTQ older people 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 PEOPLE

The disparities faced by LGBTQ older people, especially LGBTQ older people of color and transgender people, require New York State policymakers to adopt a comprehensive strategy that helps LGBTQ 50-plus people thrive. Policymakers should:

- Formally designate LGBTQ older people and older people living with HIV as groups of "greatest social need" under the federal Older Americans Act, the nation's primary vehicle for the organization and delivery of social and nutrition programs.
- Establish a standing State 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 New Yorkers, with an emphasis on addressing the needs of the most marginalized community members.
- Include 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 people.
- Create a task force to review how New York State currently defines family in its laws and policies and ensure that those definitions are fully inclusive of families of choice.
- Host a series of convenings to bring awareness to the unique challenges faced by LGBTQ older people, enhance information sharing, and promote community engagement.
- Require or encourage area agency advisory councils and/or long-term care councils to include racially diverse LGBTQ people.
- Seek input from, and partner with, LGBTQ organizations to inform state and area planning processes.

EQUAL ACCESS TO INCLUSIVE PROGRAMS AND SERVICES

Older LGBTQ New Yorkers should have access to the affirming supports and services they need to age successfully. To make these supports and services a reality, policymakers should:

- **Protect LGBTQ older people from discrimination by:**
 - Implementing and enforcing comprehensive nondiscrimination protections in employment, housing, public accommodations, health care and health insurance, and credit and lending.

- Updating the New York State Office for the Aging's (NYSOFA's) equal access guidance to explicitly prohibit discrimination based on gender identity or expression, provide more detailed guidance on transgender nondiscrimination and the respectful treatment of transgender New Yorkers, and ensure that contract language in provider agreements is updated to reflect these modernized requirements.
- Creating a State LGBTQ ombudsperson to advocate for LGBTQ older people who experience barriers to accessing and utilizing services.
- Adopting a comprehensive State caregiving law with an inclusive definition of caregiver that includes spouses, domestic partners, biological relatives, and non-biological individuals with the equivalent of a family relationship.
- Authorizing a state tax credit to support caregivers, including LGBTQ caregivers, and to recognize their significant contributions that reduce the demand for state-funded services.
- **Adopt an LGBTQ long-term care residents' bill of rights.** New York State should update its Elder Law to include a comprehensive long-term care bill of rights for LGBTQ older people and issue guidance to long-term care facilities and other social service providers on how to provide respectful, appropriate care to LGBTQ older people.
- **Establish an independent Long-Term Care Task Force.** In light of the impact of COVID-19 on long-term care residents, New York State should establish an independent task force dedicated to examining the state of long-term care, both home- and facility-based, and the broader long-term care system.
- **Mandate LGBTQ cultural competency training for state-funded providers.** New York State 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.
- **Promote access to affordable health care.** New York State should take a range of actions to improve access to affordable health insurance and health care by requiring cultural and clinical competency training for health care providers, and adopting comprehensive nondiscrimination standards for hospitals and outpatient health care facilities, and promoting affordable prescription drugs, among other recommendations.
- **Promote access to affordable prescription drugs.** New York State should create a safe, wholesale importation program to provide access to less costly drugs; create a systematic mechanism to trigger judicial review of predatory practices in medication price-fixing and establish penalties for prescription drug price gouging; and prohibit "pay for delay" agreements in which brand-name drug companies pay generic manufacturers to delay introduction of less costly alternative drugs.

- **Promote affordable and affirming housing for LGBTQ older people.**

New York State should take a range of actions to make housing affordable and prevent displacement, including the development of LGBTQ-affirming housing options and innovative LGBTQ elder housing models, such as the Stonewall House in Brooklyn and the Crotona Senior Residences in the Bronx.

- **Fund services that address the root causes of LGBTQ disparities and social determinants of health.** New York State 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 expanded access to services for veterans. New York State should also ensure that existing programs reflect, and are inclusive of, the unique needs of LGBTQ older people.

- **Expand LGBTQ programming and targeted outreach to LGBTQ older people.** NYSOFA and its partners should expand LGBTQ-specific programming, including virtual programming, and ensure that existing programming is LGBTQ-competent; survey NYSOFA partners to assess current LGBTQ programming, partnership, and outreach; conduct targeted outreach (including digital outreach) so LGBTQ clients, caregivers, community leaders, and partners are aware of available programs and services; and require NY Connects and other state-funded information and referral services to include comprehensive and up-to-date data on LGBTQ-inclusive aging services and elder housing.

LGBTQ-INCLUSIVE DATA COLLECTION

The needs of older LGBTQ New Yorkers will remain invisible until New York State 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 New Yorkers and the intersectionality of race and ethnicity with other factors, such as sexual orientation, gender identity, disability, and income, among other factors. Policymakers should:

- Incorporate voluntary questions about sexual orientation, gender identity, gender expression, and relationship status on every form where other demographic information, such as age and race, is asked.
- Ensure that COVID-19 surveillance efforts and patient records capture sexual orientation and gender identity as part of routine demographic information.
- Aggregate and report on existing LGBTQ-inclusive data to help policymakers understand the disparities facing LGBTQ older people and then use this data to design targeted programs and services that meet these needs.
- Issue a publicly available strategic plan and timeline to expand LGBTQ-inclusive data collection to all New York State data systems, intake forms, survey instruments, and needs assessments.
- Conduct regular assessments of the needs of older LGBTQ New Yorkers (through surveys, focus groups, informant interviews, and other tools) and ensure that LGBTQ older people are represented in broader community needs assessments.

- Utilize community-generated data (such as survey data and community-based needs assessments) to inform policymaking and resource allocation while increasing agencywide 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 New Yorkers. Visit aarp.org/NYDisruptDisparities, which hosts the latest research findings, policy updates and information related to this effort. You can also contribute your ideas and insights by emailing NYAARP@aarp.org.



What The Data Says: Disparities Faced by LGBTQ New Yorkers Over the Age of 50

The nearly three million LGBTQ people over age 50 in the United States face widespread disparities in areas that include health care, economic security, and caregiving and social connections.¹ These disparities are driven by a multitude of interacting factors, including the cumulative effect of stigma and living with discriminatory laws and policies for much of their lives.

LGBTQ older people face unique challenges as they age. LGBTQ older people 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.² These factors, in turn, make LGBTQ older people more likely to face poverty and homelessness and to have poor health.³ Disparities are often even worse

for LGBTQ older people of color and older transgender people. African American and Hispanic older LGBTQ people report lower levels of household income, educational attainment, identity affirmation, and social support.⁴

Many of these nationally observed disparities appear to exist in New York State as well. The estimated 800,000 LGBTQ adults in New York State are more likely than non-LGBTQ New Yorkers to be low-income and food insecure.⁵ LGBTQ New Yorkers, and especially transgender New Yorkers, continue to face significant challenges in access to health care, affordable housing, and public benefits.⁶ Even in areas of the state with sizeable LGBTQ populations

(such as the New York City metro area), LGBTQ New Yorkers of all ages continue to face unequal treatment in employment, homelessness, and a range of additional economic and health care-related challenges.⁷ And prior reports have documented widespread disparities that persist among 50-plus New Yorkers of color in the areas of health, economic security, and livability.⁸ These disparities limit opportunity, perpetuate inequality, and lead to negative health, economic, and social implications.

These disparities are likely exacerbated for 50-plus LGBTQ New Yorkers who comprise nearly one-third (28%) of New York State's LGBTQ population. This section of the report summarizes available data on key indicators and the disparities faced by LGBTQ older people, both nationally and in New York State, in the areas of health, economic security, and caregiving and social connections. The data presented is limited to older people who identify as LGBTQ and thus does not capture the millions more who may experience same-sex sexual behavior or attraction but do not identify as LGBTQ perhaps due to stigma.

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

New York

- **28%** of New York State's LGBTQ population are 50 and older
- In New York City, **3%** of older people are LGB and **1%** are transgender

Source: Movement Advancement Project and SAGE, [Understanding Issues Facing LGBTQ Older Adults](#) (2017). [Williams Institute, LGBTQ Demographic Data](#) Interactive: New York, (2019). New York City Department of Health and Mental Hygiene, [Health of Older Adults in New York City](#) (2019).

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 New York State, rather than LGBTQ older people, because specific data on the needs of LGBTQ older people is not available. As outlined elsewhere in this report, efforts to advance LGBTQ-inclusive data collection should be a priority for New York State policymakers.

HEALTH AND WELL-BEING

LGBTQ older people 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 people 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 people have received inferior care or been denied care altogether. This section summarizes some of the health disparities and challenges faced by LGBTQ older people.

LGBTQ Older People Face Mental and Physical Health Disparities. LGBTQ older people experience a range of disparities relative to non-LGBTQ older people, including increased rates of disability, poor physical and mental health, alcohol and tobacco use, and HIV.⁹ About 14% of LGBTQ New Yorkers over age 50 report frequent poor physical health.¹⁰ And transgender New Yorkers of all ages were nearly 50% more likely to report being in fair or poor health when compared to non-transgender respondents, even when controlling for age and education.¹¹ 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 people relative to non-LGBTQ older people.¹² Survey data from New York State confirms similar disparities: about 17% of LGBTQ New Yorkers over age 50 report frequent mental distress, 13% report probable depression, and 14% report frequent poor physical health.¹³
- **Chronic Disease.** Older LGBTQ people have a significantly higher likelihood of a range of chronic health conditions and face disparities regarding high blood pressure, cholesterol, diabetes, and heart disease.¹⁴ Disparities exist within the LGBTQ community. For instance, lesbian and bisexual older women are more likely than straight older women to report strokes, heart attacks, arthritis, or multiple chronic conditions.¹⁵ Gay and bisexual older men are more likely to report heart disease and cancer compared to straight men.¹⁶ LGBTQ American Indians, Alaska Natives, and other Native peoples in New York raise concerns about health disparities that include mental health substance use, diabetes, heart disease, and cancer.¹⁷ 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.¹⁸

- **HIV/AIDS.** An increasing number of people over the age of 50 are living with HIV, including many gay and bisexual men.¹⁹ In 2017, more than half of people living with HIV in New York State were age 50 and older.²⁰ Older people of color are disproportionately affected: nationwide, African American older people and Hispanic older people comprised 41% and 19% of new HIV diagnoses among people age 50 and over, respectively.²¹ Among respondents to the U.S. Trans Survey, 3.3% of those ages 45 to 64 reported living with HIV (compared to 1.4% of all respondents and 0.3% of the population as a whole).²² Older LGBTQ people 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.²³
- **Tobacco and Substance Use.** Elevated risks of smoking and excessive drinking are a major concern among LGBTQ older people, in part because intervention strategies are often only targeted to young people.²⁴ LGBTQ people smoke cigarettes at rates 68% higher than the general population.²⁵ LGB older people are significantly more likely to consume excessive alcohol than straight older people.²⁶ An estimated 10% of LGBTQ older people reported excessive drinking and 12% used drugs that were not prescribed.²⁷
- **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.²⁸ 41% of LGBTQ older people report

having a disability, compared to 35% of non-LGBTQ older people.²⁹ Certain populations within the LGBTQ older adult community—including older lesbian and bisexual women and older transgender people—have higher rates of disability.³⁰

- **Wellness.** Self-care is frequently more difficult for LGBTQ older people 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.³¹

LGBTQ Older People Face Challenges in Accessing Affirming Health Care. LGBTQ older people 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 LGB 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

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.

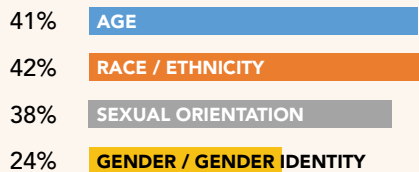
Source: Movement Advancement Project, SAGE, and Center for American Progress, [LGBTQ Older People & COVID-19](#) (2020).

number was 21%.³² Far too little has changed since then: a 2015 survey found that 9% of all LGBTQ New Yorkers reported being refused health care services for being LGBTQ, with LGBTQ New Yorkers of color much more likely to cite these health care refusals as a barrier to care.³³

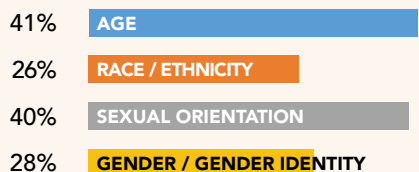
As you get older, how concerned are you that the quality of care you receive by healthcare professionals and staff will be adversely impacted based on your ...

% Very or Somewhat Concerned

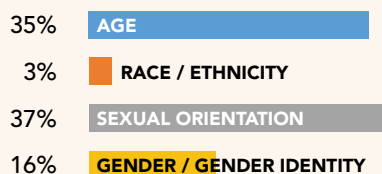
BLACK / AA



LATINO



WHITE



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

The Health Care Closet. Given past experiences of discrimination, many LGBTQ older people 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.³⁴

LGBTQ older people of color are even less likely to disclose their LGBTQ status.³⁵ Many elders of color are 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.³⁶ The potential for discrimination across a range of factors means LGBTQ older people of color feel uniquely vulnerable in the health care system.

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. Nearly one-third of LGBTQ New Yorkers of all ages report that there are too few health professionals trained in LGBTQ issues; this was an even greater barrier to care for transgender and gender nonconforming New Yorkers where more than half (56%) cited the lack

of LGBTQ-trained providers as a significant barrier to health care.³⁷ This places unique burdens on transgender people, about 24% of whom report having to teach their medical providers about transgender health care needs.³⁸

In 2015, about 23% of LGBTQ New Yorkers of all ages had no primary health care provider.³⁹ 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.⁴⁰

Insurance Improvements But High Health Care Costs. High uninsured rates and discriminatory coverage policies have historically exacerbated health dis-

parities for LGBTQ older people. 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,⁴¹ but gaps remain, particularly around high health care costs.

- In a 2015 survey, LGBTQ New Yorkers of all ages cited a lack of personal financial resources (37%) and inadequate insurance coverage (23%) as the most significant structural barriers to health care.⁴² While only 7% of LGBTQ New Yorkers were uninsured, about 22% reported being unable to see a health care provider because of cost.⁴³
- Transgender New Yorkers face even greater barriers to comprehensive insurance coverage and affordable health care. Relative to cisgender people, transgender survey respondents of all ages were three times more likely to report inadequate insurance and more than twice as likely to report that a lack of personal financial resources were barriers to accessing health care.⁴⁴ A separate survey found that about one-quarter (26%) of transgender New Yorkers had an insurance problem related to their transgender status and 28% did not see a doctor because they could not afford it.⁴⁵
- High costs are especially a barrier for accessing medications. African American, Hispanic, and Native American LGBTQ older people are more likely to face economic barriers when trying to access needed medications relative to white LGBTQ older people.⁴⁶ High costs and a lack of insurance coverage were two of the most commonly cited barriers to PrEP use for LGBTQ New Yorkers of all ages.⁴⁷

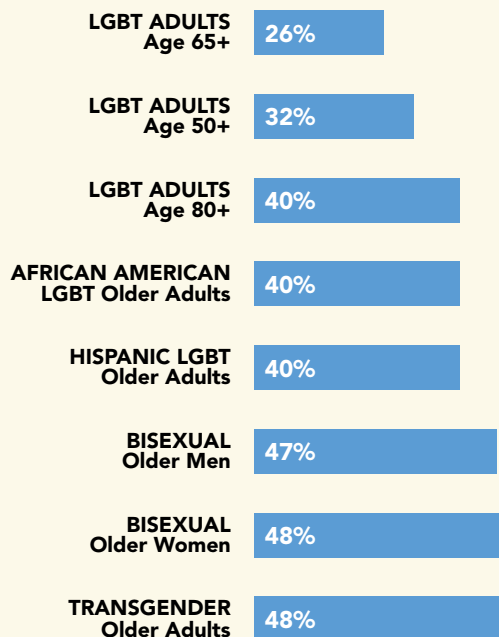
ECONOMIC SECURITY

Older LGBTQ people have fewer financial resources and are more likely to be low-income relative to non-LGBTQ older people. Several variables—including gender, generation, race and ethnicity, and marital status—can make financial decisions especially challenging for LGBTQ older people. Ongoing legal discrimination, compounded by a lifetime of challenges, make it harder for LGBTQ older people to be financially secure. This section summarizes some of the current data on the challenges faced by LGBTQ older people that lead to economic insecurity and higher rates of poverty.

One-Third of LGBTQ Older People Are Very Low-Income. Nearly one-third of LGBTQ older people age 65 and older (32%) live at or below 200% of the federal poverty level, compared to a quarter of non-LGBTQ older people.⁴⁸ Poverty rates are even higher for those aged 80 and older, bisexual older people, transgender older people, and LGBTQ older people of color.⁴⁹ Poverty rates are higher because of the cumulative impact of discrimination against LGBTQ older people over the course of their lifespan and because LGBTQ older people 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.⁵⁰

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

These trends are consistent with known data in New York State. For instance, 35% of SAGE's New York City clients are Medicaid-eligible, with annual pre-tax incomes below \$10,000.⁵¹ An additional 35% subsist on annual pre-tax incomes of \$20,000 or less.⁵² A 2015 survey showed that about 36% of LGBTQ New Yorkers of all ages lived at or below 200% of the federal poverty line, with LGBTQ New Yorkers of color and transgender New Yorkers more likely to be living in poverty.⁵³

LGBTQ Older People Have Faced Significant Employment Discrimination, Leading to Lower Earning Power. Many LGBTQ older people have faced a lifetime of employment discrimination, which contributes to lower earning power. For instance, LGBTQ older people report not being hired (27%), not being promoted (26%), or being fired (18%) because of their sexual orientation or gender identity.⁵⁴ Job discrimination is even greater for transgender older people: 51% of transgender women reported not being hired for a job because of their perceived identity.⁵⁵ Data also suggests that LGBTQ people, people of color, women, and groups living at the intersections of those identities

are disproportionately affected by unemployment during—and long after—economic downturns such as the COVID-19 crisis.⁵⁶

Discrimination in employment remains a reality for many LGBTQ New Yorkers, with significant implications for future generations of LGBTQ older people. About 12% of LGBTQ New Yorkers of all ages were not employed in 2015.⁵⁷ Transgender New Yorkers were twice as likely as non-transgender survey respondents to be unemployed, regardless of whether they had completed college.⁵⁸ Among respondents to the U.S. Trans Survey, 18% of transgender New Yorkers reported being unemployed in 2015.⁵⁹

Even in New York City, 21% of LGBTQ residents reported being denied a promotion, not hired, or fired or forced to resign from a job because of their sexual orientation or gender identity, with 42% of transgender or gender nonconforming people reporting such an experience.⁶⁰ Continued employment discrimination against LGBTQ people will further disparities for future generations of older LGBTQ people.

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 eight in 10 (83%) of LGBTQ older people report relying most on Social Security to fund their retirement years, with a majority concerned that cuts to Social Security would impact their future financial security.⁶¹ LGBTQ older people 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.⁶²

Given these barriers, it is unsurprising that 44% of LGBTQ older people 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.⁶³ This may be particularly true for LGBTQ older people living with HIV who may not have expected to live into retirement but now are living well past retirement age due to anti-retroviral therapy and finding themselves with inadequate savings.

Housing for LGBTQ Older Adults in NYC

The Stonewall Community Development Corporation commissioned a survey to better understand the housing experiences, needs, and preferences of LGBTQ older adults in New York City. Key findings include:

- 23% of respondents were living in substandard housing, with higher rates for LGBTQ older adults of color (37%) and transgender and gender nonconforming older adults (33%)
- Many respondents were eligible for housing subsidies but would face challenges in documenting their eligibility
- Most respondents wanted to age in place but 72% reported at least one serious health condition
- 58% of respondents said it was very important or important that their housing have at least 50% LGBTQ residents
- 64% of respondents preferred on-site services and programs run by an LGBTQ organization
- Respondents valued having housing with access to public transportation, cultural amenities, parks, and a hospital

Source: Strength in Numbers Consulting Group, Inc. & Stonewall Community Development Corporation, [Housing for LGBTQ Older Adults in New York City: Survey Results](#) (2017).

Housing Discrimination Limits Options for LGBTQ Older People.

Affordable housing is a challenge for many older people. This is especially true in New York City where fewer than half of older New Yorkers live in homes owned by someone in the household.⁶⁴ But accessing rental or elder housing can be even more challenging for LGBTQ older people who are more likely to be low-income and face housing discrimination in elder living communities.

Housing discrimination 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.⁶⁵ Surveys confirm this experience: 13% of LGBTQ older people reported housing discrimination based on sexual orientation and 25% of transgender people reported discrimination based on gender identity.⁶⁶

Older LGBTQ Americans in LGBTQ-unfriendly communities were seven times more likely to report recent housing discrimination (14% vs. 2% in LGBTQ-friendly communities).⁶⁷ In light of discrimination, 34% of LGBTQ older people and 54% of transgender and gender nonconforming older people were at least somewhat worried about having to re-closet themselves to seek housing.⁶⁸ This may be why 90% of older LGBTQ survey respondents were extremely, very, or somewhat interested in LGBTQ-welcoming older adult housing developments.⁶⁹

Housing disparities faced by LGBTQ older people may be further exacerbated by prior housing instability or homelessness, an unfortunate trend that is only

Serving LGBTQ Veterans in New York State

New York State and New York City are among the top 10 states and cities with highest concentrations of LGBTQ veterans. Three-quarters (76%) of LGBTQ veterans are from Upstate New York, and more than half (56%) are over the age of 50. Nearly one-third are transgender. An estimated 43% of LGB and nearly 60% of transgender veterans in New York are low-income, and many have faced homelessness or fear discrimination by providers.

Older LGBTQ veterans served in the military at a time when LGBTQ discrimination was even more rampant and a matter of official government policy. (Discrimination against transgender service members was reinstated as official government policy in 2017, although this policy is being challenged in court.) As a result, many older LGBTQ veterans cannot or have not accessed their federal VA and related benefits.

The SAGEVets program, developed with support from the New York State Assembly, helps identify, support, and provide access to care for LGBTQ older veterans statewide. Through this program, SAGE provides New York's LGBTQ elder veterans with LGBTQ-competent case management support, benefits advocacy, access to legal counsel, and enhanced wrap-around services in order to improve their overall well-being. The program also educates veterans groups across the state about the unique challenges of the LGBTQ veterans.

expected to increase during the current real estate and eviction crisis. And this crisis has been magnified by the disparate impact of COVID-19 on elders' safety, support networks, and economic stability.

More than a third (36%) of LGBTQ New Yorkers of all ages reported housing insecurity in 2015, and 18% had been homeless at some point in their lives.⁷⁰ These disparities were even greater for LGBTQ New Yorkers of color (47% reported housing insecurity and 30% reported homelessness) and transgender and gender nonconforming New Yorkers (49% reported housing insecurity and 28% reported homelessness).⁷¹ More than one in 10 transgender New Yorkers reported being refused housing because of their gender identity or expression, and more than one quarter had been harassed by their neighbors.⁷² And transgender elders are facing compounded barriers, exacerbated by attempts to roll back federal Fair Housing Act protections, implement religious exemptions, and eliminate explicit federal housing and homeless shelter protections for transgender people.⁷³

LGBTQ New Yorkers were more likely to report inadequate housing in New York City (16%) compared to upstate New York (13%).⁷⁴ Overall, 18% of LGBTQ residents of New York City reported experiencing homelessness, leading about 30% of these respondents to use the local shelter system where most felt very unsafe.⁷⁵ Much higher rates of homelessness were reported by LGBTQ people of color and transgender and gender nonconforming New York City residents.⁷⁶

CAREGIVING AND SOCIAL CONNECTIONS

Older LGBTQ people are often disconnected from services and have thin support networks. Many were shunned by their families and, as a result, are less likely to have close relatives to call for help. Although the networks that LGBTQ older people 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 people in their care. Thinner support networks, in turn, make LGBTQ older people more reliant on community service providers even though LGBTQ older people are more likely to face discrimination. This section summarizes some of the current data including research supported by AARP Foundation and AARP on the challenges faced by LGBTQ older people with respect to caregiving and social connections.

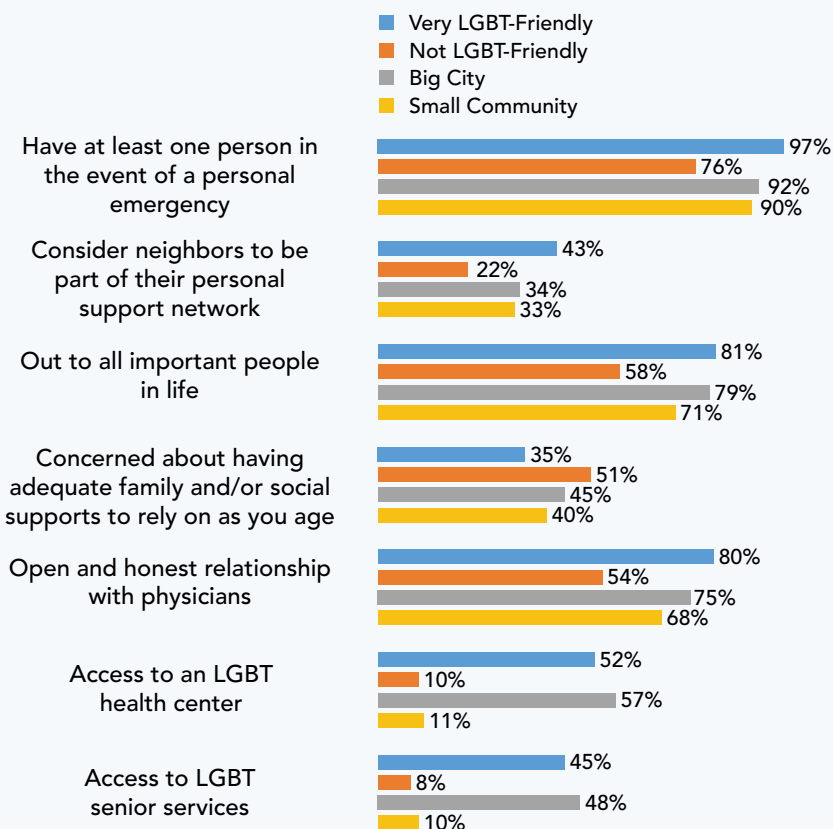
Thin Support Networks Exacerbate Social Isolation. Three out of four LGBTQ people age 45 and older are concerned about having enough support from family and friends as they age.⁷⁷ This is because LGBTQ older people are more likely to live alone than non-LGBTQ individuals and less likely to rely on adult children or other family members for informal caregiving.⁷⁸ And LGBTQ people are more likely than non-LGBTQ people to report being lonely.⁷⁹

This isolation contributes to the physical and mental health disparities noted above. Nearly 60% of LGBTQ older people report feeling a lack of companionship, with over 50% reporting feeling isolated from others.⁸⁰ LGBTQ older people are also more likely to report fear of dying alone and in pain.⁸¹ The limited data that exists suggests that LGBTQ older people may face high rates of elder abuse due to their isolation, vulnerability, and reliance on others.⁸²

Disparities exist even within the LGBTQ community, putting certain segments of the community at greater risk of isolation. Gay men, for instance, report being

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

less connected in a range of relationships relative to lesbians.⁸³ Although 53% have children or grandchildren, transgender or gender expansive people were the least likely to say they consider gay or straight friends, family, or neighbors part of their personal support network.⁸⁴

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 people 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.⁸⁵ 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.⁸⁶

LGBTQ Older People Often Serve as Caregivers. Thinner support networks mean that many LGBTQ older people rely on other LGBTQ people, such as friends and family of choice, as caregivers. LGBTQ older people become caregivers more often than their non-LGBTQ counterparts.⁸⁷ An estimated 21% of LGBTQ older people 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.⁸⁸ In one study of LGB older people in New York City and Los Angeles, 65% of respondents had provided care to another LGB older person in the last five years.⁸⁹

LGBTQ caregivers face unique obstacles, from laws that privilege biological families to a lack of resources for LGBTQ-specific needs. Given that caregivers tend to have poorer mental and physical health than non-caregivers, LGBTQ older people 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 people 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 people whose primary caregiver is not a legal next of kin.

Many LGBTQ Older People Fear Discrimination By Aging Services Providers. LGBTQ older people have lived through discrimination, social stigma, and family rejection. About two-thirds of LGBTQ older people have experienced victimization at least three times in their lives, with higher rates of discrimination for LGBTQ older people of color and transgender older people.⁹⁰ This includes discrimination in long-term care facilities.⁹¹

Fears of discrimination in New York State are not unfounded. In a survey of LGBTQ residents of New York City, 47% reported being denied equal treatment or services or verbally or physically harassed in public spaces as a result of being LGBTQ.⁹² This mistreatment often occurred while using public transportation, at places of public accommodations (such as retail stores, restaurants, or hotels), and in health care settings (such as the doctor's office, hospital, nursing home, or an extended family care facility).⁹³ About 70% of transgender and gender nonconforming respondents reported this negative experience.⁹⁴

Given these experiences, many are understandably concerned about continued discrimination from the staff of traditional senior centers, long-term care and social services, and by their peers. Continued fear of discrimination in care settings forces many LGBTQ older people to go back into the "closet" to preserve their safety and dignity.⁹⁵ To avoid having to go back into the closet, LGBTQ older people want long-term care providers that understand the specific needs of LGBTQ older people. Most LGBTQ older people would feel more comfortable with providers who are trained in LGBTQ patient needs (88%), use

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

advertising to promote LGBTQ-friendly services (86%), have some LGBTQ staff members (85%), or display LGBTQ-welcoming signs or symbols (82%).⁹⁶

In some communities, LGBTQ community centers try to fill these gaps by providing competent care for LGBTQ older people. However, these centers often lack crucial resources with very little grant support dedicated to programs for LGBTQ older people. Funding disparities persist despite the fact that LGBTQ community centers typically serve a high proportion of LGBTQ older people: 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 50.⁹⁷

Data from New York State confirms that LGBTQ health and human service providers are often the first point of contact for LGBTQ New Yorkers in need of health and social services. About half of LGBTQ New Yorkers of all ages reported attending an event at an LGBTQ health and human service providing organization in 2015, and 79% had been to an event at an LGBTQ center within the prior year.⁹⁸ LGBTQ people of color were more likely to visit an LGBTQ center monthly or more often and to have recently used LGBTQ health and human services.⁹⁹



A Comprehensive Strategy to Support LGBTQ Older People

The disparities faced by LGBTQ older people mean that New York State must develop a fully inclusive, comprehensive strategy to help ensure that LGBTQ 50-plus people thrive. This includes a sustained commitment to understanding and advancing the needs of LGBTQ older people and the designation of LGBTQ older people as a target population for resources and services.

A comprehensive strategy is consistent with long-standing efforts of the New York State Office for the Aging (NYSOFA) to better serve and foster the inclusion of LGBTQ older people. Past and current efforts by NYSOFA include:

- Identifying LGBTQ older people as a vulnerable population within target groups with the greatest economic and social needs;
- Incorporating questions on sexual orientation and gender identity into the COMPASS screening tool used in assessing an older person's need for services;
- Encouraging area agencies on aging (AAAs) and grantees to describe specific strategies for reaching and seeking input from unserved and underserved older people, including LGBTQ older people;
- Identifying—as specific objectives for AAAs—the need for case managers to be trained in cultural competency and skilled in working with LGBTQ older people and caregivers;
- Including the need to address equal access to services for the LGBTQ community within the State Plan on Aging;
- Referencing examples of LGBTQ-specific outreach in memos to AAAs on implementation of NYSOFA four-year plans and providing technical assistance to AAAs on strategies to increase efforts to better serve LGBTQ communities;
- Encouraging AAAs to receive LGBTQ cultural competency training offered by SAGE through the SAGECare training and credentialing program;
- Collaborating with the New York State Department of Health's AIDS Institute to help inform the state's blueprint on ending the AIDS epidemic and the development of the *Older Adults and Sexual Health: A Guide for Aging Services Providers* report;
- Encouraging aging network providers to create community linkages to identify and provide services to LGBTQ older people;
- Increasing the visibility of LGBTQ older people and their needs by:
 - o Identifying LGBTQ-specific resources for older people and caregivers in NYSOFA resource guides and NY Connects;
 - o Including LGBTQ-specific programming at aging conferences; and
 - o Recognizing the contributions of LGBTQ leaders.

These efforts are critical, but gaps remain. Without targeted and sustained attention, LGBTQ-specific disparities will simply go unaddressed. Given the tools and resources that New York State has at its disposal, there is no reason to perpetuate these disparities any longer. This section identifies policy recommendations to increase resources for, and further improve the lives of, LGBTQ older people.

MAKE LGBTQ OLDER PEOPLE AND OLDER PEOPLE LIVING WITH HIV A TARGET POPULATION

The Older Americans Act is the nation's leading vehicle for funding and delivering services to older people nationwide with the goal of ensuring that older people 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 age 60 or older but Congress and ACL recognized that individuals in certain subpopulations (often those belonging to marginalized communities) 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, such as those in rural areas, those with severe disabilities, those with limited English proficiency, those with greatest economic need, and those with greatest social need. Aging network providers must prioritize the delivery of services and supports to these groups and specifically address their needs in developing resources, engaging in advocacy, and participating in planning.

Given the disparities faced by the LGBTQ community, LGBTQ older people fit squarely within the Older Americans Act's definition of "greatest social need." The same is true of older people living with HIV. The Act defines "greatest social need" as "need caused by non-economic factors" including but not limited to "cultural, social, or geographical isolation, including isolation caused by racial or ethnic status, that (i) restricts the ability of an individual to perform normal daily tasks; or (ii) threatens the capacity of the individual to live independently."¹⁰⁰ ACL has recognized as much, affirming in 2012 that the definition of "greatest social need" may include isolated populations other than racial and ethnic minorities, including individuals isolated due to sexual orientation or gender identity.¹⁰¹ 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 people, collect data on the needs of LGBTQ older people, and collect data on whether they are meeting the needs of LGBTQ older people.¹⁰²

Three states—California, Illinois, and Massachusetts—have already designated LGBTQ older people as a group of greatest social need under the Older

Americans Act. And Illinois recently became the first state to additionally identify older people living with HIV as a population of greatest social need.

New York State requires the targeting of aging services and supports to older people who are low-income, minority, frail, or vulnerable.¹⁰³ In a program instruction, NYSOFA defined “vulnerable” populations to include LGBTQ older people based on documented economic and social need.¹⁰⁴ This makes LGBTQ older people eligible for targeted services, but LGBTQ New Yorkers would benefit from an even more formal designation.

By formally designating LGBTQ older people and older people living with HIV as a group of greatest social need, New York State will ensure that the provision of services and supports under the Older Americans Act matches the population’s need. With this designation, the aging network must identify and provide services specific to LGBTQ older people and older people living with HIV; collect data on the geographic distribution of LGBTQ older people and older people living with HIV; target services and supports to these communities; and provide technical assistance to and training of service providers. NYSOFA has encouraged some of these steps already, but New York State should—at a minimum—formalize its designation of LGBTQ older people and older people living with HIV as a groups of “greatest social need” in statute and regulations. Identifying LGBTQ older people and older people living with HIV as populations of greatest social need would move beyond the idea that “our doors are open to everyone” and instead hold the aging network accountable for actually meeting the needs of these populations.

ESTABLISH A STATEWIDE COMMISSION ON LGBTQ AGING

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

Several states have already established similar commissions or initiatives. Massachusetts established a first-in-the-nation statewide LGBTQ Aging Commission to address the unique concerns and needs of older LGBTQ people. The Commission is charged with 1) investigating, analyzing, and studying the health, housing, financial, psychosocial, and long-term care needs of older LGBTQ people 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.¹⁰⁵

New York State should establish a similar standing commission to inform its efforts to advance equality and provide affirming services to 50-plus LGBTQ New Yorkers. This commission would provide an ongoing forum to identify

challenges and best practices related to serving LGBTQ older people in New York and solicit expert recommendations on improving the quality of life of 50-plus LGBTQ New Yorkers. 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 LGBTQ Aging Alliance. This collaborative effort will help inform communities and service providers about inclusive practices to ensure that LGBTQ older people feel welcome and supported across the state.¹⁰⁶ And AAAs in Michigan participated in a statewide LGBTQ and Aging Initiative to help identify LGBTQ-friendly community services, update policies and practices, and develop materials on best practices for cultural competency.¹⁰⁷

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 a standing commission on the needs of LGBTQ older New Yorkers, NYSOFA could host a series of events to bring awareness to the unique challenges faced by LGBTQ older people, to share best practices among providers, and to take questions from attendees. 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 people, the national LGBTQ liaison for the AARP, the chief executive officer of SAGE, and local service providers.¹⁰⁸ The Summit helped highlight the barriers faced by LGBTQ elders and promoted regional planning sessions with tangible community outcomes.¹⁰⁹

CREATE LGBTQ-INCLUSIVE STATE AND AREA PLANS ON AGING

As the number of LGBTQ older people continues to climb, the needs of LGBTQ people should be considered during New York State's process of designing, implementing, and evaluating its aging services and programs. Building an inclusive planning process requires 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.


New York State's 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.

In its 2019 to 2023 Plan on Aging, NYSOFA noted its continued efforts to target services to the LGBTQ community, ongoing data collection through COMPASS, increased technical assistance to AAAs on better serving the LGBTQ community, and continued collaboration with the AIDS Institute.¹¹⁰ NYSOFA encouraged AAAs to take advantage of SAGE's training on LGBTQ cultural competency and noted that about one-sixth of the state's aging network is currently SAGECare certified. Finally, NYSOFA included an ongoing objective for case managers to be trained in sexual orientation and gender identity aspects of working with older adults and caregivers.

These references to LGBTQ needs, ongoing efforts, and specific objectives are critical to serving LGBTQ older people. However, more can be done to promote LGBTQ inclusion, with additional goals, objectives, strategies, and metrics that focus specifically on LGBTQ older people. LGBTQ-specific objectives promote accountability and help ensure true inclusion by partners.

NYSOFA's objectives should be measurable, time specific, and attainable. For instance, NYSOFA identified LGBTQ cultural competency training as a case management objective and encourages SAGE training. But there is no specific goal on the number or percentage of case managers that should be trained (e.g., increasing the number of case managers trained by 20%) or the frequency of training. The lack of a specific goal makes it challenging to assess progress on this outcome. NYSOFA should continue, and expand, its current efforts to create LGBTQ-inclusive aging plans. (For additional information, SAGE developed a practical guide to strengthen state and local aging plans by expanding the inclusion of LGBTQ older people.¹¹¹)

LGBTQ-specific objectives should also be informed by data and input from community leaders and LGBTQ older people themselves. In Michigan, for instance, aging officials included LGBTQ older people in its 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 people.¹¹²



Beyond data collection, NYSOFA could require or encourage AAAs to include racially diverse LGBTQ people on area agency advisory councils and/or long-term care councils and partner with organizations such as the New York State LGBTQ Health and Human Services Network to inform the planning process and help identify partners for AAAs. Area Plans on Aging should similarly incorporate measurable, time specific, and attainable goals for promoting LGBTQ inclusion.

ASSESSING THE DEFINITION OF FAMILY IN NEW YORK STATE

New York State's laws and policies should be modernized to fully recognize LGBTQ families and consider definitions of family that better reflect the needs and realities of diverse families, which may include extended family members and chosen family. The failure to have fully inclusive family definitions can cause real harm, including the insult of not having your family be recognized to not being included in or covered by certain benefits or programs.

Some New York State agencies have issued guidance to implement marriage equality as it pertains to issues such as civil service benefits and adoption statutes. And recent laws, such as those extending paid family leave, ensure that benefits are available regardless of sexual orientation or gender identity. However, more could be done to ensure that existing laws fully recognize and account for the needs of families of choice, especially for caregiving and eligibility for benefits.

Because the broadness or narrowness of family inclusion has many implications, New York State should establish a task force to review how "family" and "family member" is currently defined in State laws and policies and ensure that those definitions are fully inclusive of families of choice. This task force would evaluate the benefits and impact of modernizing current legal definitions of family and make recommendations to the legislature and administration on whether further changes are needed.



Equal Access to Inclusive Programs and Services

LGBTQ older people face unique barriers when seeking home and community-based services, social services, and long-term care. Key challenges include a lifetime of discrimination, 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 people 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 people face as they age. Due to their sexual orientation and/or gender identity, many older LGBTQ people 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 people 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 people have access to the affirming supports and services they need to age successfully. These policies make a difference. Research shows that LGBTQ older people who receive culturally competent health and support services in their community report higher physical and emotional quality of life scores and better overall health.¹¹³

IMPLEMENT AND ENFORCE COMPREHENSIVE NONDISCRIMINATION PROTECTIONS

States should implement and enforce comprehensive bans on discrimination based on sexual orientation, gender identity, and/or gender expression in employment, housing, public accommodations, health care and health insurance, and credit and lending. 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 people who can face multiple sources of discrimination, such as age discrimination, racism, and discrimination based on their LGBTQ status.

The New York State Human Rights Law bans discrimination based on sexual orientation and gender identity or expression in employment, housing, public accommodations, and credit.¹¹⁴ Sexual orientation discrimination was banned in 2002, and gender identity or expression discrimination was banned in 2019. These protections explicitly extend to programs and services provided under the Older Americans Act, the Community Services for the Elderly program, and

the Expanded In-Home Services for the Elderly Program, among other NYSOFA programs.¹¹⁵

However, NYSOFA's primary nondiscrimination guidance—the Equal Access to Services and Targeting Policy and the Provider Agreements and Targeting and Equal Access policy—have not been updated since 2012 and 2013, respectively.¹¹⁶ As a result, NYSOFA guidance on equal access does not explicitly prohibit discrimination based on gender identity or expression. Nor has NYSOFA issued more detailed guidance on transgender nondiscrimination and the respectful treatment of older transgender New Yorkers.

Inclusive Family Caregiver 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 people 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.

New York State should adopt a comprehensive caregiving law 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.

New York State should also recognize the contributions of caregivers, including LGBTQ caregivers, by authorizing a caregiver state tax credit. In New York State, approximately 3 million caregivers provide more than 2.4 billion hours of care to loved ones each year at an economic value of \$31 billion dollars. A family caregiver state tax credit would support caregivers, including LGBTQ caregivers, and recognize their significant contributions that reduce the demand for state-funded services.

To modernize its standards and assist AAAs and service providers on compliance with state law, NYSOFA should issue a new program instruction on equal access to services and targeting policy. This policy should specifically address transgender-specific nondiscrimination protections, such as referring to older transgender people by their chosen name or pronoun and otherwise treating older LGBTQ people in a respectful manner that is consistent with their gender identity or expression. NYSOFA should also ensure that the contract language in AAA provider agreements is updated to reflect these modernized requirements. This will help ensure that all service providers comply with these nondiscrimination provisions in the performance of their subgrants or subcontracts with AAAs.

NYSOFA should ensure that its nondiscrimination policies are advertised to the aging network, LGBTQ older people, and the public on its website, in fact sheets, and in public-facing documents. Compliance with these provisions should also be monitored and fully enforced. As part of this effort, NYSOFA should create 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 people who experience barriers to accessing and utilizing services.

ADOPT AN LGBTQ LONG-TERM CARE RESIDENTS' BILL OF RIGHTS

New York State should ensure that LGBTQ older people are fully protected while in long-term care. Because many LGBTQ older people lack traditional support

systems, many end up relying on nursing homes or other institutions providing long-term care. While existing nondiscrimination protections in New York State extend to long-term care facilities, specific protections are needed for LGBTQ older people and older people living with HIV in assisted living communities, 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 people, providers, and support systems shows that LGBTQ older people continue to face discrimination and mistreatment while in long-term care settings.¹¹⁷ 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 schoolmates, coworkers, and society at large, some LGBTQ older people are forced to share a room with homophobic or transphobic 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, refused access to services, and harassment.¹¹⁸ 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.¹¹⁹

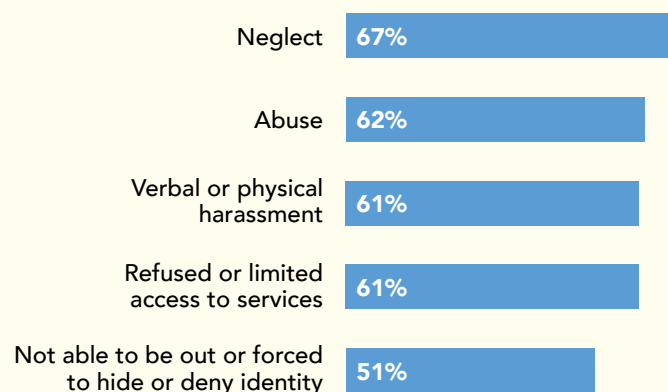
Some states, such as California, have already taken action to recognize and address the need for specific LGBTQ and HIV protections in long-term care settings. California adopted an LGBTQ Long-Term Care Facility Residents' Bill of Rights in 2017 to protect people from discrimination on the basis of their actual or perceived sexual orientation, gender identity, gender expression, or HIV status. The goal of the legislation was to help protect LGBTQ older people and older people living with HIV when they are at the most vulnerable and ensure that facilities provide culturally competent services and care.

New York State should update its Elder Law to include a comprehensive long-term care bill of rights for LGBTQ older people and older people 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, NYSOFA and other agencies such as the New York State Department of Health should issue guidance to long-term care facilities and other social service providers on how to provide respectful, appropriate care to LGBTQ older people and older people living with HIV. This guidance should address standards for maintaining privacy, ensuring safety, preventing harassment, allowing for individual gender

expression, and providing LGBTQ affirming mental health services and other community resources.

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

ESTABLISH AN INDEPENDENT LONG-TERM CARE TASK FORCE

The COVID-19 pandemic has laid bare concerns about the health, safety, and well-being of nursing home and long-term care residents. Adult care facilities house some of society's most vulnerable, including many LGBTQ older people and people with preexisting medical conditions, and many facilities were woefully unprepared for the outbreak and crisis.

The pandemic has made clear that New York State should devote additional resources to and increase its understanding of the need to improve the long-term care system. Doing so is particularly critical given the virus' disproportionate impact on communities of color and the need to ensure that our long-term care system is better coordinated and able to address the current pandemic and future outbreaks.

New York State should establish an independent long-term care task force to examine the state of long-term care, both home- and facility-based, including how LGBTQ older people and other

marginalized communities fare in the system, as well as potential models for improvement. An independent, in-depth review of nursing homes is especially important and should be led by strong academic institutions with expertise in long-term care who can provide an objective review of how the pandemic was handled and develop recommendations for the future.

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 people. Without this competency, LGBTQ older people may feel misunderstood or unwelcome and avoid assistance altogether.

Indeed, most LGBTQ older people have lived through discrimination, social stigma, 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 of them wary of

health care professionals and service providers, making LGBTQ older people less likely than non-LGBTQ peers to access aging network services and providers, senior centers, and meal programs. Some LGBTQ older people may access aging service agencies but choose to remain closeted while others resist accessing these services altogether, seeking help only for emergencies.

Promoting Access to Affordable Health Care and Prescription Drugs

Access to affordable health insurance and health care remains a significant concern for LGBTQ people, including LGBTQ older people, and contributes to health disparities such as higher rates of HIV, mental health issues, and substance use disorder. New York State should take a range of actions to address these disparities, including:

- Ensuring that LGBTQ people, particularly transgender people, have access to medically appropriate care in a nondiscriminatory manner through public and private insurance.
- Requiring all current medical providers and other licensed professionals—including physicians, psychiatrists, psychologists, nurses, nursing assistants and social workers—to receive a minimum level of training on LGBTQ cultural and clinical competency.
- Adopting and monitoring comprehensive nondiscrimination standards for hospital and outpatient health care facilities.
- Incentivizing HIV-specific Medicaid special-needs plans, which have been shown to reduce costs while improving outcomes.
- Increasing access to preventive health care and enhanced access to health promotion and wellness for LGBTQ individuals and families.
- Promoting affordable access to prescription drugs, including HIV medications, by:
 - Creating a safe, wholesale importation program to provide access to less costly drugs;
 - Creating a systematic mechanism to trigger judicial review of predatory practices in medication price-fixing and establish penalties for prescription drug price gouging; and
 - Prohibiting “pay for delay” agreements in which brand-name drug companies pay generic manufacturers to delay introduction of less costly alternative drugs.
- Developing and implementing LGBTQ-specific standards of practice, with related indicators for monitoring the provision of quality health care services to LGBTQ patients and their families, in all state-licensed primary care settings.
- Requiring all future health professionals to receive LGBTQ cultural competency training.

Additional recommendations are included in [A Blueprint for Meeting LGBTQ Health and Human Services Needs in New York State](#), a report prepared for the Empire State Pride Agenda Foundation and the New York State LGBTQ Health and Human Services Network.

To ensure that service providers understand these unique needs, New York State should mandate 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—to receive a minimum level of training in LGBTQ cultural competency. The training should cover LGBTQ-specific terminology, disparities, the unique needs of LGBTQ older people 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.

While NYSOFA has long encouraged SAGE training, only about one-sixth of the state’s aging network is currently SAGECare certified. Mandatory training will ensure that NYSOFA-funded services are delivered in a professional manner by staff that feels both prepared and empowered to meet the needs of LGBTQ older people. New York State 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 PEOPLE

Given the disparities faced by LGBTQ older people, New York State should continue to support programs and initiatives that address many of the root

causes of these disparities, especially for LGBTQ older people of color. This includes addressing many social determinants of health for LGBTQ older New Yorkers by increasing access to affordable housing initiatives, affordable health care (especially prescription drugs), economic and employment opportunities, programs for individuals living with HIV, and services for veterans.

The SAGEVets program, for instance, was developed with support from the New York State Assembly to respond to the swelling need among LGBTQ veterans and to identify, support, and provide access to care for LGBTQ veterans statewide. This program remains critical in light of enactment of the 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.¹²⁰

Additional support is needed for elder housing, health care services, and employment support (such as workforce development and job readiness programs) for older LGBTQ New Yorkers. For instance, New York State should promote the development of LGBTQ-affirming housing options as well as innovative LGBTQ elder housing models, such as the Stonewall House in Brooklyn and the Crotona Senior Residences in the Bronx. There is also an urgent need to ensure that human services programs that are most relevant to the needs of older LGBTQ people—including substance use, behavioral health, suicide prevention, domestic violence, and emergency shelter—understand the unique needs of LGBTQ older people.

EXPAND LGBTQ-SPECIFIC PROGRAMMING AND TARGETED OUTREACH TO LGBTQ OLDER PEOPLE

One way to combat social isolation and promote inclusion is to offer and publicize LGBTQ-specific programming (including virtual programming) for older people 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, NYSOFA 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. NYSOFA 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.

NYSOFA can also do more to ensure that LGBTQ people, caregivers, community leaders, and partner organizations are aware of available programs and services. Targeted outreach is critical because of the long history of discrimination faced by LGBTQ older people. Unless informed otherwise, many LGBTQ older people 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 people are accessing the services they need and are entitled to, such as veterans services.

NYSOFA, partner agencies, and service providers should also conduct outreach on topics that disproportionately or uniquely impact LGBTQ older people. For instance, state officials could develop an aggressive public outreach campaign that promotes advance planning among older people 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 to improve utilization of available benefits and services.

Although proactive outreach is critical, NYSOFA should also require that NY Connects and other state-funded information and referral services include comprehensive and up-to-date data on LGBTQ-inclusive aging services and elder housing.

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 people 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 people 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 can exacerbate the unique challenges facing LGBTQ older people.

COVID-19 and Why LGBTQ Data Collection is Crucial

LGBTQ people, including LGBTQ older people, are highly vulnerable to COVID-19. Despite these vulnerabilities, few states are collecting data on sexual orientation and gender identity to understand how COVID-19 is impacting the LGBTQ community.

Pennsylvania Gov. Tom Wolf [announced](#) that his administration will modify its systems to collect LGBTQ-inclusive data and work with the eHealth Authority Board to capture LGBTQ electronic health record patient data. Legislation is pending in [California](#) and [New Jersey](#) to require LGBTQ data collection in COVID-19 efforts.

To enable providers and state officials to fully understand the rates of COVID-19 in the LGBTQ community and help LGBTQ older people get the resources and support they need, NYSOFA should work with partner agencies to ensure that surveillance efforts and patient records capture sexual orientation and gender identity as part of routine demographics.

The data gap means policymakers and providers lack the information they need to better understand and serve LGBTQ older people and to target resources appropriately. Ongoing collection of demographic data is especially important to understanding racial inequities among older New Yorkers and the intersectionality of race and ethnicity with other factors, such as sexual orientation, gender identity, disability, and income, among other factors. The lack of systematically collected health data complicates the ability to draw conclusions about prevention and risk mitigation efforts. For instance, studies

have noted a shortage of evidence on the impact of loneliness initiatives on LGBTQ older people due to a lack of data collection and analysis to understand what approaches might work best.¹²¹ Further, the broader research field is left with little data to study questions related to health and well-being among older LGBTQ populations.¹²²

“Data collection is essential to identifying the unique needs and issues facing vulnerable LGBTQ older adults. Sexual orientation and gender identity data will provide tools to measure the effectiveness of outreach policies and identify opportunities to better serve LGBTQ older adults in a culturally competent manner throughout the various regions of NYS.”

*Acting Director Greg Olsen
New York State Office for the Aging*

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 people, New York State can better understand the needs of this community and use accurate data to enhance and improve services throughout the state.

NYSOFA has already taken an important step to enhance LGBTQ-inclusive data collection. Recognizing that LGBTQ older New Yorkers need to feel welcome at all NYSOFA offices to receive adequate services, the agency updated the COMPASS data system—the agency’s primary screening tool—in 2012 to collect information about sexual orientation and gender identity.* Data collected through COMPASS assists local AAAs in developing client-centered planning and services and targeting their outreach efforts to ensure clients receive necessary services. NYSOFA also worked with SAGE to train providers on best practices for collecting data on sexual orientation and gender identity.

The update to the COMPASS system has served as a model for other New York State agencies to enhance their LGBTQ-inclusive data collection efforts.¹²³ NYSOFA also asks questions about how AAAs meet the needs of underserved populations, such as the LGBTQ community, in grantee forms and the Annual Implementation Plan. Data collection helped increase awareness of the needs of 50-plus LGBTQ New Yorkers, leading several AAAs to update their programs. For instance, the Cattaraugus County AAA held cultural competency training for all case management staff with the local Seneca Nation of Indians on LGBTQ elders, provided two staff trainings on LGBTQ aging issues, and sponsored a new local LGBTQ group.¹²⁴

LGBTQ-INCLUSIVE DATA COLLECTION AS STANDARD PRACTICE ACROSS AGENCIES

The inclusion of questions on sexual orientation and gender identity in COMPASS is a critical step towards addressing a lack of LGBTQ data in New York State. 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 New Yorkers, such as individual

* COMPASS assesses persons for community-based long-term care services, including case management, home health aides, adult day care services, and home-delivered meals.

assessments, program monitoring data systems, participant satisfaction surveys, and program evaluation.

The fact that COMPASS has been used to successfully collect LGBTQ-specific data since 2012 suggests that the aging network and older New Yorkers have become accustomed to LGBTQ-inclusive questions and data collection. It is also time to expand New York State's efforts to collect additional data and publicly report on that data and the needs of LGBTQ older people. 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 people, and whether they are meeting those needs.

"The goal was to learn if LGBTQ 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. LGBTQ older people exist. They have needs."

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

It is not enough to simply collect data on LGBTQ older people. Even if data is being collected, the failure to report out this data means that LGBTQ older people 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 people. In turn, it helps government officials and other funders understand the importance of funding programs and services that support LGBTQ clients. The COVID-19 crisis has highlighted the need to report demographic data and understand disparities, including LGBTQ disparities, more than ever.

Other states have already expanded their efforts to collect LGBTQ-inclusive data. California enacted the LGBTQ 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.¹²⁵ 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.

To aid the process of expanding its data collection efforts, New York State should renew its focus on developing a strategic plan and timeline for expanding LGBTQ-inclusive data collection, including to all NYSOFA data systems, intake forms, survey instruments, and needs assessments. This should be accompanied by a publicly available report or fact sheet to memorialize NYSOFA'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 the strategic plan, New York State should:

- **Ensure that State-regulated forms are designed to 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 people). 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.
- **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 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 NYSOFA, should include data on LGBTQ older people alongside any reporting of other demographic information, such as age and race. NYSOFA would also be able to develop LGBTQ-specific reports, such as annual assessments of service delivery for LGBTQ older people for Pride Month in June and transgender older people for Transgender Awareness Month in November.

Even as agencies work to increase LGBTQ-inclusive data collection agencywide, State leaders should utilize community-generated data to inform policymaking and resource allocation. This includes surveys and community-based needs assessments—such as the New York State LGBTQ Health and Human Services Needs Assessment, which reached a significant sample of LGBTQ New Yorkers.¹²⁶ This data can be used to 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 agencywide data collection, NYSOFA should conduct regular assessments of the needs of 50-plus LGBTQ New Yorkers. This could be done through surveys, focus groups, key informant interviews, and other tools used to solicit feedback from LGBTQ older people, LGBTQ community leaders, and service providers. Given a dearth of data on LGBTQ older people, needs assessments are an important tool to assess the social, economic, housing, public health, and long-term support service needs of LGBTQ older people and caregivers.

NYSOFA could, for instance, partner with AAAs, LGBTQ-serving organizations, and service providers to survey LGBTQ older people in New York State on their needs and experiences. This information could be used to inform the next State Plan on Aging and enable NYSOFA to target its resources in an evidence-based way. NYSOFA should also ensure that LGBTQ older people are fully included in broader (non-LGBTQ-specific) needs assessments. This can be done through outreach to, and partnership with, LGBTQ older people, LGBTQ community leaders, and service providers.

Conclusion

LGBTQ older people 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, New York State 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 New York'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 New Yorkers. Visit aarp.org/NYDisruptDisparities which will serve as a platform to host the latest research findings, policy updates and information related to this effort, and contribute your ideas and insights by emailing NYAARP@aarp.org.

The time to act is now.



End Notes

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