

# LGBTQ+ Caregivers: Challenges, Policy Needs, and Opportunities

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**L**esbian, gay, bisexual, transgender, queer, and people with additional sexual and gender identities ([LGBTQ+](#)) have a rich history of caring for both biological and chosen family. Compared to their non-LGBTQ+ peers, LGBTQ+ people are [1.2 times more likely to be primary caregivers](#) and [3.5 times more likely](#) to provide care for friends and chosen family.

LGBTQ+ caregivers also report higher rates of [social isolation and depression](#), as well as [high rates of discrimination](#) in health care settings. These challenges, coupled with fear of additional discrimination, result in caregivers and care recipients [delaying or forgoing care](#).

As the U.S. population ages overall, the LGBTQ+ older adult population will increase to an anticipated [five million by 2030](#) and the number of LGBTQ+ caregivers will grow as well. Responding to their unique needs is becoming increasingly critical.

## Challenges Facing LGBTQ+ Caregivers

Caregiving can be a challenging experience on its own and LGBTQ+ caregivers experience additional complexity when navigating health and human services systems.

### 1. LGBTQ+ caregivers are traditionally overlooked.

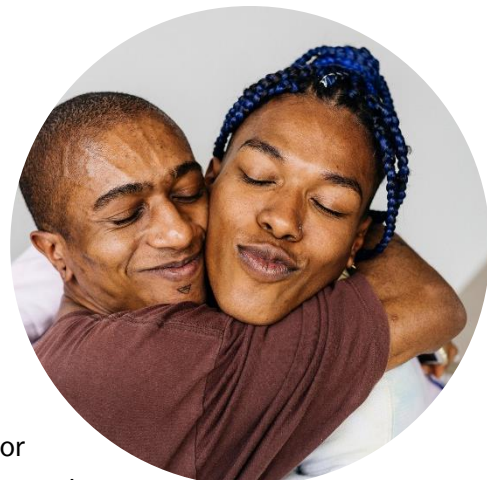
Policies and programs that support caregivers often assume care recipients have a single caregiver who is legally or biologically related. This assumption excludes those who are cared

#### Who is an LGBTQ+ caregiver?

The term “LGBTQ+ caregiver” refers to members of the LGBTQ+ community who provide informal care for aging or disabled friends, partners, or family members. Frequently, people who provide informal caregiving to family or friends may not identify as a caregiver but meet the criteria.

#### What is a chosen family?

“Chosen family” is a term commonly used among LGBTQ+ communities to refer to people who share close social and familial bonds without necessarily being legally or biologically related.



for by a group of chosen family, partners, friends or neighbors, sometimes referred to as care circles, [which is especially common in the LGBTQ+ community](#). When policies and programs use terms such as “family” or “spouse,” LGBTQ+ caregivers may experience actual or perceived exclusion, resulting in decreased access. To access services, some LGBTQ+ caregivers resort to misrepresenting relationships, for example by saying a partner is a sibling.

## **2. Non-LGBTQ+ groups overlook the diversity and experiences of discrimination within the LGBTQ+ community.**

Recognizing that experiences of discrimination vary and intersect across sexual orientation and gender identity — in addition to race, ethnicity, and other identities — is critical to ensuring LGBTQ+ caregivers receive culturally appropriate care. Transgender caregivers, for example, have different experiences and needs than their gay, lesbian, or bisexual counterparts. Transgender people face [even greater health disparities](#) and [challenges accessing care](#) because of interpersonal transphobia, exclusion in the medical system, or other forms of discrimination.

## **3. Providers’ lack of awareness and training impacts access to services for LGBTQ+ caregivers.**

Lack of provider training on working with the LGBTQ+ community contributes to higher rates of discrimination in health and social care settings for LGBTQ+ caregivers. When providers don’t understand the health needs of the LGBTQ+ community, they can unintentionally limit access to competent care.

## **4. LGBTQ+ caregivers of color must navigate the compounding burden of racism.**

Many [estimates suggest](#) that Black, American Indian, and Alaska Native individuals are more likely to be primary caregivers. LGBTQ+ caregivers of color experience the compounded burdens of racism, homophobia, and/or transphobia when navigating the health and social service systems. These experiences may contribute to further fear and anxiety and impact overall well-being for both the caregiver and care recipient.

## **5. LGBTQ+ caregivers are forced to navigate ageism and ableism within their own community.**

Within the LGBTQ+ community, ageism and ableism pose significant barriers to services and are uniquely tied to generational disconnect and historical discrimination. Younger LGBTQ+ people may lack connection to LGBTQ+ older adults and therefore [feel disconnected from LGBTQ+ elders](#). Simultaneously, LGBTQ+ older adults may be [less likely to publicly identify as a member of the LGBTQ+ community](#) — many opt to go “[back in the closet](#)” when seeking aging services. As a result, ageism and ableism impacts programming at LGBTQ+ centers, where resources and supports largely exclude LGBTQ+ older adults and caregivers.

# Policy Recommendations to Better Support LGBTQ+ Caregivers

The Center for Health Care Strategies identified the following caregiving policy recommendations by reviewing lessons from successful programs across the nation that support LGBTQ+ caregivers.

## 1. Affirm chosen family and care circles.

Including “chosen family” and other related terms in policy increases access which can help mitigate existing disparities. More states are embracing an inclusive approach to recognizing caregiving. California [recently passed a law](#) allowing workers to take job-protected leave to care for anyone considered “equivalent of a family relationship.” Additionally, many states are updating the language used in outreach materials. The [New York State Office for the Aging](#), for example, defines “caregiving” broadly in program standards to include chosen family. Expanding the language used to affirm caregivers benefits the LGBTQ+ community and others who are not recognized by the traditional single caregiver system.

## 2. Embrace an intersectional approach to supporting LGBTQ+ caregivers.

LGBTQ+ caregivers' additional identities, including their racial, linguistic, and religious backgrounds, impact their experience accessing services. As providers, policymakers, and others work to better support LGBTQ+ caregivers, embracing an intersectional approach to policy and program design is crucial. Developing resources in multiple languages, partnering with local affirming religious communities, and requiring anti-racism training for all staff can help ensure LGBTQ+ caregivers feel affirmed in all their identities.

## 3. Increase sexual orientation and gender identity data collection.

For programs supporting caregivers, collecting sexual orientation and gender identity (SOGI) data may allow the program to better meet the needs of caregivers by referring them to LGBTQ+-specific resources. As providers and states move to include SOGI data, forms should clearly state that such information is optional and explain how the data will be used. Massachusetts' Medicaid program recently implemented a [policy to incentivize providers](#) to collect data, report on, and monitor health disparities by sexual orientation and gender identity. At the federal level, Indian Health Services recently started [collecting SOGI data](#) through health records to better understand the health and social needs of LGBTQ+ communities. Provider training on best practices for SOGI data collection may help address [provider hesitancy](#), encourage more [consistent collection](#), and lead to more [complete data](#). More accountability in SOGI data collection could help identify LGBTQ+ caregivers, better understand their needs, and more easily connect them to culturally appropriate services.

## 4. Address ageism and ableism within LGBTQ+ spaces.

The LGBTQ+ community can take steps to recognize and become more inclusive of older adults and caregivers. LGBTQ+ health and community centers can offer services and resources specifically

designed for older adults and their caregivers. Center on Halstad, an LGBTQ+ community center in Chicago, offers [weekly programs for LGBTQ+ older adults](#) that foster community and belonging. Additionally, just as aging-focused programs have started incorporating LGBTQ+ cultural competency trainings, LGBTQ+ centers can consider incorporating trainings on aging and ageism.

## 5. Tackle homophobia and transphobia within aging spaces.

Aging organizations need to address homophobia and transphobia and recognize the diversity of backgrounds of the communities they serve. Providers in aging, such as home health aides, nursing home staff, geriatricians, and others need stronger trainings on the unique needs and perspectives of the LGBTQ+ community and their caregivers. Implementing and requiring participating in training programs, like [SAGECare](#), may help meet this need. Additional recommendations that embrace intersectionality are included in the Diverse Elders Coalition’s toolkit, “[Caring for Those Who Care.](#)”

## 6. Listen first, act later.

LGBTQ+ caregivers know what works for them and their community. Stakeholders should collaborate with community leaders to understand their needs, the barriers they face, and the existing strengths of LGBTQ+ caregivers. Policies and programs can build on existing infrastructure and practices within the LGBTQ+ community — such as care circles and mutual aid networks — rather than forcing LGBTQ+ caregivers to participate in systems that are culturally misaligned and have historically discriminated against them. By co-developing *with* the LGBTQ+ community, providers and policymakers are more likely to support caregiving investments that will resonate and be sustainable.

# Looking Ahead

Caregivers — including LGBTQ+ caregivers — are the backbone of our health care system and social safety net. Addressing their needs can help create systems that are more responsive to a variety of caregiving structures, more adaptable, and more humane. More inclusive policies, robust SOGI data collection, intersectional programming, and stronger provider training are meaningful changes that can contribute to better outcomes. Strengthening supports for LGBTQ+ caregivers can lead to better outcomes for those in their care, as well as for caregivers themselves.



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