

Caregiving in the LGBT Community



**A Guide to Engaging
and Supporting LGBT
Caregivers through
Programming**

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The production of this guide was generously supported by the Harry and Jeanette Weinberg Foundation.

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Introduction

Caregiving is emerging as an increasingly important area of focus in the social services sphere, and service providers are seeking effective ways to support the growing caregiving population. While all caregivers can benefit from supportive services, not all caregivers are the same. Those who belong to the lesbian, gay, bisexual and transgender (LGBT) community have much in common with other caregivers, but also have unique experiences and needs.

Successfully supporting LGBT caregivers requires an understanding of these differences as well as modified interventions designed to meet their needs. This guide will provide an overview of what caregiving looks like in the LGBT community, and offer service providers ideas and best practices for reaching and supporting these caregivers.

LGBT Older Adults



The population of LGBT older adults in the U.S. is expected to double by 2030.

LGBT older adults make up 2.7 million of the quickly growing aging population in the United States.¹ By 2030, that number is expected to more than double. As social service providers prepare for the oncoming wave of older adults nationwide, it is critical that the unique needs of LGBT older adults and the people who care for them are taken into account and addressed.

Many LGBT older adults have experienced a lifetime of discrimination and social stigma, as well as institutionalized discrimination in health care, employment, and social services. Because of this history, LGBT older adults as a group experience social, financial, physical and mental health disparities, and are at higher risk for developing chronic diseases, being diagnosed with depression and anxiety, living in poverty, and experiencing social isolation.^{2,3} While the provision of social services and quality medical care can help to alleviate some of these challenges, research shows that older LGBT adults are significantly less likely to access medical and social services than their non-LGBT peers.⁴ This can lead to a delay in care, premature institutionalization, and even premature death.^{5,6}

Though the statistics seem troubling, the older LGBT population is in fact a vibrant and resilient community, who have persevered by coming together and caring for their own. An example of this resilience can be found in the ways in which the LGBT community came together during the HIV/AIDS crisis in the 1980s. It was LGBT people who stepped up to provide caregiving support for lovers, friends and even strangers who were living with HIV/AIDS. As a result, social networks were expanded and strengthened, and survivors of that time have continued to rely on these care networks.

This guide is intended to help you activate that type of resiliency as you seek to support LGBT older adults and LGBT caregivers.

We realize that LGBT family caregivers face unique challenges,

Robert Stephen

Vice President,
Health Security Programming,
AARP, Washington, D.C.

particularly as they see their friends and community as family. We are working closely with SAGE to support those caregivers across the country as they care for their loved ones. With SAGE's recognition, energy, and experience, together we will make this work a success."

Caregiving



Unpaid caregiving accounts for over 85% of elder care in the U.S.

Caregiving is the act of providing physical, psychological, and/or emotional assistance to another person, typically for an extended period of time. As people age, their needs may become greater and their abilities may start to decline. In the event of a serious health problem, the onset of dementia, or other debilitating circumstances, care may be needed as much as 24 hours a day to keep the older adult safe.

Though long-term care facilities may be an option, most people prefer to age in place, meaning they want to remain in their homes and communities for as long as they can. In most cases, this is made possible by the assistance of caregivers—unpaid family members and others who can provide the assistance needed for the older adult to maintain a good quality of life.

According to *Caregiving in the U.S.*, a 2015 study by AARP and The National Alliance for Caregiving, there are 34.2 million Americans who provide unpaid care to another adult who is over the age of 50. The care they provide is a



A note on terminology: The term “caregiver” is sometimes used to refer to professional care providers, such as home health aides or nurses, but in this guide we use the term “caregiver” to refer specifically to those caring for their friends and loved ones.

Caregiving is usually not something that is on our bucket list of things that we want to do; caregiving just happens!

Christopher MacLellan, M.A.

“The Bow Tie Guy”

Author: “What’s The Deal with Caregiving?”

Certified Caregiving Coordinator & Educator
WholeCareNetwork.com
Lake Worth, FL

Suddenly, there is an untimely diagnosis, or an unfortunate accident, and within a moment’s notice, two or more lives are forever changed and you are a family caregiver. Caregiving can be an intense experience which will ask you to surrender yourself and your own needs for the needs of someone else. As a caregiver, you often give up things you love to care for the one you love. That is why there are no gender or orientation boundaries when it comes to being a family caregiver, we simply care for the one we love.”



1 in 5 LGBT people is providing care, compared to 1 in 6 non-LGBT people.

critical part of the aging service provider network, as it accounts for over 85% of all elder care in the U.S. These unpaid hours of care for older adults are valued at \$522 billion annually.⁷

Most people will experience caregiving as an important, meaningful, yet challenging role. It is very common for caregivers to feel stressed or overwhelmed, especially as they try to balance caregiving with other aspects of their lives, such as work or raising children. Many caregivers neglect their own wellness while they are busy caring for another—skipping their own doctor’s appointments, giving up time with friends, and decreasing their exercise, sleep, or relaxation time. These lead to health disparities among caregivers, who experience increased rates of depression, anxiety, isolation, financial strain, poorer subjective health and increased mortality risk.^{8,9,10} The stress associated with caregiving is often referred to as *caregiver burden*.



Caregiver Burden: The stress associated with caregiving, including the physical, social, psychological, emotional, and financial strain that is associated with caring for someone over a long period of time. Signs may include depression, withdrawal, poor diet, exhaustion, and health problems.¹¹

Though there is a network of supportive services available for caregivers, many do not know how to access those services or, very commonly, do not realize that they are caregivers at all. Most caregivers will say that they are “just doing the right thing,” “helping a friend,” or “being a good son,” without having any idea that they belong to a large cohort of people who share similar feelings and experiences. They may also reject the idea that they could use any support or assistance themselves, though in fact we know that caregiver burden can have a negative impact on both the caregiver and the person they’re caring for, and that proper support can help to alleviate that impact.

Caregiving in the LGBT Community

LGBT caregivers make up 9% of the 34.2 million Americans caring for adults over age 50, which is an estimated 3 million people.¹² LGBT people also become caregivers at a slightly higher rate than their non-LGBT peers: 1 in 5 LGBT people is providing care for another adult, compared to 1 in 6 non-LGBT people.¹³ LGBT caregivers come from a variety of different backgrounds and provide care in a variety of different relationship structures, but there are some common themes in the unique needs and experiences of most LGBT caregivers, as well as those who are caring for LGBT older adults but may not be LGBT-identified themselves. The next section will explore some of these unique needs and relationships.

LGBT Caregivers in Context

In the general population, the vast majority of caregivers (85%) are caring for either a parent, spouse, or other relative.¹⁴ Looking at that statistic in reverse, we see that when older adults need care, they typically turn to a child, spouse, or other relative for assistance. LGBT older adults are 4 times less likely to have children and twice as likely to be single as their non-LGBT peers.¹⁵ They may also be estranged from their biological or legal family members if those people do not accept their sexual orientation and/or gender identity.



If an LGBT older adult has no legal family to rely on, who cares for them?

“I believe to be entrusted with the care of another human being is one of the greatest honors bestowed on us.”

Yes, there will be difficult days, but there will be days that are filled with the most beautiful and meaningful conversations two people will ever have in life.”

Christopher MacLellan, M.A.

Author: “What’s The Deal with Caregiving?”
Certified Caregiving Coordinator & Educator
WholeCareNetwork.com
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Incorporate *Families of Choice* into all discussions about caregiving.

Families of Choice

In the absence of people to rely on from their families of origin, LGBT individuals have a long history of creating *Families of Choice*, typically made up of friends, partners, ex-partners, and perhaps a few relatives. As an LGBT person ages they may turn to their family of choice to ensure their social, physical and emotional well-being. It is common for the majority of an LGBT older adult's close friends and chosen family to be older adults themselves, which means that many older LGBT individuals rely on one another for caregiving, and a large number of LGBT older adults find themselves becoming caregivers.



Families of Choice: Diverse family structures and support networks that include but are not limited to life partners, close friends, and other loved ones not biologically related or legally recognized but who are the source of social and caregiving support.



Be careful when using the term *Family Caregiver*. If you mean to include friends and other unrelated loved ones, be sure to state that, or explain that you mean “family” as defined by the care recipient.

LGBT people become caregivers at a higher rate than non-LGBT people, and make up 9% of the caregivers in the United States.¹⁶ Yet a large number of LGBT caregivers continue to go “under the radar” of aging service providers. This is partially due to a lack of understanding about what “LGBT caregiving” is and who the people in this category typically are.

Three Types of Caregivers

When we talk about “LGBT caregiving,” we are referring to three primary groups, each of which has its own unique challenges and experiences:

1. LGBT Older Adults Caring for Other LGBT Older Adults

Examples: *A gay man caring for his husband; a bisexual woman caring for her ex-partner*

The peer networks where LGBT older adults find care stem from families of choice, and provide critical support in times of need, often in the absence of biological family. These caregivers generally do not see themselves as caregivers; they simply see themselves as “doing the right thing” for a close friend or partner. This is typical of all caregivers, but may be exacerbated in the LGBT community because of non-traditional family structures. The term *Family Caregiver* may be particularly alienating to this group, both because they are not accustomed to their families of choice being recognized as “families,” and because so many have strained relationships with their families of origin.

When the caregiver and the care recipient are both older adults, the caregiver may experience diminished capacity to provide some types of assistance. That can be problematic, especially if there are few others to

step in. For example, if the primary caregiver is hospitalized, what happens to the care recipient? Additionally, older LGBT people frequently adhere to a cultural norm of “taking care of our own,” and may be particularly reluctant to reach out to service providers or to accept outside help when it is offered.

LGBT older adults are more likely to be caring for one another in isolation, without other people involved to share the burden. Only about half of all caregivers have another unpaid caregiver to help them,¹⁷ and about 2/3 of family of choice caregivers, many of whom identify as LGBT, provide sole care (43%) or are the primary caregiver (25%).¹⁸ Having just one caregiver means that the person receiving care lacks a safety net, and that the caregiver is likely to experience increased burden, both of which could ultimately jeopardize the care recipient’s ability to age in place.

2. Caregivers Who Happen to Identify as LGBT

Example: A lesbian daughter caring for her aging mother

When a group of siblings need to provide care for an aging parent, it is common for the LGBT member of the group to become a primary caregiver. This may be because families of origin perceive their LGBT relatives to have more time and availability—especially if they do not have children or are not open to their families about their relationships and families of choice.¹⁹

These caregivers are primarily young or middle-aged adults caring for their aging parents. Resources and services intended for general or non-LGBT audiences will likely be more relevant to this group, because the relationship between the caregiver and a parent is a common one recognized by many service providers. There are, however, some specific issues that arise for these caregivers.

LGBT caregivers may seek out LGBT affirming services or facilities for their loved ones, so that they will feel welcomed and respected themselves. However, depending on the attitudes of their care recipient, they may be reluctant to talk about their identities or even involve a partner in providing care. Also noteworthy is that these LGBT caregivers may be providing care to a family member with whom there is a strained

Multiple Caregiving Experiences

Many LGBT older adults fall into multiple categories of caregiving at the same time. With LGBT individuals more likely to provide care to non-relatives and their family members seeing them as more available to provide care, LGBT individuals may be going through multiple caregiving experiences and therefore have increased caregiving-related stress. (Fredriksen-Goldsen et al., 2011)





40% of LGBT older adults age 45-75 say that their support networks have become smaller over time, compared to 27% of non-LGBT older people.

SOURCE: OUT & VISIBLE, 2014

relationship—it is not uncommon to hear of an LGBT individual caring for an ill parent who never accepted his or her identity. These caregivers may require some additional emotional support to cope with caregiver burden.

3. Others Caring for LGBT Older Adults

Examples: A nephew caring for his transgender aunt; a neighbor concerned about the isolated gay man next door.

Lastly, non-LGBT people caring for LGBT older adults may personally feel welcomed in a wide variety of organizations and have other supportive resources for their own wellbeing. However, when seeking resources for their care recipient they may be surprised to find limited LGBT-specific or openly affirming services. Because LGBT older adults are often quite isolated, an observant neighbor, acquaintance or distant relative may be the one who calls an aging service provider to seek help for that person. If they know the individual is LGBT, they may seek assistance locating an LGBT program or help from the local LGBT community. It should be noted that these non-LGBT caregivers provide access to some of the most isolated members of the LGBT aging community.

IN CONCLUSION: The most vulnerable of these groups is LGBT older adults caring for their LGBT peers. These caregivers experience compounded health disparities, and many have the added stress of knowing that there is no one else to care for their loved one should they need to relinquish their caregiving duties. They may be reluctant to access services for either themselves or their loved ones, and require particular attention to engage and support.

As we look at the caregiving relationships within the LGBT community, we see similarities and differences among several different kinds of caregivers. It is our hope that this guide will help you to support all of these populations by providing information and tools to assist you in creating programs that are responsive to the common needs of caregivers in the LGBT community.

SAGE LGBT Elder Hotline

There are some LGBT older adults who are so isolated they truly have no one who can serve as a caregiver. Connecting them with resources and organizations that are LGBT affirming is critical. One resource for these older adults is the SAGE LGBT Elder Hotline: 1-888-234-SAGE. This toll-free number connects older LGBT people to a trained volunteer who can provide resources and peer-to-peer support.



Common Issues Facing LGBT Caregivers

Legal Recognition of Families of Choice

For many LGBT people, families of choice are the cornerstones of caregiving. These chosen families provide social, emotional and physical support, and often serve as advocates when medical needs arise. However, most families of choice are not afforded any legal recognition or protection, and service providers may not think to inquire about or include these people in their work. It is important to recognize these relationships, and to provide support in completing paperwork that ensures the wishes of the care recipient are recognized.



The CARE Act

A majority of states have adopted some version of the CARE (Caregiver Advice, Record, and Enable) Act. This legislation varies from state to state, but its basic premise is that hospitals are required to ask patients at admission whether they'd like to designate a caregiver.



Once a caregiver is named, regardless of that person's relationship to the patient, the hospital is generally required to record the name of the caregiver in medical records, inform the caregiver when the patient is being discharged, and give the caregiver adequate training on how to perform any medical tasks needed at home.

Importantly, most versions of the CARE Act have no stipulations about who may be named as the caregiver, which means that the patient can name a friend or chosen family member and have the hospital formally recognize that person as the caregiver.

Contact your local AARP office for more information about the CARE Act in your state.



Help to ensure that ALL older adults have advance directives in place.

Guidelines released by the Obama administration in 2011 extended hospital visitation rights to individuals regardless of sexual orientation, gender identity, or family makeup. However, in the absence of advance directives that specifically name the person(s) appointed by an individual to make medical decisions on their behalf, hospital personnel are obligated to rely on the patient's next of kin for any medical decisions. Assisting the care recipient with completing advance directives is essential to help ensure that their caregiver has the right to make medical decisions during a time of medical crisis. You'll find more information about advance directives at the end of this section.

Likelihood to Access Services



LGBT older adults are five times less likely to seek medical care or social services

LGBT older adults are five times less likely to seek medical care or social services than the general public.²⁰ This is understandable when considering that older LGBT individuals endured decades of stigma and even harassment from providers. By avoiding medical care, they are often putting themselves at risk for negative health and mental health outcomes. With this strong mistrust and skepticism towards providers, some LGBT caregivers and the LGBT individuals they care for may choose to keep their identities secret, or simply not engage in services unless they are certain that they will be welcomed.

When they do reach out to providers, caregivers may be reluctant to share the nature of their relationship, either to protect their loved one from being outed, or for fear of being shunned or dismissed from their loved one's care team. This lack of transparency may not only invalidate the identity of the caregiver but has serious ramification in providing comprehensive care and services. In order to support LGBT older adults and caregivers, it is crucial for care providers to anticipate non-traditional family structures and provide support to them as they would caregivers who are traditional relatives.



Our program had a client who was very hesitant to reveal her relationship to the woman she was caring for. When she was finally asked directly, she shared that the woman was her ex. She had been afraid to reveal that because of the reactions she'd received in other settings where she tried to access services.

One telephone operator at a local resource hotline asked her rudely “Why are you caring for your ex?!”

and encouraged her to be less involved. It was from their former relationship that our client knew this woman did not have family supports. When someone steps up, we have to support them for it.”

Nate Sweeney, MA, LNHA

Executive Director
The LGBT Health Resource Center
of Chase Brexton Health Care
Baltimore, MD

Financial Concerns

LGBT older adults are less likely to be financially ready for life after retirement.²¹ The financial barriers can make it difficult for an LGBT older adult to coordinate and afford additional support and resources, thus increasing their reliance on loved ones. When the care recipient has fewer resources, caregivers may feel pressure to help provide health care, food, and other essentials for their loved one and, in turn, neglect themselves. Caregivers who qualify for public benefits or other assistance themselves may not seek them out because they are too busy providing care.

Caregiver Burnout and Isolation

The act of providing physical, emotional, and perhaps financial support to an ill or aging person can lead to isolation, stress, and eventually caregiver burnout. When a caregiver burns out it may result in their care recipient being temporarily neglected or being moved into long-term care prematurely. Caregiving in isolation, without others to share the burden, may increase the risk of burnout.

Though caregivers often express the benefits of caregiving, such as forming a close bond with the care recipient or a sense of satisfaction from giving back,



One research study found that adult children of lesbian, gay, bisexual and transgender elders faced discrimination as they advocated for the care and empathy of their loved ones. The findings showed that inequities exist in their ability to access health care for their loved ones and in the delivery of such services. Such discrimination was often based on the perception of the elder being a gay male or lesbian woman (Brotman, Ryan, Collins, et al., 2007).

One can imagine the hurt and hopelessness of the caregiver trying to advocate for quality and necessary services for their LGBTQ loved one, and to find subtle and not so subtle indicators that they and the person they love are being treated in such a manner. Also, if the loved one is a same-gender partner, how can the caregiver protect her/him/themselves and their mate? Must they pass as siblings? Perhaps, as a safety plan in the face of staff that is prejudicial and untrained in basic LGBTQ/Same-Gender Loving (SGL) culture.

Combined perceived or actual oppression of homophobia hurts the very people needing social services.

I would go further and affirm that by virtue of the frequent social isolation of LGBTQ/SGL people, LGBTQ/SGL elders will be less likely to access the very social networks that are important factors to successful aging, like Caregiving Circles and Support Groups.”

Dr. Imani Woody

President and CEO,
Mary's House for Older Adults, Inc.
Washington, D.C.

they are also at high risk for emotional distress and poor health outcomes. The strain of putting another person's needs first can be compounded by employment and other time commitments outside of caregiving, by the caregiver not being out in their social or work life, or by a conflict in the relationship (as in the case of an LGBT child caregiving for an unsupportive parent). All caregivers are susceptible to caregiver burnout; the LGBT caregiver is likely to experience some additional factors that can increase caregiver burden and lead them to burn out more quickly.

Whether an LGBT caregiver is providing care for a member of their family of origin or family of choice, it is apparent that this population is in need of supportive services. It is important to understand the complexities and challenges LGBT individuals face, as well as the unique issues of LGBT caregiving in light of what is known about caregivers in general. By reaching a point of understanding, organizations can begin to develop meaningful and approachable direct services and support for LGBT caregivers.

Special Topic: Advance Directives

Advance directives allow an individual to ensure that their wishes will be honored should they become unable to communicate or make decisions for themselves. All adults should have advance directives in place, but they are particularly important for people whose caregivers or closest loved ones are not legal relatives, as is the case for many LGBT people.

Anyone whose primary caregiver is not their legal next of kin should consider putting together the following documents to ensure their wishes are respected (adapted from Lambda Legal's *Take the Power* toolkit):

- Medical Power of Attorney (sometimes called a Health Care Proxy)
- Living Will
- Hospital Visitation Directive
- HIPAA Waiver
- Financial Power of Attorney
- Will
- Written documentation of an individual's wishes upon their death—may include funeral arrangements, disposition of remains, organ/tissue donation, pre-written obituary, etc.

State-specific advance directive forms and instructions can be obtained from your state health department or local Area Agency on Aging, or at the following websites:

- AARP: aarp.org/advancedirectives
- National Hospice and Palliative Care Organization: caringinfo.org/advancedirectives
- National Healthcare Decisions Day: nhdd.org/state-specific-resources



Creating and Sustaining LGBT Caregiving Services

Supporting LGBT caregivers through programs and services is one of the best ways for an agency or organization to have a positive impact on the lives of both caregivers and older adults receiving care. This section includes a number of programs that have been found to be helpful for caregivers, along with notes about things to keep in mind regarding LGBT caregivers specifically.

Service providers are encouraged to pick and choose among the programs suggested here, in order to best match the capacity of your agency to the needs of the local service population.

It is not necessary to start from scratch in creating programs for LGBT caregivers; in fact, you may be more successful if you work to build on existing programs. Assess what your organization already does well, and look for



LGBT caregivers' needs are unique since often they are not biological family members and are not treated with the same respect or understanding. Many of the LGBT caregivers in our program are LGBT older adults themselves. Both caregivers and care recipients benefit from our programming—from support groups for caregivers to Friendly Visitors for homebound care recipients, and case management to address concrete needs for both, SAGE ensures that a holistic care plan is enacted. Challenges can emerge when care recipients refuse help from anyone except a caregiver, which puts tremendous strain on that caregiver. And sometimes caregivers are reluctant to accept help themselves, prioritizing care recipients' needs over their own. Further, sometimes friends and members of chosen family involved in a loved one's care don't think of themselves as caregivers and so may not want to attend a support group or accept other assistance."

Teresa Theophano

Assistant Director
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opportunities to expand your programming to include this particular audience. That may mean adding a caregiver support group at your LGBT center, or making sure that your case managers know which external resources will be welcoming to your LGBT clients. Whatever path you choose, know that a little effort can go a long way toward improving the lives of LGBT older adults and caregivers.

On the following pages we provide suggestions in the areas of supportive services, educational programming, socialization & wellness, and grief counseling.

Before You Begin



Ensure that your agency is welcoming to LGBT older adults.

If you have not yet worked with older LGBT communities, it is recommended that you implement some best practices to make your agency generally welcoming to LGBT older adults before you move on to specific programs. Assess your organization's knowledge of LGBT issues, and consider going through formalized LGBT cultural competency training in order to best understand the history, language, and social and political context of the community. If you believe your organization could use a refresher, if you have never had a formal LGBT cultural competency training, or if you would like to learn more specifically about LGBT aging, request a SAGECare training (see below) or visit the National Resource Center on LGBT Aging to find resources, such as the Best Practice Guides on the following page.

Likewise, LGBT organizations that have not done extensive work with older populations might consider training on aging issues, ageism, the older adult population, and LGBT aging specifically. The National Resource Center on LGBT Aging offers a guide designed for LGBT organizations (also on the following page) and SAGECare offers trainings on ageism that are specially intended for those that already have a high level of LGBT competency.

Supportive Services

Many LGBT older adults are distrustful of service providers and may be reluctant to reach out for help. Like other caregivers, they have a tendency to reach out only once they reach a point of crisis. Making changes to your services proactively will ensure that you are prepared to welcome LGBT people whenever they engage with your organization.

SAGECare Training



SAGECare is SAGE's training and consulting division. They partner with your agency to deliver the tools necessary to create a culture of dignity and respect for all clients, including LGBT individuals. Trained agencies may qualify for a SAGECare credential. For more information about SAGECare training, visit sageusa.care.





Ask ALL clients about their care relationships on intake in order to identify caregivers.

INTAKE

An intake or initial evaluation is typically one of the first points of contact with a client, so the language used and types of questions asked may set the tone for the comfort level of a client who is LGBT. Using inclusive and affirming language may help a client feel more comfortable and open to sharing important information related to their care and relationships, and can make LGBT clients more comfortable even if they do not choose to come out as LGBT. When working with caregivers, it is particularly important to acknowledge families of choice and ask open-ended questions that leave room for answers about many different types of relationships. You might ask simply “Who do you consider family?” to learn more about a client’s social network and family of choice. Questions such as “Who can you rely on?” and “Who would you call

Best Practice Guides

For resources and best practices on supporting inclusion in your organization, see these guides provided by the National Resource Center on LGBT Aging:



- For aging organizations: *Inclusive Services for LGBT Older Adults: A Practical Guide to Creating Welcoming Agencies* provides a general overview of best practices for serving LGBT older adults.
- For LGBT organizations: the *Age-Friendly Inclusive Services* guide offers insights and best practices for working with older adults in an LGBT setting, and was updated in 2017 to include information on caregiving.

Both guides are available free at lgbtagingcenter.org/guides.

Linking Programs to Behavioral Health Services

by Nate Sweeney, MA, LNHA

Executive Director, The LGBT Health Resource Center of Chase Brexton Health Care
Baltimore, MD

Our menu of caregiver support services included monthly lunch & learns, a support group, one-on-one support, and navigation to LGBT affirming aging services.

As a Federally Qualified Health Center [FQHC], we were also connecting participants to our medical services, including Behavioral Health. When an opportunity presented itself, we reorganized the program by bringing in a clinically licensed social worker as the program manager, leveraging our organization's existing Behavioral Health services to integrate the program more completely. In practice, this has allowed us to offer individual counseling to more of our participants, expand the number and types of groups we can run, and to meet people where they are with a higher level of service.

The decision to integrate Behavioral Health into our caregiver support program came in response to several observations. Based on what we heard from participants, we felt that there was a need for expanded Behavioral Health services for LGBT older adults, and that assumption was swiftly validated as appointments with the new provider filled up. We also wanted to address the fear that many LGBT older adults feel about connecting with a provider—by threading the program management together with the clinical services, we are able to put a face and voice out for the participants to meet, and



build familiarity and trust before they ever enter into formal counseling. Finally, this new model offers sustainability for the program; having billable services directly integrated has created a reliable funding stream, making us less dependent on grants and other external funding.



For more information about the services offered by the LGBT Health Resource Center of Chase Brexton Health Care, visit resourcecenter.lgbt.



Expand your definition of family, and be open-minded about who might serve as a caregiver.

in an emergency?” help clients to think about their care networks in realistic ways, and give you information that is much more valuable than a simple emergency contact, which could be a distant next of kin. These entry points can also open up discussions about people for whom the client provides care, helping the provider to identify the client’s need and eligibility for caregiver support services.

Keep in Mind: Specific questions about sexual orientation and gender identity should be asked of all clients, not just those who are presumed to be LGBT. Clients should always have the option to not answer these questions if they don’t feel comfortable doing so.

COUNSELING

Counseling and social support may come in various forms, however at its core, “counseling” refers to offering direct support and facilitated guidance to the caregiver, with the goal of improving the caregiver’s wellbeing. Caregivers very often experience feelings of stress, frustration, guilt, sadness, and other emotions that may be difficult to manage, and counseling can be beneficial for



copied with those feelings. Unfortunately, it can be extremely difficult to engage caregivers in counseling, as they are frequently overwhelmed and often feel they must prioritize the needs of their care recipient. It is common for caregivers to either struggle to make time for their own care, or decline assistance for themselves outright.

Keep in Mind: For LGBT caregivers, there may be an added barrier of a distrust of mental health providers, based on personal experience or historical knowledge. There’s also a cultural value of “taking care of our own,” among many LGBT older adults, who may distrust anyone that they don’t know well. If an LGBT caregiver is engaged in counseling, there may be particular conflict to explore regarding the relationship between the caregiver and the care recipient, for example if the care recipient does not accept the caregiver’s identity. It’s also useful for providers to be aware that caregiving now may bring up difficult feelings or memories related to the AIDS epidemic, as many surviving LGBT people acted as caregivers for friends during that time.

CASE MANAGEMENT



Advocate for the caregiver's right to serve as a caregiver, regardless of their relationship to the care recipient.

Case management, sometimes referred to as geriatric case management for older adults, refers to the coordination of services on behalf of an individual and their loved one's needs. This service can often alleviate the burden of a caregiver by offering support in managing some of the needs of their care recipient. For example, a home health aide who visits regularly can provide a much-needed break for someone whose care recipient cannot be safely left alone. A case manager could suggest this type of service, assess the care recipient's eligibility, and help to set up the aide's initial visits.

While many caregivers may turn away direct help for themselves, case management can be an indirect way of providing support, and can significantly reduce caregiver burden. By keeping the focus on helping the care recipient, providers may be able to “break through” to caregivers who are otherwise reluctant to accept help. Repeated meetings about the care recipient can be an opportunity to slowly introduce the idea of direct support (perhaps counseling or a support group) for the caregiver themselves.

Keep in Mind: When making referrals for someone who is LGBT and/or has an LGBT caregiver, be sure that any organization you are referring them to will be welcoming and respectful. Communicate with the caregiver and care recipient about whether they want their relationship (whatever that may be) revealed to external providers. If the caregiver is not a spouse or relative, you may need to advocate for their right to act as the caregiver in other settings. This may include completing release of information forms, advance directives, and other documents that safeguard the rights of the care recipient and caregiver.



As a health resource center we had to look at integrative care and how we can support a caregiver in their journey. Because our program includes case management, we can have an individual who comes in looking for resources actually establish a connection with a case manager who will work to explore their needs.

By asking the right questions, the case manager can determine whether the individual is a caregiver.

If so, she can assist that individual in recognizing that they are a caregiver, which so many do not realize, and connect them to resources that specifically support them in that role.”

Monte Ephraim, LCSW-C

Manager, Psychosocial Services and LGBT
Older Adult Programming
The LGBT Health Resource Center
of Chase Brexton Health Care
Baltimore, MD

SUPPORT GROUPS

Many social service agencies already offer support groups and are familiar with how to run them, so this may be an appealing option for organizations seeking to begin caregiver support. Support groups can offer emotional support to caregivers as well as an opportunity to socialize and meet others who are going through similar experiences. Caregivers may be surprised to discover that other people share the same feelings of frustration, anger, etc., and this shared experience can be extremely validating.

Caregiver support groups can be challenging to get started, as caregivers often find it difficult to make time to attend programs consistently. Be mindful of where and when your group takes place—you may want to do some local research first to determine when caregivers will be most likely to attend. For example, if most of them work full-time jobs, it may be important to hold groups in the evening or on weekends. Be prepared for the group to start with small numbers, and allow time for it to build. Once established, these groups can become essential resources for the caregivers who participate, and group members tend to form strong bonds that carry beyond the group meetings.

Keep in Mind: Effective LGBT-inclusive support groups require setting a tone that is respectful and welcoming of LGBT voices and stories. Provide facilitators with LGBT cultural competency training. Be up front with group members from the beginning that the support group is inclusive of LGBT caregivers, and set expectations that all group members will be treated with dignity and respect. LGBT caregivers may not be accustomed to openly discussing their relationships and may find themselves fearful of disclosing



The group cohesion and spirit of mutual aid has made for many successful caregiver support group meetings.

Some challenges can emerge when group members aren't getting enough support elsewhere, including individual services; it can be hard when a member comes in with the same problem each week and isn't amenable to hearing other members' ideas. My advice for others looking to start similar groups is to screen prospective members carefully, let the members set the topics/agenda, and keep a basic structure in place—for example, doing a round-robin check-in followed by time for open discussion. It is important to adhere to basic group guidelines such as starting and ending on time, maintaining confidentiality, and allowing everyone a chance to speak."

Teresa Theophano

Assistant Director,
Care Management Services
SAGE
New York, NY

information—encourage facilitators to model LGBT affirming language when discussing caregiving relationships. Facilitators may also need to redirect questions being asked of LGBT participants if they are intrusive or based only on curiosity. Provide space for LGBT caregivers to meet privately with the facilitator if they are not feeling safe or comfortable in the group setting. Finally, remind all group members to respect the confidentiality of stories and personal experiences being shared in the group. This can be especially important for LGBT caregivers who may not be out publicly.

RESPITE CARE

Respite care is care provided by a qualified facility or individual that allows the primary caregiver to take a break and leave their loved one in good hands. Though caregivers frequently express the need for time off from caregiving, many are unfamiliar with respite care services and may not know what is

Friendly Visitor Programs

As LGBT older adults and caregivers are more likely to experience social isolation, a Friendly Visitor program may be a nice complement to your existing programs. Friendly Visiting engages volunteers from the LGBT community who have been carefully screened and trained, and matches them with homebound older adults (“Friends at Home”) to provide socialization and support. When an individual reaches out to the organization, a social worker or staff member does an initial intake and in-home assessment, after which the staff member will make a referral to the Friendly Visitor program.

SAGE has offered this program in New York City with great success, as have several SAGE affiliates and partners. While this program is successful at leveraging



intergenerational support and expanding the network of care for the Friend at Home, there are some challenges that can arise. A dedicated staff member is strongly recommended to ensure adequate support for the volunteers and the Friends at Home.

If a non-LGBT-specific Friendly Visitor program already exists in your area or within your organization, consider adding questions to participant screenings to assess each person’s comfort level with LGBT people. Adding an awareness of LGBT identity to the existing matching process is an easy way to ensure that both Friends at Home and volunteers are respected and comfortable.





Wondering how to find services that are LGBT-friendly? Check out *10 Tips for Finding LGBT-Affirming Services* and hundreds of other resources at lgbtagingcenter.org.

available to them. Respite care that is covered by medical insurance or Medicaid does exist, but it can be difficult to access due to limited resources and waiting lists. Other options might include private-pay care, an Adult Day program, a part-time home health aide, or visits from trusted friends. For a caregiver whose care recipient cannot be left alone, even a few hours of respite can make a significant difference in their wellbeing, allowing them an opportunity to recharge and focus on self-care for a while.

Keep in Mind: Whether it's provided in a congregate setting or by an individual, respite care must be LGBT affirming. LGBT older adults can be particularly nervous about someone coming into their home if they do not know how that person feels about LGBT people. One option may be to provide training to members of the care recipient's existing social network, so that they can be the ones who provide care.

Educational Programming

Education is a key component of supporting caregivers and their care recipients. Better preparing and educating caregivers for both their caregiving duties and their own self-care can lessen caregiver burden and lead to better outcomes for the care recipient.

LUNCH AND LEARN WORKSHOPS

A "Lunch and Learn" is typically a structured program that involves a shared community meal and an educational presentation. If your organization can provide lunch, it will serve as an incentive and likely attract a larger crowd. If not, a "brown bag" lunchtime event may still be effective, as the lunch hour can be an easier time for some caregivers to attend. The meal helps to make the event less formal and more socially oriented, which can create an easier environment for reluctant participants to join in. Think about workshops that

Our monthly Lunch and Learn series has been one of our most consistently attended programs.

Taking place on the second Thursday of every month, the workshops feature a different topic of interest to our participants, presented by various partner agencies in our local area. Participants come for the information, the free lunch, and the chance to socialize. The monthly program keeps our participants engaged and helps us to build and maintain relationships with them, and also provides an easy way for us to build partnerships with other organizations."

Kelli Abbott, MSW

SAGECAP Outreach Counselor
The LGBT Health Resource Center
of Chase Brexton Health Care
Baltimore, MD

can help to educate caregivers about issues that affect both themselves and their care recipients. There is a list of suggested topics on the next page.

If a “lunch” format does not work, the educational component can be the entirety of the program, which might instead be called a Workshop or Seminar. These programs can still provide some socialization along with education and empowerment. Workshops (which are typically interactive) and seminars (generally didactic) can cover the same sorts of topics as Lunch and Learns, but might take a more formalized approach. Topics can range from practical, such as learning how to properly transfer a care recipient using a gait belt, to emotional, such as tips for coping with stress, as well as informational, such as exploring long-term care options or understanding Medicare. Some topics will help participants to better care for their loved ones, while others will encourage them to plan for their own futures and take care of themselves.

If resources allow for it, it is ideal to produce these programs as a series, perhaps once every month or four times per year. Scheduling and advertising multiple sessions at once will help you to more easily manage logistics, and will help participants to plan ahead so that they’ll be able to attend. Consider setting up a carpool, or providing fare cards for public transportation. Everything you can do to make it easier for caregivers to attend will help to encourage participation.

Keep in Mind: When recruiting presenters for these programs, set clear expectations that the workshop should be educational, not a marketing presentation. Ensure that the presenter is knowledgeable about any LGBT considerations relevant to the topic and prepared to answer specific questions.



Giving caregivers a chance to socialize at informational events may make them more likely to attend repeatedly.

Lunch & Learn Topics

Below is a list of popular topics for Lunch & Learn events or Caregiver Workshops/Seminars. When planning events of your own, think about who you know and what they can offer—community partners, local businesses, and even your own staff can likely share information that would be of great value to caregivers. Tap into existing partnerships, or use the events as opportunities to build new ones.



- Financial Planning & Budgeting
- Navigating Long Term Services and Supports
- Coping with the Holidays: Stress Management Tips
- Security & Fraud Awareness
- Know the 10 Signs of Dementia
- Medication Management
- Conquering Clutter
- Advance Directives
- Open Enrollment for Medicare
- Long-Term Care Planning
- Energy-Saving Tips

LIFE PLANNING CLINICS

Lunch and Learn workshops are a great place to feature information about life planning issues, but if you have the opportunity, consider taking it one step further. A life planning clinic enables participants to complete some of their advance directives on the spot, with the help of qualified volunteers. You may be able to partner with a local law firm, Legal Aid office or even a law school student group to provide the expertise and assistance. Be sure to have a notary on hand if your state's forms require them. National Healthcare Decisions Day, which takes place annually on April 16th, is an ideal tie-in for this type of program; visit their website at nhdd.org for more details.

Keep in Mind: Advance directives are important for all older adults, but are particularly important for LGBT people. Make sure presenters understand current law as it pertains to families of choice so they can answer questions.

ON-DEMAND RESOURCES

Caregivers are busy, and it can be hard for them to make time to attend programs. Many do not look for help until they are in crisis, so when they do realize they need help, they may already be at a breaking point and need it immediately. For these reasons it is unsurprising that caregivers seem to be drawn to resources that they can access on demand, such as websites, downloadable flyers or fact sheets, and podcasts. Post information online and consider developing resources that caregivers can access through your website. Make printed copies as well, as not all older adults can easily access a computer.



The Maryland Caregiver Teleconnection was designed to allow family caregivers to connect to experts with information—and other caregivers with similar life experiences—to provide emotional, educational and social support without having to leave their home. Family caregivers had the opportunity to call in toll free for a one-hour conversation or listen to the recorded session on the Called to Care website at a later time. We soon discovered that offering live sessions was not beneficial to our community, and

family caregivers preferred to listen to the sessions at a time that was more convenient for them.

We're now replacing the live sessions with podcasts that are organized similarly to a talk radio show, in which an expert and a facilitator are engaged in conversation about a caregiving-related issue, in order to make the information more accessible."

Kimberly Monson

Community Program Coordinator
Called to Care
Johns Hopkins Bayview Medical Center
hopkinsmedicine.org/jhbmc/c2c
Baltimore, MD

Keep in Mind: Be sure to include information about LGBT people and families of choice when you develop these resources, and make it clear when you are discussing family caregivers that anyone can be considered a member of the family. Consider using LGBT-inclusive images in your materials, such as photos of same-sex couples, the transgender pride flag, or the rainbow. Once you have produced this content, do not assume that LGBT people will come to you and find it; reach out to your local LGBT center, PFLAG chapter, or the LGBT media to let people know about your resources.

Socialization and Wellness

WELLNESS PROGRAMS

Caregiving, even for the most experienced and prepared caregiver, is stressful. While programs pertaining to education and resources are helpful, at times a program focusing on self-care can be the most impactful. Whether yoga, relaxation classes, or a celebratory lunch, moments of respite and self-care can be critical to sustaining caregivers during the most difficult times. Workshops that teach caregivers skills for relaxing on their own may be particularly effective, as they encourage long-term shifts in the caregivers' behavior.

Keep in Mind: LGBT participants may have difficulty relaxing if they are not in an environment in which they feel respected. Do everything you can to make your space and programs welcoming and affirming of LGBT identities, without calling attention to any particular individuals. You may also consider hosting programs at a local LGBT community center or group, so that LGBT participants will be in a familiar and safe space.



SAGE conducts quarterly special events for caregiver clients, recruiting from our client base via email, snail mail, and telephone; they are welcome whether or not they are members of our support groups. The events have ranged from a half-day wellness fair with yoga and tai chi to a mini CPR training to an advance directives workshop led by two volunteer attorneys. Our next event will be a meditation and Feldenkrais (gentle movement) workshop for caregivers, and a recent one that featured Reiki mini-sessions and a massage therapist teaching self-massage techniques was a big hit.

The events offering relaxation and stress relief tend to be especially popular,

and are direct results of suggestions that emerged in the caregiver support groups.”

Teresa Theophano

Assistant Director
Care Management Services, SAGE
New York, NY

Creating Resources in Michigan

by Kathleen LaTosch, MSW

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Detroit, MI

In 2016, the Kendal Charitable Trust provided a grant for the three Area Agencies on Aging serving the Detroit area in Michigan to expand an existing collaborative and help support those who either were caring for an LGBT older adult and/or who were themselves an LGBT older adult and caregiver. The model involved creating a Caregiver Guide—available free and online at sagemetrodetroit.org/caregiving-lgbt-concerns-guide. The guide includes valuable information on legal concerns, healthcare, financial concerns, and discrimination and includes a list of questions that caregivers may want to consider if they are caring for an LGBT older adult.

Early on, collaborators discussed and planned around how to best reach caregivers of LGBT older adults and decided to use the existing aging services network, along with the LGBT community, to reach people.

After developing a number of simple print pieces, the group collectively distributed over 4,300 flyers at a variety of events, including:

- Area Agency on Aging mailings to their mailing lists
- Regional Caregivers Conference
- Michigan Medicare/Medicaid Assistance Program Partner Sites
- Creating Confident Caregivers—State of Michigan training series

The model involved creating a Caregiver Guide—available free and online at sagemetrodetroit.org/caregiving-lgbt-concerns-guide.

- LGBT organizations—websites, e-newsletters and print materials
- Several live events and activities, such as public events geared toward seniors (Senior Power Day, Palmer Park Senior Walk), MAP open enrollment sessions, senior center events and workshops (Medicare 101, Safety Summit, etc)

Because the initiative was collaboratively based, each partner organization took part in identifying key events/activities and made materials available to staff who would already be attending tabling events. This minimized overtaxing project staff and helped each agency practice getting the word out.

The collaboration has since completed this cycle of work and now mentors other regions in the State of Michigan to build their LGBT cultural competency through policy, procedure, and training development with Area Agencies on Aging serving rural parts of the state. The new project, the Michigan LGBT & Aging Initiative, began in January 2017 and will run through December of 2018.



For more information about any of these initiatives, visit SAGE Metro Detroit online at SAGEMetroDetroit.org.

SOCIAL EVENTS

Though caregivers might have a social network outside of their caregiving experience, they may not know many individuals who truly understand what they are going through. Social events provide an important means of connecting caregivers to one another and combating the isolation they often experience. By facilitating social events, the organization is offering another opportunity for the caregiver to engage in informal support and encouraging the natural formation of peer networks.



These brief breaks from the daily grind can be opportunities for the caregiver to acknowledge their own wants, needs, and individual identities, which can be very empowering and rejuvenating.

If it is at all possible to provide respite care during your social and educational programs, it will enable caregivers to attend who are likely in greatest need of these services. Respite care can be complicated to set up; consider working with a community partner that already provides respite care to make it available to your participants during your programming.

Because of their busy schedules and dueling priorities, caregivers may be less likely to attend a program that is purely social in nature, and you may find that a support group or educational series is your best bet for getting them through your door. If this is the case, capitalize on it by extending the time of the program to allow for socializing, or by scheduling or suggesting a coffee hour



It can be a challenge to reach participants

in the community who are unable to come to workshops and programming.

The reality is that we will never reach everyone, and that may be due to caregiving responsibilities, health issues, work obligations, social anxiety or extreme isolation.”

Kelli Abbott, MSW

SAGECAP Outreach Counselor
The LGBT Health Resource Center
of Chase Brexton Health Care
Baltimore, MD

or meal immediately following the planned program. The peer networks that develop among your participants may well be the most valuable things they gain from your programming.

Keep in Mind: LGBT caregivers may be more interested in social events that are exclusively for LGBT people, especially if they are interested in connecting with other LGBT people, dating, or if they have encountered negativity around their identity in the past. This is a good opportunity to partner with a local LGBT organization or hold an event at an LGBT-specific location.

Finding Participants

You likely have LGBT participants in your programs already, but finding more may require some targeted outreach. In addition to getting the word out, you will need to establish enough trust with the community for LGBT people to feel comfortable utilizing your services. Here are some suggestions:



- Be sure to include signals that you are LGBT welcoming in your marketing and outreach materials. This may include text, like “all families welcome,” symbols like the rainbow flag, or images of LGBT couples and families.
- If there are local LGBT organizations in your area, partner with them to produce programming and to promote your services. Specifically, you might look for:
 - An LGBT community center (visit CenterLink at lgbtcenters.org to find one)
 - An LGBT Chamber of Commerce
 - A local SAGE affiliate (sageusa.org/sagenet)
 - A local PFLAG chapter (pflag.org)
 - LGBT Resource Centers at local colleges and universities
 - HIV/AIDS Advocacy Organizations
- Advertise in LGBT media and on LGBT-targeted websites or social media groups.
- Participate in local Pride events.
- Find places where LGBT people gather, such as a particular neighborhood, restaurant, or bar. In addition to advertising your services, consider hosting programs at those locations.
- Use word of mouth—if you have current participants, staff or supporters who are openly LGBT, ask them to spread the word about specific programs or services through their networks.
- Don’t forget that LGBT people are everywhere, and not all of them are actively engaged in LGBT-specific activities. It is just as important to display LGBT resources and include information about your welcoming services when you do outreach in non-LGBT settings.

Meeting the Needs of LGBTQ Caregivers in San Francisco

*Ariel Mellinger, MSW, Program Coordinator
and Fairley Parson, LCSW, Program Manager
Openhouse, San Francisco, CA*

Openhouse, a San Francisco-based organization, enables Lesbian, Gay, Bisexual, and Transgender seniors to overcome the unique challenges they face as they age by providing housing, direct services and community programs.

In partnership with the Alzheimer's Association, Openhouse offers an LGBTQ-specific drop-in group for caregivers of those with dementia in order to support the unique challenges and strengths of LGBTQ caregivers. These can include:

- Lack of biological children and/or familial support
- LGBTQ Chosen Families: such families may play a critical role in caregiving. Still, chosen families tend to be made up of people from the same age cohort; this can present challenges as caregivers themselves experience age-related challenges such as mobility, illness, financial stress, etc.
- Concerns around heteronormativity, homophobia and transphobia in assisted living facilities and within in-home care
- Needing a space where one can feel centered as an LGBTQ person
- Many LGBTQ older adults lived through the AIDS crisis and have forged their lives with great resiliency. For some, living through the AIDS crisis or being a part of the long-term survivor community

has strengthened coping, caregiving, and advocacy skills. These experiences can also present challenges for those who have experienced losses that were marginalized by the greater society, as age-related loss can bring up traumatic memories. Moreover, many long-term survivors did not think they would live so long and have outlived their savings.

The LGBTQ Caregivers Group serves caregivers of all kinds: children caring for their parents, partners for their partners, friends for friends, and more. The way that folks provide care ranges from over the phone to 24/7 in-home care. A framework for understanding the challenges and strengths of the LGBTQ community is critical in creating a space where caregivers feel safe and supported to grieve, vent, strategize, get support, learn, and laugh with other caregivers—every 4th Wednesday of the month.

Openhouse, in partnership with Family Caregiver Alliance and the Alzheimer's Association, also offers free trainings to San Francisco health and social service providers on the dementia care needs of LGBT individuals and care partners. Many caregivers also find Openhouse groups such as “Self-Compassion and Resiliency” and “Grief Support” useful in their experience as caregivers. All of these groups take place in an LGBT-affirming environment.



For more information about the programs and services offered by Openhouse, visit openhouse-sf.org.

When Caregiving Ends

GRIEF COUNSELING

While caregivers need support throughout the caregiving process, they also need it after their care recipient has passed away. The care recipient is someone with whom the caregiver had a close and intense relationship, and after their passing the caregiver will be faced with the dual challenge of mourning the loss of their loved one and adjusting to a life without caregiving. They may need the support of peers and providers more than ever.

Bereaved caregivers should be transitioned out of caregiver support groups within a few group meetings, so as not to absorb the group's entire focus. Recognize that this may be difficult for someone who has found significant support through the group, and put a plan in place to transition them to either a bereavement group or individual counseling.

Keep in Mind: This is a time when it is particularly important not to make assumptions about the relationship between two people—just because the care recipient wasn't a family member, for instance, doesn't mean the caregiver's grief is any less painful. This is also why it's important to have a real understanding of a caregiver's family structure. Thinking that someone has lost a friend or "roommate" when they have in fact lost their long-term partner will prevent you from offering the appropriate support.



There are two common aspects every caregiver faces—a beginning and an end,

and in most cases, we are not prepared for these life changing events. Suddenly, caregiving is over and what is there left for the caregiver to do? Immersed in the care of someone else, now the former family caregiver is learning to live life differently, learning to be a caregiver to themselves.”

Christopher MacLellan, M.A.

Author: “What’s The Deal with Caregiving?”
Certified Caregiving Coordinator & Educator
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Measuring Success



To find existing caregiving programs in your area, contact your local Area Agency on Aging or use the Eldercare Locator at eldercare.gov.

In our current data-driven world, no new program should be undertaken without some plan for measuring impact or success. How you track your impact will be guided by your programming and your capacity. Consider planning the assessment at the earliest stages of the program design and implementation to ensure that you create effective and efficient methods of both understanding and communicating the success of your programming.

Caregiver support programs are particularly difficult to measure because in many cases the ultimate goal is to keep care recipients in their homes and healthy, and it is impossible to know if or when they might have had a different outcome without your programs. You should also be aware that participation numbers may be lower than they are for other programs because caregivers are difficult to get in to programming, and LGBT older adults may be isolated and difficult to reach. Serving this particular population often means making a big impact on a relatively small number of people, with each of those people having multiple, complex needs.

At a minimum, consider measuring the number of people who have participated in the programs, the number of counseling hours delivered, or the number of times a digital resource has been downloaded. Each of these puts some numbers to what has been produced, though none actually touches on the emotional or lived impact of the program. Collecting data on the caregiver's quality of life is possible with the consistent use of evidence-based assessment tools. For example, there are several "Caregiver Burden Scales," most of which are freely accessible online. Consider adding one of these to your intake process, in order to have a baseline against which to measure progress. Ultimately, if caregiver burden decreases and quality of life improves, the program has been successful.

**“We hear our participants say,
'I didn't realize these resources were here,**

I am glad I don't have to do this alone.' We have seen friendships form and support systems emerge as participants connect beyond our doors.”

Monte Ephraim, LCSW-C

Manager, Psychosocial Services and
LGBT Older Adult Programming
The LGBT Health Resource Center
of Chase Brexton Health Care
Baltimore, MD



Conclusion



For more resources on LGBT Caregiving, visit the National Resource Center on LGBT Aging at lgbtagingcenter.org/caregiving.

With caregiver support emerging as a major priority for aging service providers, professionals seek the best and most effective interventions for their needs. However, not all caregivers are the same. LGBT caregivers experience their own unique challenges, many of them stemming from the fact that they tend to rely on families of choice for their care. Often caring in isolation, LGBT caregivers are particularly vulnerable to caregiver burden and stress. They may be less likely to self-identify as caregivers because of their unique family structures, and they are less likely to seek out services or assistance due to fears of being treated poorly.

While service providers cannot take away all the stress in a caregiver's life, they have the capacity to serve a crucial role in easing burden by identifying caregivers and connecting them to services. By creating welcoming and inclusive programming for LGBT caregivers based on an understanding of their needs, and by proactively reaching out to caregivers in the LGBT community, service providers can deliver critical support and services that not only support and sustain the caregiver, but ultimately lead to a better quality of life for the person for whom they provide care. Through greater understanding of the LGBT population and the programmatic interventions provided by this guide, it is our hope that service organizations will be better prepared to recognize and attend to the needs of LGBT caregivers within their service populations.

References

- ¹ Fredriksen-Goldsen, K. I. (2016). The Future of LGBT+ Aging: A Blueprint for Action in Services, Policies, and Research. *Generations*, 40(2), 6-15.
- ² Choi, S.K. & Meyer, I. H. (2016). LGBT aging: A review of research findings, need, & policy implication. Los Angeles: The Williams Institute.
- ³ Fredriksen-Goldsen, K. I., Kim, H-J, Barkan, S. E., Muraco, A., & Hoy-Ellis, C. P. (2013). Health disparities among lesbian, gay, & bisexual older adults: Results from a population-based study. *American Journal of Public Health*, 103(10), 1802-1809.
- ⁴ Movement Advancement Project (MAP) & SAGE (2010). *Improving the Lives of LGBT Older Adults*. Denver, CO: Movement Advancement Project.
- ⁵ Fredriksen-Goldsen, K. I. (2011). The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults. Seattle, WA: Institute for Multigenerational Health. The full report and related publications may be accessed at caringandaging.org.
- ⁶ Movement Advancement Project (MAP) & SAGE (2010). *Improving the Lives of LGBT older adults*. Denver, CO: Movement Advancement Project.
- ⁷ Chari, A. V., Engberg, J., Ray, K. N., & Mehrotra, A. (2015). The opportunity costs of informal elder care in the United States: new estimates from the American Time Use Survey. *Health Services Research Journal*, 50(3), 871-882.
- ⁸ Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disable spouse: Longitudinal findings from the caregiver health study. *Psychology and Aging*, 15(2), 259-271.
- ⁹ Del-Pino-Casado, R., Perez-Cruz, M., Frias-Osuna, A. (2014). Coping, subjective burden and anxiety among family of older dependents, *Journal of Clinical Nursing*, 23(23-24), 3335-3344.
- ¹⁰ Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *jama*, 282(23), 2215-2219.
- ¹¹ Schulz, R. & Sherwood, P. R. (2008). Physical and mental health effects of family caregivers. *The American Journal of Nursing*, 108(9), 23-27.
- ¹² National Alliance for Caregiving, American Association of Retired Persons (AARP) (2015). *Caregiving in the U.S., 2015*. Retrieved June 2, 2017, from caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.
- ¹³ *Ibid.*
- ¹⁴ *Ibid.*
- ¹⁵ SAGE (2014). Out and visible: The experiences and attitudes of lesbian, gay, bisexual, and transgender older adults, ages 45-75. Retrieved from sageusa.org/resources/outandvisible.cfm.
- ¹⁶ National Alliance for Caregiving, American Association of Retired Persons (AARP) (2015). *Caregiving in the U.S., 2015*. Retrieved June 2, 2017, from caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.
- ¹⁷ *Ibid.*
- ¹⁸ Shippy, R. A. (2014). We cannot go it alone: The impact of informal support and stressors in older gay, lesbian, and bisexual caregivers. In K. Fredriksen-Goldsen (Ed.), *Caregiving with Pride* (pp. 46). New York, NY: Taylor & Frances.
- ¹⁹ Wenzel, H. V. (2002). Fact sheet: LGBT caregiving: Frequently asked questions. Retrieved July 2, 2017, from caregiver.org/lgbt-caregiving-frequently-asked-questions.
- ²⁰ Funders for Lesbian and Gay Issues (2004). Aging in equity: LGBT elders in America. Retrieved from lgbtfunders.org/research/?aging-in-equity-lgbt-elders-in-america.
- ²¹ SAGE (2014). Out and Visible: The experiences and attitudes of lesbian, gay, bisexual, and transgender older adults, ages 45-75. Retrieved from sageusa.org/resources/outandvisible.cfm.

Additional Resources

AARP

Resources for caregivers, including LGBT caregivers.

aarp.org/caregiving

Alzheimer's Association

Resources for caregivers of people with Alzheimer's disease or dementia.

alz.org

Eldercare Locator

Database of programs and services for older adults from the U.S. Administration on Aging
eldercare.gov

Family Caregiving Alliance

Resources for caregivers, including an online LGBT caregiver support group co-facilitated with Openhouse.

caregiver.org

National Alliance for Caregiving

Coalition of national organizations addressing caregiving through research, innovation and advocacy.

caregiving.org

National Resource Center on LGBT Aging

Resources and education for providers, LGBT older adults and caregivers.

lgbtagingcenter.org

National Respite Locator

Searchable database of respite programs.

archrespice.com/respitelocator

SAGE

The country's largest and oldest organization dedicated to improving the lives of LGBT older adults, SAGE provides direct services to constituents in New York City and nearly 30 affiliates around the country.

sageusa.org

SAGECare

Cultural competency training and consulting on LGBT aging issues for service providers, and a searchable database of providers who have earned a SAGECare credential.

sageusa.care

SAGE LGBT Elder Hotline

Peer support, information & local resources.
1-888-234-SAGE

Publications

Caregiving in the U.S., 2015 Report (NAC & AARP Public Policy Institute, 2015)

caregiving.org/caregiving2015

Create Your Care Plan! An LGBT Person's Guide to Preparing for Medical Procedures (SAGE, 2017)

lgbtagingcenter.org/caregiving

Fact Sheet: LGBT Caregiving (SAGE, 2016)

tiny.cc/lgbtcaregiving

LGBT Programming for Older Adults: A Practical Step-by-Step Guide (SAGE, 2015)

lgbtagingcenter.org/guides

Prepare to Care: A Planning Guide for Caregivers in the LGBT Community (AARP & SAGE, 2017)

sageusa.org/preparetocare

Take the Power: Tools for Life and Financial Planning (Lambda Legal, 2014)

lambdalegal.org/takethepower



Visit lgbtagingcenter.org/caregiving for even more resources!



We refuse to be invisible

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