

# Sexual and Gender Minorities & Dementia Caregiving



**Jason Flatt, PhD, MPH**

**Pronouns: He/They**

# OUR TIME TODAY



- Terminology
- Historical & Social Context
- Dementia & Caregiving Research
- Collecting Sexual Orientation, Sex Assigned at Birth, and Gender Identity
- Future Research
- Q&A

**Sexual minority** – individuals who self-identify as **asexual, bisexual, gay, lesbian, queer**, as well as those who do not self-identify with these terms but whose sexual orientation varies from heterosexual

**Gender minority** – individuals who self-identify as **transgender & non-binary**, as well as those with a gender identity and/or expression that does not conform to social & cultural expectations based on the sex assigned to them at birth.

**Cisgender** - a term used to describe people whose gender identity aligns with the sex assigned to them at birth.

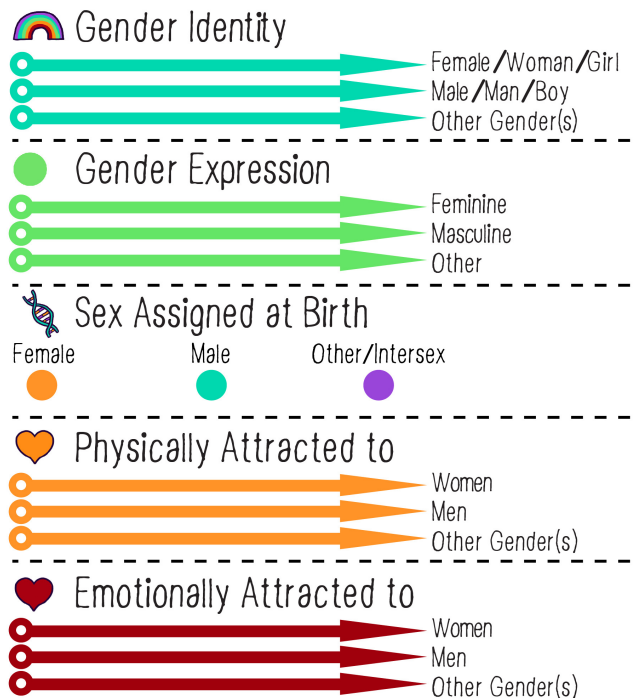
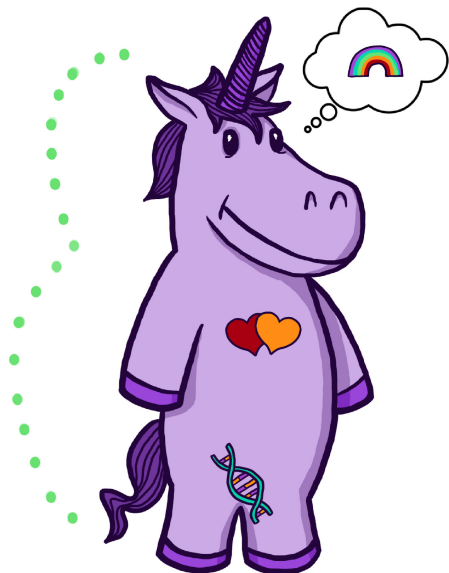
***Sexual orientation & gender identity may evolve over the lifespan.***





# The Gender Unicorn

Graphic by:  
**TSER**  
Trans Student Educational Resources



To learn more, go to:  
[www.transstudent.org/gender](http://www.transstudent.org/gender)

Design by Landyn Pan and Anna Moore



**1970**

To commemorate Stonewall, one of the first gay pride parades occurs in NYC.

**1993**

"Don't Ask, Don't Tell" policy was signed into law. Forbidding openly gay people from serving in the military.

**2015**

Same-sex marriage legalized nation-wide after a 5-4 decision by the United States Supreme Court.

**1969**

Stonewall Riots take place in NYC, sparking the modern LGBTQ+ movement.

**1978**

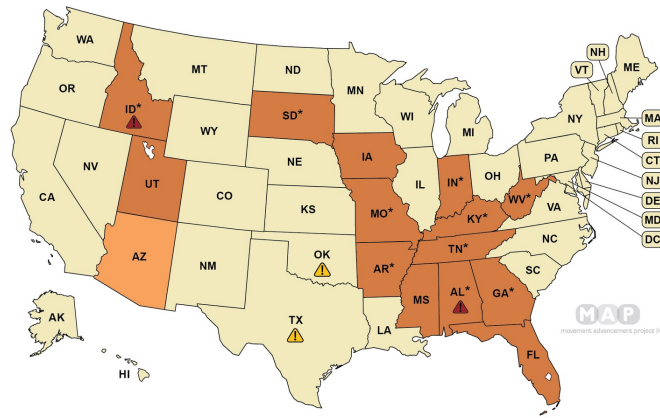
The rainbow flag is designed by Gilbert Baker to create a symbol of pride for the LGBTQ+ community.

**2011**

"Don't Ask, Don't Tell" policy is repealed. Gay community allowed to openly serve in the military.

**2020**

Supreme Court rules that 1964 Civil Rights Act protects LGBTQ+ workers from workplace discrimination.



## BANS ON BEST PRACTICE MEDICAL CARE FOR TRANSGENDER YOUTH

- State bans best practice medication and surgical care for transgender youth (7 states)
- State bans best practice surgical care for transgender youth (1 state)
- State does not ban best practice medical care for transgender youth (42 states, 5 territories + D.C.)
- State ban makes it a felony crime to provide best practice medical care for transgender youth (1 state)
- State has taken steps to ban or restrict best practice medical care for transgender youth, but state law does not ban this care (3 states)



## CORNERSTONES OF SUCCESSFUL AGING

- ECONOMIC SECURITY
- SOCIAL CONNECTIONS
- HEALTH AND WELL-BEING

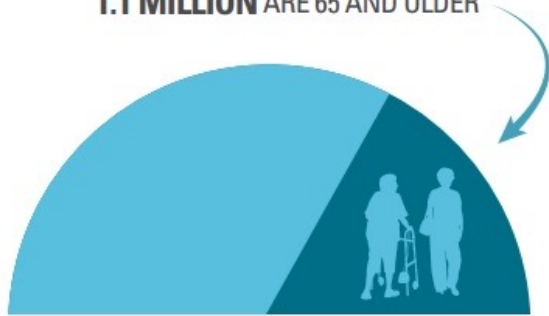
## KEY CHALLENGES FOR LGBT OLDER ADULTS

- A LIFETIME OF DISCRIMINATION AND LACK OF LEGAL AND SOCIAL RECOGNITION
- A RELIANCE ON CHOSEN FAMILY
- A LACK OF COMPETENT INCLUSIVE HEALTHCARE

- Historical & current pathologizing of sexual & gender identities in DSM
- Lack protections for basic human rights (*e.g.*, housing, employment, healthcare)
- Compounded for intersecting marginalized identities (gender, race/ethnicity, serostatus, disability)

## 2.7 MILLION LGBT ADULTS AGED 50 AND OLDER

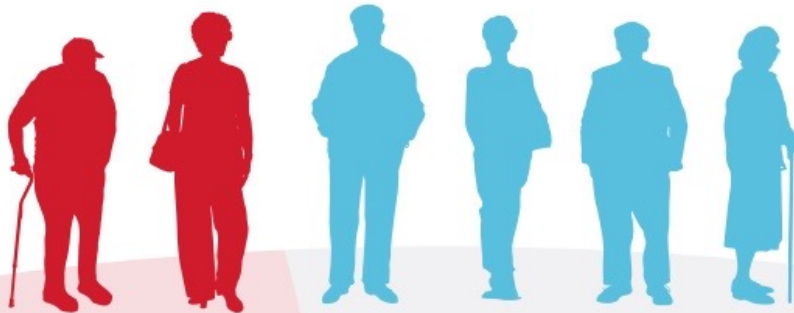
1.1 MILLION ARE 65 AND OLDER



APPROXIMATELY **ONE IN FIVE** (20%) LGBT OLDER ADULTS ARE PEOPLE OF COLOR



**ONE-THIRD** OF LGBT OLDER ADULTS LIVE AT OR BELOW 200% OF THE FEDERAL POVERTY LEVEL



- Barriers to healthcare access & use
- Lifetime exposure to discrimination & trauma

Unique concerns:

- Intersect with race/ethnicity
- Less likely to be married or have children
- 2-3X as likely to live alone
- Little to no caregiver support





# SGM DEMENTIA & CAREGIVING RESEARCH



# SUBJECTIVE COGNITIVE DECLINE AMONG LESBIAN, GAY, BISEXUAL, TRANSGENDER (LGBT) ADULTS

2015–2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from Lesbian, Gay, Bisexual, Transgender (LGBT) Adults in 25 States: People Aged 45 Years and Older



alzheimer's  
association

cdc.gov/aging  
CS 303070-A June 2020

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DOI: 10.1002/trc2.12197

Advances in  
Translational Research  
& Clinical Interventions

## RESEARCH ARTICLE

### Subjective cognitive decline higher among sexual and gender minorities in the United States, 2015–2018

Jason D. Flatt<sup>1</sup> | Ethan C. Cicero<sup>2</sup> | Nickolas H. Lambrou<sup>3</sup> | Whitney Wharton<sup>2</sup> | Joel G. Anderson<sup>4</sup> | Erin D. Bouldin<sup>5,6</sup> | Lisa C. McGuire<sup>5</sup> | Christopher A. Taylor<sup>5</sup>

16%  
SGM

vs

11%  
Non-SGM



Study supported by NIA - K01AG056669 (Flatt)



# LGBT OLDER ADULTS AND DEMENTIA

Age is the greatest risk factor for Alzheimer's disease.

An estimated **2.7 million** LGBTQ+ people are over age 50.

LGBT people have greater health disparities, many of which are risk factors for dementia, including:

- Depression
- Obesity
- Alcohol and tobacco
- Lower rates of preventive screenings
- Cardiovascular disease
- HIV/AIDS



**7.4%**

of the lesbian, gay and bisexual older adult population is living with dementia



LGBT adults living with dementia face unique challenges in accessing support:

**40%** report that their support networks have become smaller over time



**34%** live alone



Up to **30%** experience lower rates of access to care



Alzheimer's is the most expensive disease in the nation

**51%** of LGBT older people report being very concerned about having enough money to live on



Fear of discrimination can delay access to care

**40%** say their health care providers don't know their sexual orientation



## ISSUES BRIEF: LGBT AND DEMENTIA



alzheimer's association®

sage | Advocacy & Services for LGBTQ Elders  
We refuse to be invisible

<https://www.sageusa.org/wp-content/uploads/2018/08/lgbt-dementia-issues-brief.pdf>

alzheimer's association®

sage | Advocacy & Services for LGBTQ Elders  
We refuse to be invisible

#### Sources

- Alzheimer's Association and SAGE, Issues Brief: LGBT and Dementia
- Jason Ratz, Ph.D., MPH, et al. Dementia Prevalence Among Sexual Minority Older Adults. *Funder: U.S. National Institute on Aging*
- Harneke Rhodus-Meester, MD, et al. Median Survival in Memory Clinic Cohort Is Short. Even in Young Onset Dementia. *Funders: Alzheimer Nederland, Sochong Dongsong.*
- Yvonne Leung, Ph.D., et al. 100 Years and Beyond: Investigating the Prevalence of Dementia in Centenarians and Near Centenarians from 17 Population-Based Studies. *Funder: The Dementia Momentum Initiative.*

Visit [alz.org](http://alz.org) for additional information, support and resources.



## lgbt caregiver concerns

Many lesbian, gay, bisexual and transgender (LGBT) people have experienced difficult and alienating relationships with family, friends, employers and service providers. Some have felt the need to move away from their families of origin, to stay in the closet or to distance themselves from discriminating and prejudiced situations. Yet, LGBT people are more likely to become caregivers for a partner, friend or biological family member. While caregiving can be rewarding, it can also be isolating. This brochure will help you navigate community resources and options for support.



The Alzheimer's Association welcomes, and is supportive of, all persons regardless of age, race, gender identity, class, ethnicity, sexual orientation, language, physical ability or religion.

While LGBT-specific services may not be available everywhere, the Alzheimer's Association is here to help you find the right care and support options.

## caregiver stress daily checklist

How many signs have I experienced today?

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Health problems

Whenever stress is a concern, consult your doctor, and contact the Alzheimer's Association for information and support.

alzheimer's  association®

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's®.

For information and support,  
contact the Alzheimer's Association:

800.272.3900  
alz.org

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082112.01 686-74-0016

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## lgbt caregiver concerns

Assisting a person  
with dementia in  
planning for the future



the compassion to care, the leadership to conquer®

- Alzheimer's caregivers provide care for a **longer time** than other caregivers of older adults without Alzheimer's
- 35% of Alzheimer's caregivers report their **health has gotten worse**
- SGM people become caregivers at a higher rate than the general population (**1 in 5** vs. 1 in 6)

# CAREGIVING

AMONG LESBIAN, GAY, BISEXUAL, TRANSGENDER (LGBT) ADULTS

2015–2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from Lesbian, Gay, Bisexual, Transgender (LGBT) Adults in 20 States



1 in 4 adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

## WHO ARE CAREGIVERS?

43% are women

less than 10% are 65 years old or older

43% are caring for a parent or parent-in-law

Nearly 10% are providing care for someone with dementia



## FUTURE CAREGIVERS

1 in 5 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years



## CAREGIVING CAN BE

LENGTHY  
Over 40% have provided care for at least two years  
INTENSE  
30% are providing care for at least 20 hours per week



## HOW DO CAREGIVERS HELP?



8 in 10 manage household tasks

Over half assist with personal care



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention

[cdc.gov/aging](https://cdc.gov/aging)

CS 317547-A June 2020



76%

are concerned about having adequate family and/or social supports to rely on as they age.

## LGBT Concerns About Long Term Care



67%

neglect



61%

limited access to services



60%

verbal or physical harassment



52%

52% will be forced to hide/deny identity

## LGBT Adults Want Welcoming Long-Term Care Services Designed for Them

88%

want LGBT trained providers

85%

want providers that are also LGBT

86%

want advertising for LGBT friendly services

82%

want LGBT signs displayed onsite



63% have provided caregiving to an adult loved one such as a relative, friend, spouse or partner

61% think it is likely they will be a caregiver to a loved one in the future



23%

have received caregiving as an adult from a loved one such as a relative, friend, spouse or partner

66%

think it is likely they will need caregiving from a loved one in the future



54%

are parents or grandparents

82%

are concerned about having adequate family and/or social supports to rely on as they age



## The three most common concerns for LGBTQ caregivers are:

64%

feeling emotionally stressed

60%

finding it difficult to exercise

57%

finding it difficult to get enough rest

Source: Maintaining Dignity: A Survey of LGBT Adults Age 45-plus, March 2018  
([www.aarp.org/dignitysurvey/](https://www.aarp.org/dignitysurvey/)), <https://doi.org/10.26419/res.00217.004>  
Contact: Angela Houghton, AARP Research, [ahoughton@aarp.org](mailto:ahoughton@aarp.org)



Dignity 2022: The Experience of LGBTQ Older Adults, June 2022  
<https://www.aarp.org/LGBTQdignity>

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# Characteristics of Sexual and Gender Minority Caregivers of People With Dementia

Journal of Aging and Health  
2021, Vol. 0(0) 1–14  
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DOI: 10.1177/08982643211014767  
[journals.sagepub.com/home/jah](https://journals.sagepub.com/home/jah)  




Joel G. Anderson, PhD, CHTP, FGSA<sup>1</sup> , Jason D. Flatt, PhD, MPH<sup>2</sup>,  
Jennifer M. Jabson Tree, PhD, MPH<sup>3</sup>, Alden L. Gross, PhD, MHS<sup>4</sup>,  
and Karen M. Rose, PhD, RN, FGSA, FAAN<sup>5</sup> 

- 1 in 3 living in a small town/rural area
- 63% providing care to SM person living with dementia
- 1 in 5 were providing care to a GM person living with dementia
- 1 in 3 found it difficult to afford the very basics
- Most cared for their spouse/partner
- Average of 2 years providing care
- More than half did not live with their care recipient
- Most did not use respite or transportation services



- 1 in 3 had below average health status
  - **Greater for lesbian & transgender caregivers**
  - **Queer caregivers - more discrimination, victimization, and microaggressions**
- 73% reported moderate to high levels of stress
  - **Higher bisexual & queer caregivers**
- 78% reported probable depression
  - **Higher for queer & African American LGBTQIA+ caregivers**
- LGBTQIA+ caregivers of color had lower family quality of life than Whites



# Conclusions

1. **Similar or higher risk of Alzheimer's disease in SGM community & unique caregiving/care partner needs**
2. **Promote resilience, cultural humility, consider trauma-informed care approaches, & give back!**
3. **We need more SOGI data**



# Collecting SOGI – Sexual Orientation & Gender Identity

- NASEM report (2022) provided foundation for recommendations
- National Alzheimer's Coordinating Center - UDS 4.0

<https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>

Flatt, J. D., & Cicero, E. C. (2023). Advancing equity in Alzheimer's disease and mental health research for LGBTQIA+ older adults. *Nature Mental Health*, 1(6), 385-387.

**INITIAL VISIT PACKET** UNIFORM DATA SET (UDS) VERSION 4.0

**Form A1: Participant Demographics**

In-person ☐ Remote ☐

ADRC name: \_\_\_\_\_ Participant ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_ Language: English ☐ Spanish ☐

**INSTRUCTIONS:** This form may be completed by intake interviewer based on ADRC scheduling records, participant interview, medical records, and proxy co-participant report (as needed). This information can be collected by mail-in survey, electronic capture (web-based), phone or video interview, or during the in-person visit to accommodate and lessen participant visit burden. For additional clarification and examples, see the UDS Coding Guidebook, Form A1. Check only one box per question unless otherwise specified.

**Section 1 — Demographics**

1. What is your month and year of birth (MM/YYYY)? \_\_\_\_ / \_\_\_\_

2. What is your ethnicity and race? (Check all that apply)

2a. ☐ 1 White

2b. ☐ 1 Black or African American

2c. ☐ 1 American Indian or Alaska Native (AIAN)

2d. ☐ 1 Native Hawaiian or other Pacific Islander

2e. ☐ 1 Asian

2f. ☐ 1 Hispanic

2g. ☐ 1 Other (SPECIFY): \_\_\_\_\_

2h. ☐ 1 Don't know

The next four questions ask about your gender identity, sex assigned at birth, sexual orientation, and intersex status. This information will be used to help us improve health, well-being, and quality of care. By gender identity, we mean the inner sense that you have of yourself as being a man, woman, or a different gender. Gender identity can be different from your sex assigned at birth or your sexual orientation, and it can change over time.

3. Which term(s) best describes your current gender identity? (Check all that apply)

3a. ☐ 1 Man

3b. ☐ 1 Woman

3c. ☐ 1 Transgender man

3d. ☐ 1 Transgender woman

3e. ☐ 1 Non-binary/genderqueer

3f. ☐ 1 Two-Spirit (if you are AIAN)

3g. ☐ 1 I use a different term (SPECIFY): \_\_\_\_\_

3h. ☐ 1 Don't know

3i. ☐ 1 Prefer not to answer

4. What sex were you assigned at birth, on your original birth certificate?

☐ 1 Male

☐ 2 Female

☐ 3 Don't know

☐ 4 Prefer not to answer

5. Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a "Difference of Sex Development (DSD)" or were you born with (or developed naturally in puberty) genital, reproductive organs, and/or chromosomal patterns that do not fit standard definitions of male or female?

☐ 0 No

☐ 1 Yes

☐ 2 Don't know

☐ 3 Prefer not to answer

6. Which term(s) best describes your sexual orientation? (Check all that apply)

6a. ☐ 1 Lesbian or gay

6b. ☐ 1 Straight/heterosexual

6c. ☐ 1 Bisexual

6d. ☐ 1 Two-Spirit (if you are AIAN)

6e. ☐ 1 I use a different term (SPECIFY, e.g., asexual, queer, questioning): \_\_\_\_\_

6f. ☐ 1 Don't know

6g. ☐ 1 Prefer not to answer



# Collecting Sexual Orientation

The next questions ask about your gender identity, sex assigned at birth, and sexual orientation. This information will be used to help us improve health, well-being, and quality of care. By gender identity, we mean the inner sense that you have of yourself as being a man, woman, or a different gender. Gender identity can be different from your sex assigned at birth or your sexual orientation, and it can change over time.

## Which term(s) best describes your sexual orientation?

(Check all that apply)

- ☐ Lesbian or gay
- ☐ Straight/heterosexual
- ☐ Bisexual
- ☐ Two-Spirit (*if respondent is AIAN*)
- ☐ I use a different term (*Please specify. Ex: asexual, queer, questioning*) \_\_\_\_\_
- ☐ Don't know
- ☐ Prefer not to answer

AIAN = American Indian and Alaska Native population

# Collecting Sex Assigned at Birth and Gender Identity: Two-Step Method

**What sex were you assigned at birth, on your original birth certificate?**

☐ Male

☐ Female

**Which term(s) best describes your current gender identity? (Select all that apply)**

☐ Man

☐ Woman

☐ Transgender man

☐ Transgender woman

☐ Non-binary/Genderqueer

☐ Two-Spirit (*if respondent is AIAN*)

☐ I use a different term (*Please specify*) \_\_\_\_\_

☐ Don't know

☐ Prefer not to answer

AIAN = American Indian and  
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- ☐ Transgender man
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- ☐ I use a different term (*Please specify*) \_\_\_\_\_
- ☐ Don't know
- ☐ Prefer not to answer

AIAN = American Indian and  
Alaska Native population



# Intersex/DSD status

Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a “Difference of Sex Development (DSD)” or were you born with (or developed naturally in puberty) genitals, reproductive organs, and/or chromosomal patterns that do not fit standard definitions of male or female?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Prefer not to answer

# Conclusions

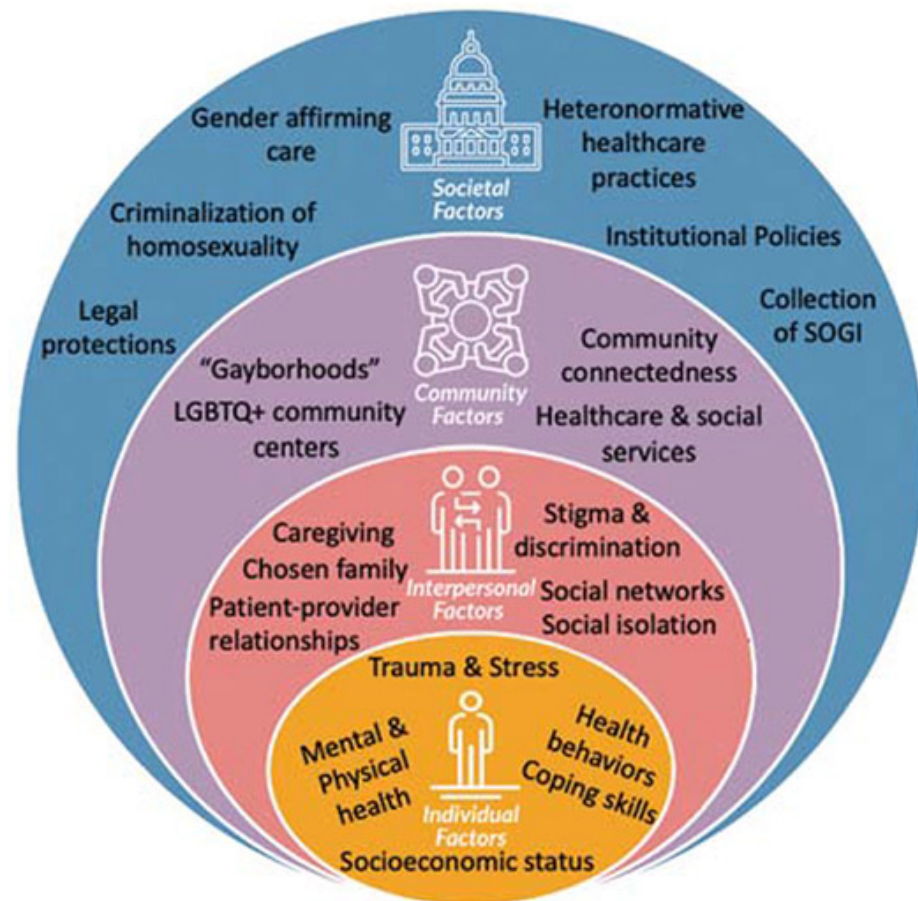
1. **Similar or higher risk of ADRD & cognitive impairment in SGM populations & unique caregiving/care partner needs**
2. **Promote resilience, cultural humility, consider trauma-informed care approaches, & give back!**
3. **We need more SOGI data**
4. **More research (e.g., RISE, Stonewall Generations Study)**

# Enhancing Measurement & Characterization of Roles & Experiences of Sexual & Gender Minority Caregivers of Persons living with Alzheimer's Disease & Related Dementias

Aim 1: Identify & explore domains of ADRD caregiving for SGM ADRD caregivers

Aim 2: Develop & refine new measures of ADRD caregiving for SGM ADRD caregivers

Aim 3: Test the new and existing measures with SGM and non-SGM ADRD caregivers



Supported by NIH/NIA R01AG083177 (Flatt/Anderson/Dowling) - 8/2023-4/2028



[www.theriseregistry.org](http://www.theriseregistry.org)

Join the registry -  
<https://is.gd/RISEREGISTRY>

Supported by NIH/NIA R24AG066599 (Wharton, Flatt, Anderson)



# The Stonewall Generations Study



## WHAT IS THIS STUDY ABOUT?

- Memory, thinking, and health

## WHO IS THIS STUDY FOR?

- All adults over 50 years of age
- Self-identify as LGBTQIA+ or non LGBTQIA+
- Speaks English

FOR MORE INFO:  
CONTACT THE PRINCIPAL INVESTIGATOR,  
JASON FLATT, PHD, MPH

INTERESTED IN PARTICIPATING?  
**CALL THE 800 NUMBER BELOW  
TO COMPLETE A 1-TIME 45 MINUTE  
SURVEY AND RECEIVE A \$25 GIFT  
CARD**



rainbowsofaging@unlv.edu



1-833-966-6974

## Goals of the Study

- Recruit 500 diverse LGBTQ+ (n=250) and non-LGBTQ+ (n=250) older adults
- Compare differences in memory and thinking skills between LGBTQ+ and non-LGBTQ+ older adults
- Identify health and social factors linked with memory and thinking skills among LGBTQIA+ adults

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# Conclusions

1. **Similar or higher risk of ADRD & cognitive impairment in SGM populations & unique caregiving/care partner needs**
2. **Promote resilience, cultural humility, consider trauma-informed care approaches, & give back!**
3. **We need more SOGI data**
4. **More research (e.g., RISE, Stonewall Generations Study)**
5. **Advocacy: Support SGM caregivers, families of choice, and ensure inclusive services for all people**
6. **Mentoring others and funding to support new programs, services and research**





**Jarmin Yeh, PhD , MSW, MPH**  
 Assistant Professor  
 University of California  
 San Francisco  
 School of Nursing  
 Institute for Health & Aging







# The LGBTQ Caregiver Center



## Welcome

The LGBTQ Caregiver Center is a developing virtual resource hub that aims to raise awareness of the unique needs, challenges and experiences of LGBTQ Caregivers and those who care for LGBTQ individuals. We engage in advocacy and research activities, provide training and deliver services that promote caregiver well-being and cultivate belonging.

<https://lgbtqcaregivers.org/>



# Acknowledgements

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- The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health
- No conflicts of interest to report

# Thank you!



**Rainbows**  
of  
**Aging**

## Questions?

Email: [Jason.Flatt@unlv.edu](mailto:Jason.Flatt@unlv.edu)  
[www.RainbowsofAging.org](http://www.RainbowsofAging.org)