

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

Email To: equitabledata@ostp.eop.gov

Subject Line: Federal Evidence Agenda on LGBTQI+ Equity RFI

Date: October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Avenue, NW
Washington, DC 20504

Submitted via email to equitabledata@ostp.eop.gov

Dear Subcommittee Members:

Thank you for the opportunity to comment on the importance of LGBTQI+ data collection to LGBTQI+ older adults. Justice in Aging writes in response to the Office of Science and Technology Policy's request for information (RFI) to help develop the Federal Evidence Agenda on LGBTQI+ Equity (87 FR 52083). Our response centers on older LGBTQI+ adults.

Justice in Aging is an advocacy organization with the mission of improving the lives of low-income older adults. We use the power of law to fight senior poverty by securing access to affordable healthcare, economic security, and the courts for older adults with limited resources. For 50 years, we have used the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources. Our mission is to secure the opportunity for older adults to live with dignity, regardless of financial circumstances—free from the worry, harm, and injustice caused by lack of health care, food, or a safe place to sleep. We focus on the needs of low-income communities that are most marginalized and excluded from justice such as women, people of color, LGBTQI+ individuals, and people with limited English proficiency.

Question 1: What disparities faced by LGBTQI+ people could be better understood through data collection? What do you see in your work?

Accurate data collection and counting is essential for fair representation and to combat discrimination experienced by LGBTQI+ older adults. LGBTQI+ communities deserve accurate representation in federal data collection.

Understanding no group is a monolith, the COVID-19 pandemic made clear that underrepresented groups are extremely vulnerable during economic and health emergencies. Lack of specific questions about sexual orientation, gender identity, and variations in sex characteristics mean that surveys do not account for single LGB people or LGB people who are in a relationship but not cohabitating with their partner(s), and overlook transgender and

Washington, DC



Los Angeles, CA



Oakland, CA

intersex populations entirely. For example, it is estimated that only approximately 1 in 6 LGBT adults (those in cohabitating same-sex couples) can be identified from non-experimental U.S. Census Bureau data.¹ Unfortunately, in collection processes, LGBTQI+ individuals are not measured at the same rate as others, or we see issues with lack of routine and consistent data.² Limited sample sizes constantly inhibit understanding trends taking place in LGBTQI+ communities, and many continually do to not ask sexual orientation and gender identity (SOGI) questions.³

Although data collection is making strides in the right direction, there is a need to move to an intersectional approach to understand the nuances of a community's experiences. Highlighted by Michael Adams in "An Intersectional Approach to Services and Care for LGBT Older Adults," we must focus on ways to provide an intersectional approach such as looking into demographics, financial security, and disparities in health, to name a few.⁴ Specifically, the lack of intersectional data on the bases of multiple identities, like SOGI and age, or SOGI, race, and age, (e.g., gay older Latino men or transgender Black older women) can mask disparities experienced by LGBTQI+ older adults as a result of systemic and compounding discrimination. This intersectional framework allows for a clearer understanding of the compounding and unique effects of systemic and intersectional discrimination. If we want to understand the compounding impact of discrimination along the lifecycle, we must have intersectional data that includes age as a metric.

Furthermore, our experience in California demonstrates that even when sexual orientation and gender identity data collection is required under state law, enforcement and implementation may still face hurdles. We saw all this play out again in the COVID-19 context when case reporting and testing demographics consistently lacked SOGI data. To date, California has sexual orientation data for only 10.1% of reported COVID-19 cases and 4.3% of reported COVID-19 related deaths.⁵ Therefore, we encourage the federal government to pair data reporting requirements with the resources and training necessary to ensure the success and completeness of these efforts.

Question 2: Are there surveys or administrative data you'd look to if they had questions about LGBTQI+ people? Are there data points that you want that you don't have?

¹ Caroline Medina and Lindsay Mahowald, Collecting Data About LGBTQI+ and Other Sexual and Gender-Diverse Communities, Center of American Progress (May 24, 2022), <https://www.americanprogress.org/article/collecting-data-about-lgbtqi-and-other-sexual-and-gender-diverse-communities/>.

² *Id.*

³ Washington Center for Equitable Growth, LGBTQ+ Economic Data and Disparities: What We Still Need to Know, YouTube (Jul 12, 2022), <https://www.youtube.com/watch?v=vmqeSWxnaSo>.

⁴ Michael Adams, *An Intersectional Approach to Services and Care for LGBT Elders*, 40 *Generations* 94, 96-97 (2016) (discussing ways to provide intersectional approach) Available at <https://www.lgbtagingcenter.org/resources/resource.cfm?r=818>.

⁵ California's commitment to health equity, COVID19.CA (Last Updated Sept. 29, 2022, 10:00 AM), <https://covid19.ca.gov/equity/>.

Universally, a major need is detailed data collection across an array of areas. There is a need for a robust data collection procedure to include all LGBTQI+ experiences. It is pivotal we understand that we need deeper insights in healthcare data sets. We see what a lack of results can do to critical infrastructures, especially living during COVID-19 and Monkey Pox pandemics.

Furthermore, in healthcare, we believe it is important that data is collected about the access, utilization, and quality of Medicaid home and community-based services for LGBTQI+ older adults. This would allow for greater insights into care and how individuals are treated in real-time. For example, we urge the creation and collection of measures like access and whether individuals have been discriminated against in the provision of services. Similarly, such access, utilization and quality metrics are necessary for Medicaid covered care in institutional care settings, like skilled nursing facilities, which have been a particular context in which LGBTQI+ older adults have experienced some of the most flagrant discrimination.⁶

More data is necessary in other contexts outside of healthcare. As laws change communities are left behind. In one instance, Social Security is available to survivors of same-sex couples who could not marry. We remain concerned that survivors of same-sex couples are not aware of their eligibility.⁷ We need data on the eligibility rates after the policy went into effect and data on the communities who were impacted by outreach efforts to share information on the policy change.

Additionally, it is necessary to have intersectional data regarding income disparities, poverty levels, access to Social Security and Supplemental Security Income (SSI), for LGBTQI+ older adults, especially in communities of color. The intersectional data will only allow us to mend gaps that have promulgated disparities experienced by disenfranchised communities.

Question 3: Describe your own community-based research that you've done or findings you rely on.

Team members at Justice in Aging and a consortium of five agencies were able to put together a report on LGBTQ+ nursing facility residents. The report was published in 2010 and updated and re-released in June 2015. It is regarded as one of the seminal reports in this topic. The reason for the survey was to better understand the lived experiences of LGBT older adults in long-term care facilities. Some key findings in 2015 were 1) older adults have a fear of being out and vulnerable, 2) staff refuse to accept medical powers of attorney, 3) staff refuse to refer to transgender people by their preferred pronouns, 4) staff refuse to provide basic services of care to LGBT older adults, 5) verbal or physical harassment by staff or residents toward LGBT

⁶ Brief for Application for leave to file Amicus Curiae brief in support of Defendant/Respondent State of California, by California Commission on Aging, Sage, Justice in Aging, California Advocates for Nursing Home Reform, and Openhouse, *Taking Offense v. State of California*, No. S270535 (CAL. Jul 22,2022) Available at <https://justiceinaging.org/wp-content/uploads/2022/07/Justice-in-Aging-Amicus-Brief-07222022.pdf>.

⁷ Paula Span, *Social Security Opens to Survivors of Same-Sex Couples Who Could Not Marry*, N.Y. Times, Jan 23, 2022, Available at <https://www.nytimes.com/2022/01/23/health/social-security-same-sex.html>.

older adults and numerous other findings.⁸ Now the snapshot of issues is still problematic especially when data are needed on a continued basis. We cannot move forward with positive change unless there is a genuine sharing of information and data. Accurate statistics and data combined with federal support would allow for true representation for continued updated reporting.

Thank you for the opportunity to comment on LGBTQI+ data inclusion with an emphasis on older adults. If any questions arise concerning this submission, please contact Archie Roundtree Jr. at aroundtree@justiceinaging.org.

Sincerely,

A handwritten signature in black ink, appearing to be 'Denny Chan', with a long horizontal line extending to the right.

Denny Chan
Managing Director, Equity Advocacy

⁸ Justice in Aging et al, LGBT Older Adults In Long-Term Care Facilities: Stories from the Field 9 (2015) Available at https://justiceinaging.org/lgbt-older-adults-in-long-term-care-facilities-stories-from-the-field/re_lgbt-stories-from-the-field/.