

Policy Brief

June 2023

***MAKING THE INVISIBLE **VISIBLE**: RAISING AWARENESS
TO MEET THE NEEDS OF LGBT+ CAREGIVERS***

Executive Summary Caregivers are invaluable to American society as nearly every person will require care in their lifetime. The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act calls for supporting our nation’s growing diversity of caregivers – including the growing cadre of LGBT+ caregivers. To better serve the LGBT+ community of caregivers, it is essential to determine their prevalence and needs. This brief builds upon the RAISE Act by calling for the development, implementation, and evaluation of a national, culturally competent public health awareness campaign about LGBT+ caregivers.

Keywords: caregiving, LGBT+, LGBTQ, health equity, culturally competent care

INTRODUCTION

Caregivers provide essential support to persons of all ages and needs, and across all areas of daily living. Their services are attributed to better quality of life among care recipients¹ as well as cost savings from reduced hospitalizations of their care recipients and delayed nursing home placement.²

Among the nation’s 34.2 million caregivers, estimates suggest that approximately one-tenth (i.e., about three million) identify as Lesbian, Gay, Bisexual, Transgender, or other queer identities (LGBT+); however, the true number of LGBT+ caregivers is not clearly known.

As the proportion of LGBT+ caregivers is projected to rise in the years ahead, it is imperative to better understand the prevalence, hardships, and needs of this population in order to provide better support for their important service to society.

Empirical understanding is necessary as designations of ‘family caregiving’ typically exclude those who provide care to someone they are not biologically or legally related to. In contrast, anecdotal data suggest that LGBT+ caregivers care for ‘found family’ and ‘family of choice’ which represents an integral part of non-traditional family systems amongst the LGBT+ community.³

“A lack of awareness of caregiving can make it difficult for agencies that provide services to family caregivers to find and reach those individuals.”

***—RAISE Family Caregiver Advisory Council
Initial Report to Congress***



Source: AARP

COMPELLING RESEARCH

Caregivers provide crucial services to our nation. Over 85% of caregivers in the United States provide unpaid care to older adults,⁴ accounting for 30 billion hours of uncompensated care each year.⁵ Nine percent of these caregivers (about three million people) openly identify as LGBT+,¹ and this number will likely continue to grow proportionately as the population increases and more individuals feel safe identifying as LGBT+.⁵

The impending boom in the older adult population⁶ will also lead to more people needing regular care, thus increasing the demand for caregivers. Research suggests that members of the LGBT+ community are more likely to be a caregiver than their non-LGBT counterparts.³

Americans' Self-Identification as Lesbian, Gay, Bisexual, Transgender or Something Other Than Heterosexual

Which of the following do you consider yourself to be? You can select as many as apply. Straight or heterosexual; Lesbian; Gay; Bisexual; Transgender



--Respondents who volunteer another identity (e.g., queer, same-gender-loving; pansexual) are recorded as "Other LGBT" by interviewers. These responses are included in the LGBT estimate.

--Data not collected in 2018 and 2019.

--2012-2013 wording: Do you, personally, identify as lesbian, gay, bisexual or transgender?

Source: Gallup.com⁵

One in five LGBT+ individuals are caregivers of someone other than their own children, compared to one in six non-LGBT+ individuals.³ LGBT+ people are also five times more likely to be a caregiver for their spouse, and two and a half times more likely to be a caregiver for a non-relative.⁸ LGBT+ older adults are responsible for 90% of the care for the 1.1 million LGBT+ older adults in the U.S.;⁸ however, the true extent of LGBT+ caregiving is unknown as many adults may not formally disclose LGBT+ identity or recognize their status as a caregivers.

LGBT+ caregivers also face a myriad of barriers in providing care to their loved ones. Unique challenges include societal and medical discrimination,⁹ higher rates of chronic health conditions,^{10,11} suicide, poverty,¹² and homelessness.¹³ These mounting disparities experienced by LGBT+ caregivers negatively impact their ability to provide sufficient care, which can lead to higher costs due to medical expenses, hospitalizations, and placement in long-term care.^{2,14,15}

Awareness of these barriers, their prevalence, and what services needed by these caregivers can help bolster the LGBT+ caregiver journey by providing them with the support, knowledge, and resources to provide less expensive care for their loved ones at home.



Source: Regenstrief Institute¹²

POLICY CONTEXT

In 2018, an Executive Order authorizing federal funding for supporting family caregivers led to the creation of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act.¹⁶ Administered by the Administration on Community Living (ACL), this act initiated development of a National Family Caregiving Strategy to identify and recommend actions to support the diverse needs of family caregivers. The RAISE Family Caregiving Advisory Council was also created, including membership from leading federal organizations such as ACL, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, among others.

In 2020, the Family Caregiving Advisory Council adopted recommendations set forth by the RAISE Family Caregivers Act to raise awareness and outreach to family caregivers along with an official strategy to implement these recommendations.

In 2021, the Council's Initial Report to Congress highlighted the challenges family caregivers face and proposed actionable recommendations to better support the needs of family caregivers.

In September of 2022, the Council's National Strategy to Support Family Caregivers was delivered to Congress including actions to be carried out by the federal government to provide family caregivers with the support that they need in order to take care of themselves and their loved ones.

The report noted that family caregiving has been overlooked as a public health issue; developing the infrastructure and systems to appropriately recognize, assist, include, support, and engage family caregivers has never been more important. It is imperative that caregivers in the LGBT+ community are visible and seen as a part of this movement.

POLICY RECOMMENDATIONS

“Goal 1: Family caregivers’ physical, emotional, and financial well-being will meaningfully improve as a result of expanded awareness, outreach, and education.”

Amplify Goal 1 of the RAISE Family Caregiving Act proposed by the Administration for Community Living:

- ✓ Funding the development, implementation, and evaluation of a national, culturally competent public health awareness campaign, specifically for LGBT+ caregivers.
- ✓ Raising public awareness of disparities faced by and services currently available to caregivers and care recipients in the LGBT+ community.

- ✓ Raising awareness regarding the importance of families of choice and incorporate language into existing and proposed family caregiving policies that is inclusive of found families and families of choice.

Implementation of these recommendations will bring attention to a population that is often overlooked and forgotten in many areas of society, including providing support for family caregivers. We aim to make these invaluable members of our community visible and raise awareness of their unique needs to ensure that they receive the care they deserve as they provide care for others.

“I know that we will create a better future for our American families because we will do it with love, understanding, experience and without a doubt with the grit and determination that every loved one brings to caregiving for their family.”

-Xavier Becarra, Secretary of the U.S. Department of Health and Human Services

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