

What You Need To Know About Informal Caregiving In The LGBTQIA+ Community

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Our Roots

Fenway Health

- Independent 501(c)(3) FQHC
- Founded 1971
- Mission: To enhance the wellbeing of the LGBTQIA+ community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research, and advocacy
- Integrated primary care model, including HIV and transgender health services

The Fenway Institute

- Research, Education, Policy



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The National LGBTQIA+ Health Education Center

- Training and Technical Assistance
- Grand Rounds
- Online Learning
 - CE and HEI Credit
- Environmental Influences On Child Health Outcomes (ECHO) Programs
- Publications and Resources



Learning Module



Publication



Toolkit



Video



Webinar

Sound Issues?

- Ensure your computer speakers are not muted
- If you cannot hear through your computer speakers, navigate to the bottom toolbar on your screen, go to the far left, and click the arrow next to the phone icon
- Choose “I will call in”
- Dial the phone number and access code



After the Webinar

- Close the browser, and an evaluation will automatically open for you to complete
- We very much appreciate receiving feedback from all participants
- Completing the evaluation is **required** to obtain a CME certificate



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CME/CEU Information

This activity has been reviewed and is acceptable for up to 1.0 Prescribed credits by the American Academy of Family Physicians. Participants should claim only the credit commensurate with the extent of their participation in this activity.

Physicians	AAFP Prescribed credit is accepted by the American Medical Association as equivalent to AMA PRA Category 1 Credit™ toward the AMA Physician's Recognition Award. When applying for the AMA PRA, Prescribed credit earned must be reported as Prescribed, not as Category 1.
Nurse Practitioners, Physician Assistants, Nurses, Medical Assistants	AAFP Prescribed credit is accepted by the following organizations. Please contact them directly about how participants should report the credit they earned. <ul style="list-style-type: none">• American Academy of Physician Assistants (AAPA)• National Commission on Certification of Physician Assistants (NCCPA)• American Nurses Credentialing Center (ANCC)• American Association of Nurse Practitioners (AANP)• American Academy of Nurse Practitioners Certification Program (AANPCP)• American Association of Medical Assistants (AAMA)
Other Health Professionals	Confirm equivalency of credits with relevant licensing body.

About NCECE

- **Who We Are:** Established in 2017, the National Center for Equitable Care for Elders (NCECE) is a training and technical assistance Center that provides innovative and culturally competent models of care, inter-professional training, and educational resources to health care professionals providing care to older adults.
- **Our Mission** is to build strong, innovative, and competent health care models by partnering with CHCs, PCAs, and FQHCs to provide quality and inclusive care for older adults.
- **Stay Connected With NCECE:**
- **Twitter:** twitter.com/NationalECE
- **Facebook:** <https://www.facebook.com/NationalECE>
- **LinkedIn:** [linkedin.com/company/ncece](https://www.linkedin.com/company/ncece)
- **Website:** ece.hsdm.harvard.edu
- **Email:** ece@hsdm.harvard.edu

LGBTQIA+ Aging Project



The LGBTQIA+ Aging Project, a program of the Fenway Institute at Fenway Health, works toward equity, inclusion and community for lesbian, gay, bisexual, transgender, queer, questioning, intersex and asexual older adults, ensuring that they can age with the dignity and respect they deserve.

Lisa Krinsky, LICSW
Director, LGBTQIA+ Aging Project
Fenway Health



Learning Objectives

Understand	Understand various roles, responsibilities, and models of informal caregiving.
Explain	Explain best practices for addressing needs or concerns related to education, access to services, and overall wellness for LGBTQIA+ caregivers and care recipients.
Implement	Implement strategies to provide affirming care and connect LGBTQIA+ caregivers to inclusive and affirming support services.



LGBTQIA+



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LGBTQIA+ Glossary of Terms:
<https://www.lgbtqiahealtheducation.org/wp-content/uploads/2020/02/Glossary-2022.02.22-1.pdf>

Foundational Concepts

Respect

Empathy

Compassion

Mirroring Language



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AFFIRMING LANGUAGE

Lesbian, Gay, Bisexual, or LGBTQIA+

Transgender

Sexual Orientation

Gender-affirming Surgery or Care

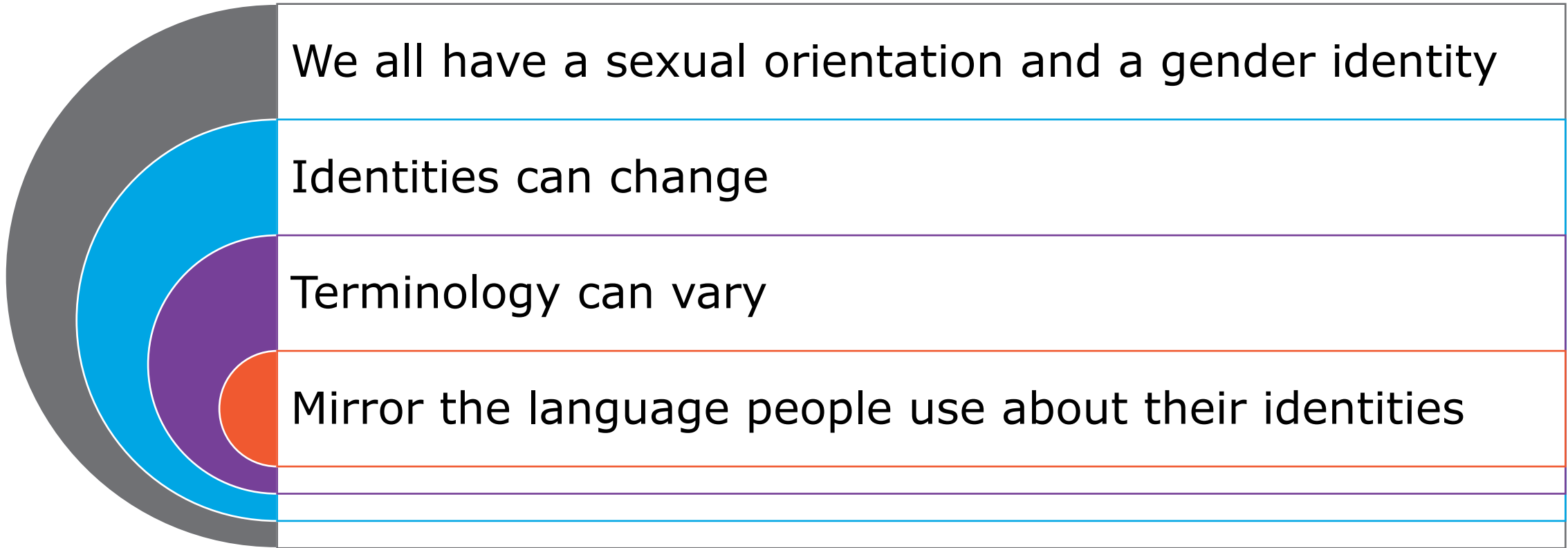
Intersex



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Sexual Orientation and Gender Identity (SOGI)

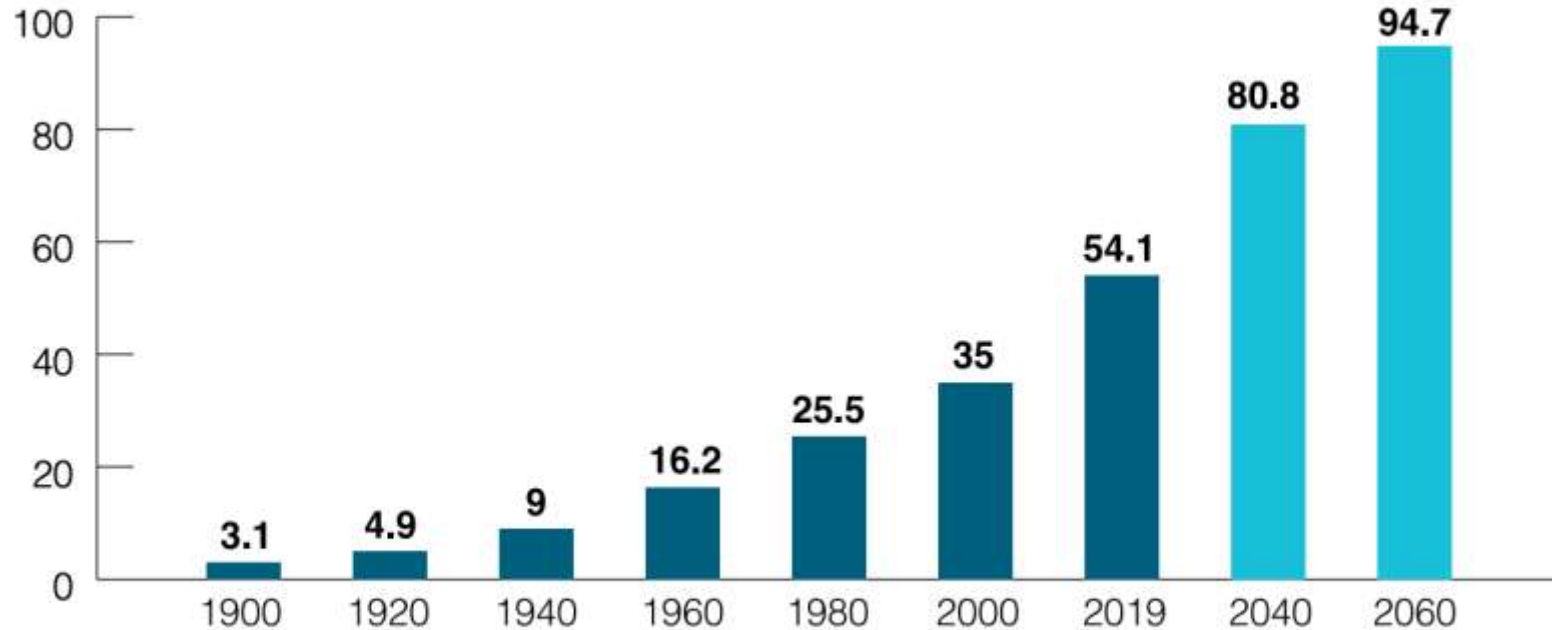


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Growth of Older Adult Population

**Number of Persons Age 65 and Older, 1900 - 2060
(numbers in millions)**



Note: Increments in years are uneven. Lighter bars (2040 and 2060) indicate projections.

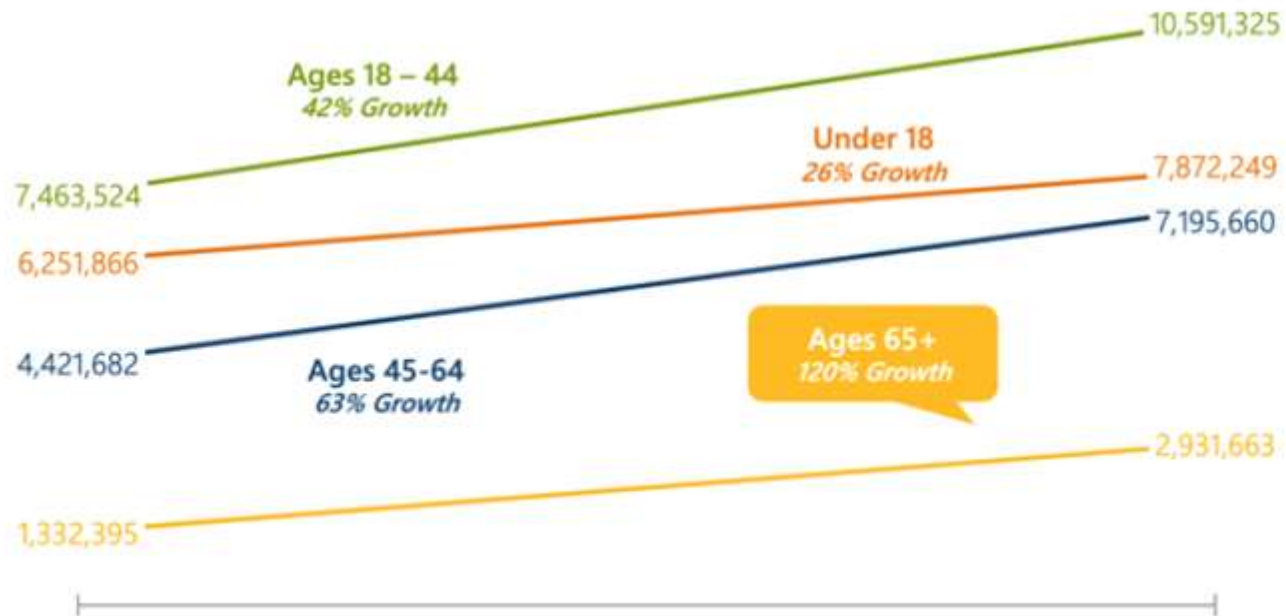
Source: U.S. Census Bureau, Population Estimates and Projections



Figure 1-12

Health Center Patients Ages 65 and Older are the Fastest Growing Age Group Over the Past Decade

Number of Health Center Patients by Age Group, 2010 – 2020



Community Health Center Chartbook:

<https://www.nachc.org/research-and-data/research-fact-sheets-and-infographics/2021-community-health-center-chartbook/>



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CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*

43.5 million
2015



53 million
2020



18%
2015



21%
2020

NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**

More Americans are caring for more than one person.



18%
2015



24%
2020

More family caregivers have difficulty coordinating care.

19%
2015



26%
2020



More Americans caring for someone with Alzheimer's disease or dementia.



22%
2015



26%
2020

More family caregivers report their own health is fair to poor.

17%
2015



21%
2020



23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Between 2015 & 2020, there was an increase of **9.5 million** informal caregivers in the United States



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National Alliance for Caregiving (NAC) & AARP Full Report
<https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020/>

Please answer in the chat.

How is informal
caregiving different than
formal caregiving?

Roles and Responsibilities of Caregivers

- Medical advocacy
- Prescription medication management
- Help with personal hygiene/care
- Assisting with meals and nutrition
- Help with mobility
- Home maintenance and basic housekeeping
- Transportation
- Legal/financial matters
- Social engagement/mental health



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What is your
experience with
informal caregiving?

POLL

**I am currently an
informal caregiver.**

**I have provided
informal caregiving
in the past.**

**I have not yet been
an informal
caregiver.**



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Valuing the Invaluable 2023

March 2023

In 2021, about 38 million Americans spent 36 billion hours caring for adults with chronic, disabling, or serious health conditions. The estimated economic value of this care is **\$600 billion**.

Diverse caregivers have distinct care experiences.

- ▶ Black/African American and Hispanic/Latino caregivers are more often involved in **high-intensity caregiving**.
- ▶ Black/African American caregivers often receive **no paid or unpaid caregiving help**.



- ▶ Hispanic/Latino caregivers are more often younger and **caring for children, too**.
- ▶ Asian American caregivers report feelings of having **no choice** in providing care.
- ▶ LGBTQ caregivers more often experience **high financial strain**, feelings of isolation, & high emotional stress tied to their role.



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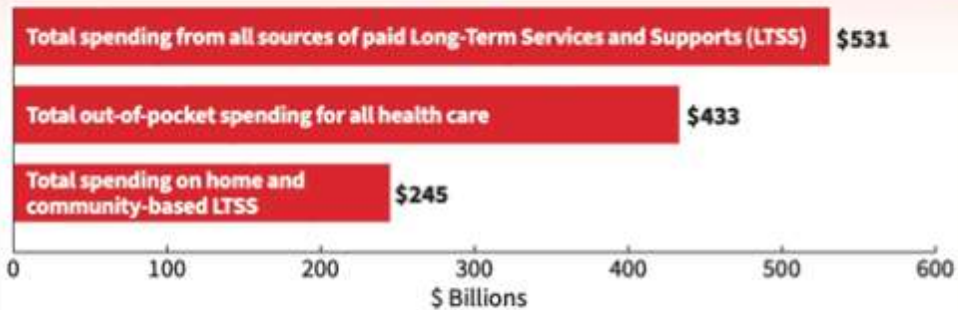
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AARP

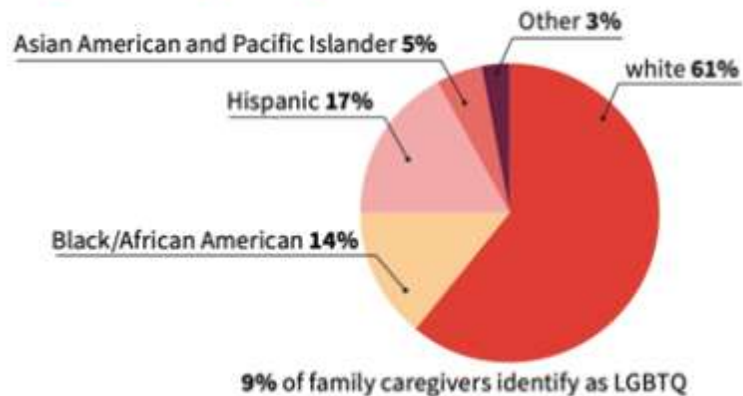
<https://www.aarp.org/content/dam/aarp/caregiving/pdf/family-caregiving-guide/lgbtq.pdf>

AARP Public Policy Institute Data

Estimated value of caregiving relative to other spending.



Today's family caregivers are diverse.



60% of caregivers juggle work and care.

- ▶ 60% of caregivers worked a full-time or part-time job.
- ▶ 40% of caregivers cite the emotional stress of juggling caregiving with paid work as biggest challenge.
- ▶ Career disruptions and breaks due to caregiving can lead to substantial economic risk and even long-term financial struggles for caregivers.



Sandwich Generation Caregivers face dual-generation care demands.

- ▶ Caring for *both* an older family member or friend and children or grandchildren results in a higher level of **emotional & financial strain**.
- ▶ 30% of all caregivers are caring for two generations.
- ▶ They increasingly include Gen Z and millennial caregivers.
- ▶ They are often balancing work with caregiving.



AARP Public Policy Institute

Six recommendations to support unpaid family caregivers:

Implement the National Strategy to Support Family Caregivers.



Support family caregivers when caring for someone in the hospital and as they transition home through the CARE Act.



Offer caregiver tax credits or other reimbursement programs to offset the costs of family caregiving.



Strengthen paid family leave and paid sick leave to help family caregivers balance care and work responsibilities.



Expand respite care services that give family caregivers a hard-earned break.



Include family caregivers in care through caregiver training & education and caregiver assessments that connect them to supports and services.



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AARP

<https://www.aarp.org/content/dam/aarp/caregiving/pdf/family-caregiving-guide/lgbtq.pdf>

Please answer in the chat.

What assumptions
do people make
about caregivers?

Circles of Care: LGBTQIA+ Caregivers and Patients



LGBTQIA+ person caring for another LGBTQIA+ person
(spouse/partner, friend/chosen family)



Non-LGBTQIA+ person caring for LGBTQIA+ person
(chosen family, friend, parent, sibling, adult child)



LGBTQIA+ person caring for non-LGBTQIA+ person
(parent/sibling, adult child, grandchildren, chosen family)



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LGBTQIA+ Caregivers

According to the most recent report from the [National Caregiver Alliance/AARP Caregiving in the US 2020](#):

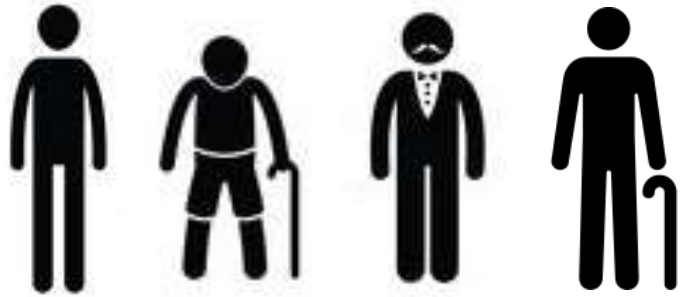
- The typical LGBTQ Caregiver is young (42.4 years old) and unmarried
- LGBTQ Caregivers are most often caring for a parent or grandparent
- Many LGBTQ Caregivers live with the person they care for or within 20 minutes drive
- LGBTQ Caregivers report high-intensity caregiving situation spending 28 hours a week assisting with care needs
- They are more often the Primary Caregiver of their care recipient
- Most LGBTQ Caregivers work while providing care and more often report financial strain related to caregiving
- LGBTQ Caregivers more often report being in fair or poor health than non-LGBTQ Caregivers
- To read the full report visit <http://www.caregiving.org/research/caregiving-in-the-us>



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Caregiving Across Generations



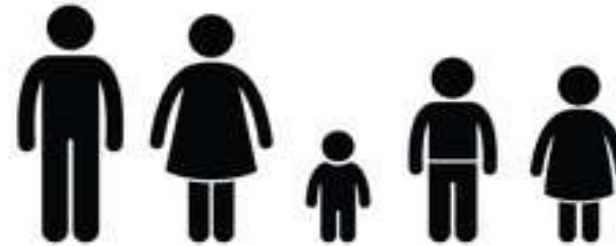
Ages 71, 88, 68, 74

Horizontal Caregiving

Age
87



Age
65



Ages 42, 39, 3, 17, 14

Vertical Caregiving

Affirming and Welcoming Care Environments

Visual Signs and Symbols of Affirmation

- Pronouns
- Visuals of LGBTQIA+ Communities and Pride
- LGBTQIA+ Events
- Affirming Imagery and Content in Marketing and Educational Materials

Policies and Procedures

- Professional Development Training
- Name Change Policies for Staff and Patients
- Enumerated Policies: SOGIE
- Inclusive Forms and Electronic Health Records
- Dress Codes
- All Gender Restrooms
- Embracing Diverse Family Structures for LGBTQIA+ People

Inclusive and Affirming Language

- Don't assume relationships, use open ended language:
 - "Who did you bring with you today?"
- Ask open ended questions of both patient and caregiver:
 - "What ways do you help?"
 - "Who else helps?"
- Not everyone will be out to you; be affirming anyway without making assumptions:
 - "You two make a great team!"
 - "You are lucky to have a roommate who can help you in so many ways!"



Legal Resources

- “Next of Kin” vs. “Family of Choice”
- Advance Directives:
<https://www.nia.nih.gov/health/advance-care-planning-advance-directives-health-care#find>
- Health care proxy, living will, do-not-resuscitate (DNR), do-not-intubate (DNI) etc.
- Power of Attorney: financial, legal, health care, can be temporary or permanent <https://powerofattorney.com>



Caregiver Resources

- National Family Caregiver Support Program

<https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

- AARP

<https://www.aarp.org/content/dam/aarp/caregiving/pdf/family-caregiving-guide/lgbtq.pdf>

- SAGE

<https://www.lgbtagingcenter.org/resources/pdfs/SAGE%20Caregiver%20Guide%20Final%20Interactive.pdf>

- LGBTQ Bereavement Support Groups : LGBTQIA+ Aging Project

<https://fenwayhealth.org/the-fenway-institute/lgbtqia-aging-project/programs-support-groups/>

- LGBTQ Caregiver Center <https://lgbtqcaregivers.org>

- Resources for Male Caregivers

- Jack's Caregiver Coalition (virtual groups) - <https://www.jackscaregiverco.org/>
- Understanding Male Caregivers' Emotional, Financial, and Physical Burden in the United States (NIH article) - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6627587/>
- The Male Caregiver (AARP article) - https://www.caregiving.org/wp-content/uploads/2020/05/Caregiving-in-the-US-2015_Male_CGProfile.pdf



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Introduction: Zander Keig



Zander Keig, MTS, MS, MSW, LCSW
CEO, Keig Consulting, LLC
Wellness & Wellbeing Coach



Let's Talk With Zander Keig!

How have your experiences as a caregiver shaped the resources and training offered by the LGBTQ Caregiver Center?

Let's Talk With Zander Keig!

What are important priorities for caregivers?

How can we encourage caregivers to take care of their own needs?



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Let's Talk With Zander Keig!

What promising practices can you share on fostering inclusion and belonging in community health settings, for both LGBTQIA+ caregivers and those providing care to LGBTQIA+ older adults?

What Questions Do You Have?





**Thank
you!**