

UNDERSTANDING INTERSECTIONAL DATA EQUITY

*FROM THE SEXUAL ORIENTATION GENDER
IDENTITY SEXUAL CHARACTERISTICS
(SOGISC OR SOGI) LENS*

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INTRODUCTION

This issue brief is an overview of the importance of data equity from the sexual orientation gender identity sexual characteristics (SOGISC or SOGI) lens. What follows is a discussion of how the Federal Government can and should expand and improve SOGISC data collection to improve health equity. Improving data quality can improve the quality of life for many underserved and undercounted communities. Better data leads to a more inclusive democracy, and better policies, programs, and service delivery.

I. National LGBTQ Task Force Data Equity Advocacy

The National LGBTQ Task Force advances freedom, justice, and equality for people who identify as LGBTQ+. We are building a future where everyone can be free to be their entire selves in every aspect of their lives. Today, despite all the progress we have made to end discrimination, millions of individuals in the LGBTQ+ community face barriers in education, housing, employment, healthcare, retirement, and basic human rights. To combat these barriers and better serve LGBTQ+ community members, it is important to gather accurate data. The Task Force is proud to stand shoulder to shoulder with our partners in the National Minority Quality Forum (NMQF) and the Blues Cross Blue Shield Association (BCBSA) Data Equity Coalition to improve healthcare outcomes for people across the United States. As such, the Task Force heartily endorsed NMQF and BCBSA's issue brief *Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy*.¹ The brief describes policy challenges and recommended solutions to advance a stakeholder-informed data equity movement with an intersectional lens.²

Furthermore, in the quest for health equity, the Task Force stands with NMQF and BCBSA to urge the Office of Management and Budget (OMB) to continue to update the *Statistical Policy Directive No. 15 (SPD 15): Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*³ to not only further expand race and ethnicity definitions, but also include language, sexual orientation, and gender identity. Doing so would ensure that all of us, especially individuals from marginalized and historically excluded communities, are represented accurately in data across the Federal Government, the Census Bureau, and other federal agencies to include questions that address sexual orientation and gender identity on future surveys and questionnaires.

Continuing to update SPD 15 after the March 2024 revision would ensure that everyone across the United States, especially people from marginalized and historically excluded communities, are represented accurately in data across the Federal Government. Data that fails to include and account for the various identities that exist in the United States continues to reinforce systems of power and oppression in this country.

1. Blue Cross Blue Shield Association and National Minority Quality Forum (NMQF). (2023, March 28). Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy. NMQF. <https://nmqf.org/wp-content/uploads/2023/09/Standardizing-Data-to-Advance-the-Health-Equity-Movement-Issue-Brief.pdf>.

2. *Ibid* at 2.

3. Orvis, K. (2022, June 15). Reviewing and Revising Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity. The White House. <https://www.whitehouse.gov/omb/briefing-room/2022/06/15/reviewing-and-revising-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity/>.

The collection of race, sexual orientation, and gender identity data fulfills the stated goals of two of President Biden's Executive Orders (EO) which emphasize data collection equity: Executive Order 13985 on "Advancing Racial Equality and Support for Underserved Communities Through the Federal Government" and Executive Order 14075 on "Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals." Section 11 of EO 14075⁴ instructs OMB and other federal agencies to begin collecting SOGI data. Section 11, Subsections (d), (e), and (f) layout OMB's role in supporting improved SOGI data practices across the Federal Government.⁵

Subsection (e) instructs the Director of OMB, through the Chief Statistician of the United States, to publish a report with recommendations for agencies on the best practices for the collection of SOGI data on federal statistical surveys, including strategies to preserve data privacy and safety.⁶ Subsection (f) instructs the Director of OMB to evaluate the efficacy of SOGI data practices across agencies, and shall consider whether to update reports, guidance, or directives based upon the latest evidence and research as needed. Additionally, the Equitable Data Working Group, established by EO 13985, published a report in 2022 recommending the collection of disaggregated data to reflect experiences of underserved groups.⁷

The Federal Government needs to understand who and where the LGBTQ+ community is located. Data helps inform policies, including access to health care, housing, and federal benefits. The community is frequently depicted as being exclusively wealthy, white, and male. That depiction is not accurate. The LGBTQ+ community is a microcosm of the larger demography in the United States. Any time there is an expansion of when, where, and how SOGI data is collected at the federal level, it is a chance to dispel those stereotypes that have contributed to so much of the advocacy against the LGBTQ+ community.

II. SOGI Data: A Critical Component of Comprehensive Health Care Policy

Collecting SOGI data provides the Federal Government with the information it needs to make more informed decisions about health care policies and regulations that have a direct and long-term impact on the federal government itself and the American public. By collecting sexual orientation gender identity data and sexual characteristics (SOGISC), the Biden-Harris Administration will ensure LGBTQ+ people are properly counted in our nation's population and policymakers have access to fuller and more deeply disaggregated data to better inform decision making. LGBTQ+ communities deserve to be counted and represented in federal data collection, so their needs and can be reflected in government policies, programs, and funding investments. Gathering demographic data on sexual orientation, gender identity, and variations in sex characteristic is critical to obtain an accurate and comprehensive understanding of LGBTQ+ people and their experiences across key areas of life, such as health, housing, employment, economic security, and public benefits use.

More than five years have passed since the U.S. Department of Justice (DOJ) and other agencies submitted letters to the U.S. Census Bureau (USCB) requesting that questions related to sexual orientation and gender

4. Federal Register Volume 87, Number 118. (2022, June 15). Executive Order 14075, Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals, Pages 37189-37195. U.S. Government Publishing Office. <https://www.govinfo.gov/content/pkg/FR-2022-06-21/pdf/2022-13391.pdf>

5. *Ibid.*

6. *Ibid.*

7. Federal Register Volume 86, Number 14. (2021, January 25). Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, Pages 7009-7013. U.S. Government Publishing Office. <https://www.govinfo.gov/content/pkg/FR-2021-01-25/pdf/2021-01753.pdf>

identity be included in the American Community Survey.⁸ The DOJ's letter included several reasons for why they need this data, including to enforce prohibitions against discrimination under Title VII of the Civil Rights Act to help administer grants, and to plan education efforts around prohibitions on discrimination. Since these letters were sent, the U.S. Supreme Court has affirmed that Title VII of the Civil Rights Act of 1964 prohibits LGBTQ+ discrimination as a form of sex discrimination,⁹ and the Biden Administration has made clear that this holding should be applied to all federal laws prohibiting sex discrimination.¹⁰

The unprecedented challenges of legal enforcement demonstrate a more critical need than ever before for the U.S. Government to collect better data on LGBTQ+ people. As part of the work to implement SOGI data questions, the Federal Government should:

- Ensure gender identity measures allow non-cisgender individuals to properly reflect their identities in responses, including by allowing participants to select all responses that apply and including a nonbinary response option;
- Evaluate standalone measures to collect data on people with intersex traits;
- Evaluate measures to incorporate emerging sexual orientation and gender identities;
- Evaluate, including through the use of existing research, the appropriate question placement and formatting of SOGISC measures;
- Ensure that SOGISC measures are translated in culturally competent ways in order to avoid barriers to non-English speakers responding to these questions;
- Assess the performance of SOGISC measures in proxy reporting settings;
- Develop strategies to address SOGISC non-responses in both in-person and proxy interviews;
- Develop trainings for Census Bureau staff who engage with the public, so they can understand how to best collect SOGISC data and address questions or concerns relating to this data collection; and
- Evaluate how the Census Bureau's efforts to use administrative records would address the lack of SOGISC data in many administrative data collection efforts.

The Task Force seeks to make health data collection inclusive and affirming for LGBTQ+ people across the United States. The government should prioritize improving all healthcare services with a specific focus on ensuring equity and access to those who are marginalized in our country, including individuals who identify as Black, Brown, LGBTQ+, disabled, and living in poverty. Health data equity is an important tool to reduce health disparities and barriers to health care and advance equality for LGBTQ populations.

8. Carper, Tom, Harris, Kamala. (May 17, 2022). [Letter from Senator Tom Carper and Senator Kamala Harris to John H. Thompson, Director, United States Census Bureau, 2022]. Retrieved March 24, 2024 from [https://www.carper.senate.gov/wp-content/uploads/archives/2017-05-22%20Carper-Harris%20Letter%20to%20Census%20Bureau%20re%20New%20Subjects%20\(press\).pdf](https://www.carper.senate.gov/wp-content/uploads/archives/2017-05-22%20Carper-Harris%20Letter%20to%20Census%20Bureau%20re%20New%20Subjects%20(press).pdf)

9. Bostock v. Clayton County, 590 U.S. 140 S. Ct. 1731 (2020). https://www.supremecourt.gov/opinions/19pdf/17-1618_hfci.pdf

10. Federal Register Volume 86, Number 14. (2021, January 20). Executive Order 13988, Preventing and Combating Discrimination on the Basis of Gender Identity or Sexual Orientation, Pages 7,023–7,025. U.S. Government Publishing Office. <https://www.govinfo.gov/content/pkg/FR-2021-01-25/pdf/2021-01761.pdf>

III. Queering The Census: Successful SOGI Data Efforts

Thankfully, key players within the Federal Government recognize the importance of SOGI data and are working to ensure an individual's full experience and identity reflected in federal data. The Census Bureau is the venerable leader of data collection in the United States. Indeed, the Decennial Census is the gold standard for demographic data in the United States. The Census Bureau is working to capture data on LGBTQ individuals through the American Community Survey (ACS), the Household Pulse Survey, and the Economic Census. The ACS is a testing ground for questions that can be added to the Decennial Census, hereinafter referenced as "the Census." The Census and the data it produces affect our daily lives, and the data is incorporated into federal funding formulas used to distribute federal resources.

Every decade, the Census misses, or undercounts hundreds of thousands of marginalized individuals, including the low-income, people of color, and very young children. There is an increasing body of information from independent researchers to give us a more thorough picture of queer populations in the United States. One such researcher, Gallup, recently released survey results which found that the percentage of Americans who identify as Lesbian, Gay, Bisexual, Transgender, or something other than heterosexual has increased to 7.1%, up from 5.6%, in the last decade.

In 2021, the Williams Institute at the UCLA School of Law estimated that approximately 1.2 million LGBTQ adults in the U.S. identify as nonbinary.¹¹ The statistical reference is an extraordinary development toward counting LGBTQ individuals. The numbers confirm the validity of LGBTQ people existing in significant numbers across the United States, and individual experiences must be reflected in health care data. The work of the Census Bureau is included in this discussion to highlight the fact that collecting SOGI, and intersectional data can be done and is, in fact, already being done successfully.

IV. A Multi-Pronged Approach to Collecting SOGI Data

Collecting SOGI data must be a multi-pronged approach. Policies and regulations have direct and long-term impact on the Federal Government and more importantly on the American public. Thus, we must improve health care equity with a keen eye toward those whose lives will be affected by these reforms. To collect more and better SOGI data in healthcare settings, people must feel comfortable sharing that information. To foster greater comfort, we must dismantle discrimination and other barriers LGBTQ+ people in accessing healthcare. The Task Force strenuously objects to discrimination against LGBTQ+ people in health care and health care settings, whatever the purported rationale.

The government should prioritize and fully fund all health care services with a specific focus on ensuring equity and access to those who are most marginalized in our country, including individuals who identify as Black, Brown, LGBTQ+, disabled, and living in poverty. U.S. health care systems fall far short of this, and the Task Force appreciated the U.S. Department of Health and Human Services' (HHS) effort in its 2022 Section 1557 rule to try and address some of these inequities.¹²

11. Williams Institute. (2021, June 22). 1.2 million LGBTQ adults in the US identify as nonbinary [Press Release]. <https://williamsinstitute.law.ucla.edu/press/lgbtq-nonbinary-press-release/>

12. Federal Register Volume 87, Number 149. (2022, August 4). Department of Health and Human Services, Nondiscrimination in Health Programs and Activities, Pages 47824-47919. U.S. Government Publishing Office. <https://www.govinfo.gov/content/pkg/FR-2022-08-04/pdf/2022-16217.pdf>

The National Academies of Sciences, Engineering, and Medicine reports that discrimination against sexual- and gender-diverse persons in obtaining health insurance and in the substantive provisions of insurance coverage remains a barrier to queer people accessing health care.¹³ LGBTQ+ people report poorer health overall and the barriers place them at increased risk of numerous health conditions such as sexually transmitted infections, human immunodeficiency virus (HIV), obesity, substance abuse, and mental health conditions. As a result of discrimination in insurance coverage and barriers to accessible health care, individuals who identify as LGBTQ+ face significant health inequalities.

According to a 2010 report by the national litigation group Lambda Legal entitled, “When Health Care Isn’t Caring”, addressing health care discrimination against LGBT people and people living with HIV, more than half of all respondents reported at least one type of discrimination in care.¹⁴ These include:

- Being refused needed care;
- Health care professionals refusing to touch them or using excessive precautions;
- Health care professionals using harsh or abusive language;
- Being blamed for their health care status; and
- Health care professionals being physically rough or abusive.

Due to the bias and discrimination in the health care industry, many members of LGBTQ communities show a “high degree of anticipation and belief that they w[ill] face discriminatory care,” which ultimately causes many people to not seek care.¹⁵

HHS’s Healthy People 2020 initiative recognized that “LGBT individuals face health disparities linked to societal stigma, discrimination, and denial of their civil and human rights.”¹⁶ Barriers to quality health care surface in a wide variety of contexts, including physical and mental health care services.¹⁷ In a study published in Health Affairs, researchers examined the intersection of gender identity, sexual orientation, race, and economic factors in health care access. The research concluded that discrimination, as well as insensitivity or disrespect on the part of health care providers, was a key barrier to health care access.¹⁸ Also, academic research confirms the problem. A recent systematic literature review conducted by the What We Know Project of Cornell University “found robust evidence that discrimination on the basis of sexual orientation or gender identity is associated with harms to the health of LGBT people.”¹⁹

13. The National Academies Press (NAP). (2020) Understanding the Well-Being of LGBTI+ Populations. NAP. <https://nap.nationalacademies.org/read/25877/chapter/1#ii>.

14. Lambda Legal (LL). (2010). When Health Care Isn’t Caring: Lambda Legal’s Survey on Discrimination Against LGBT People and People Living with HIV. LL. https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf

15. *Ibid.*

16. Office of Disease Prevention and Health Promotion. (n.d.). Healthy People 2020: Lesbian, Gay, Bisexual, and Transgender Health. U.S. Department of Health and Human Services. Retrieved March 25, 2024 from <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>

17. Human Rights Watch (HRW). (2018, February 19). All We Want is Equality: Religious Exemptions and Discrimination against LGBT People in the United States. HRW. https://www.hrw.org/report/2018/02/19/all-we-want-equality/religious-exemptions-and-discrimination-against-lgbt-people?gad_source=1&gclid=Cj0KCQjwwYSwBhDcARIsAOyL0fitHj2KyUvPJBYI-zRsBOMX_Def0seinDe4Xysa9HCikV3_-dut9i4aAil7EALw_wcB

18. Hsieh, N., Ruther, M. (2017, October). Despite Increased Insurance Coverage, Nonwhite Sexual Minorities Still Experience Disparities In Access to Care, Vol.36, No.10. Health Affairs. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0455>.

19. What We Know The Public Policy Research Portal. (n.d.). What Does the Scholarly Research Say about the Effects of Discrimination on the Health of LGBT People. Cornell University. Retrieved March 25, 2024 from <https://whatwewknow.inequality.cornell.edu/topics/lgbt-equality/what-does-scholarly-research-say-about-the-effects-of-discrimination-on-the-health-of-lgbt-people/>.

Data in a 2022 report from the Center for American Progress “reveal that LGBTQ communities encounter discrimination and other challenges when interacting with health care providers and health insurers, underscoring the importance of strengthening nondiscrimination protections through Section 1557 of the Affordable Care Act (ACA).”²⁰ The Task Force strongly supported the 2022 HHS Section 1557 rule because it prohibited health care discrimination based on sexual orientation and gender identity, provided greater access to gender-affirming care, and prohibited discrimination in health insurance coverage. “Certain populations continue to face barriers to quality, affordable health services, including those individuals who have lower incomes, live in rural communities, households with a primary language other than English, immigrants, Tribes/Native Americans, racial and/or ethnic minority communities, LGBTQ+ populations, and people with disabilities.”²¹ Once fully implemented, this rule will improve and increase access to healthcare for LGBTQ+ people in the U.S. in furtherance of the original goals of the ACA – to make healthcare in this country affordable and available.

“LGBTQ+ youth are overrepresented in foster care, often due to the lack of acceptance from family members, exposure to more traumatic experiences, and disruption in placements and extended stays in foster care than non- LGBTQ+ youth.”²² Child welfare agencies who actively identify and ensure access to foster homes that provide stable, supportive, and safe families for LGBTQ+ youth can nurture positive outcomes for such youth.²³ To achieve more intersectional health data, we need both robust SOGI data collection efforts and strong non-discrimination protections.

V. CONCLUSION

Health care is an essential part of life for every person in the United States. For better health outcomes for underrepresented communities, we need data to reflect the intersectional experiences of those whose identities and life experiences, and ultimately their health care needs, are shaped by the confluence of race, ethnicity, language, sexual orientation, gender identity, and sexual characteristics. The Task Force will continue working tirelessly to dismantle the discriminatory disparities faced by LGBTQ+ people in health care and elsewhere in this country. Consistent with Executive Order 14075, we remain steadfast in our pursuit to uproot and eradicate the insidious barriers that compromise our ability to be treated with equality in health care and every aspect of life. The Task Force thanks all the government agencies who have already begun working to collect better data on race, ethnicity, language, sexual orientation, gender identity, and sexual characteristics. However, this type of data collection must be implemented government-wide in order to improve the health of marginalized communities.

20. Center for American Progress (CAP). (2022, September 8). Advancing Health Care Nondiscrimination Protections for LGBTQ+ Communities. CAP. <https://www.americanprogress.org/article/advancing-health-care-nondiscrimination-protections-for-lgbtqi-communities/>.

21. *Ibid*

22. Baams, L., Wilson, B., Russell, S. (2019, March). LGBTQ Youth in Unstable Housing and Foster Care. National Institute of Health. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6398424/>

23. Child Welfare Information Gateway. (2021). Supporting LGBTQ+ youth: A guide for foster parents. U.S. Department of Health and Human Services, Administration for Children and Families, Children’s Bureau. <https://www.childwelfare.gov/pubs/LGBTQyouth/>