

SENATE JUDICIARY COMMITTEE
Senator Thomas Umberg, Chair
2023-2024 Regular Session

SB 957 (Wiener)
Version: January 22, 2024
Hearing Date: April 2, 2024
Fiscal: Yes
Urgency: No
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SUBJECT

Data collection: sexual orientation and gender identity

DIGEST

This bill requires the California Department of Public Health (CDPH) to collect demographic data regarding sexual orientation, gender identity, and intersexuality from third parties, as provided. The bill also adds sexual orientation and gender identity information to the demographic data that health care providers and specified agencies must disclose to local health departments and CDPH, as specified. The bill requires CDPH to prepare and post an annual report to the Legislature regarding this data.

EXECUTIVE SUMMARY

The goal of collecting demographic data is to gather accurate information in order to understand and apply that data to the enhancement and improvement of public services. Given the historic exclusion and erasure of LGBT communities, data collection that provided such insights for these communities was sparse. In response, the Lesbian, Gay, Bisexual, and Transgender Disparities Reduction Act was passed. It requires various government entities, in the course of collecting other data, to collect voluntary self-identification information pertaining to sexual orientation and gender identity. The collection and dissemination of such information was subject to clear safeguards and use limitations.

This bill expands that net, requiring CDPH to collect this data from third parties. It also requires certain providers and local entities to report this data to CDPH and local health departments. CDPH is tasked with annual reporting regarding the data collected. The bill is cosponsored by Equality California, San Francisco AIDS Foundation, and the California LGBTQ Health & Human Services Network and is supported by a wide variety of groups. The Committee has received no opposition. The bill passed out of the Senate Health Committee on a vote of 9 to 2.

PROPOSED CHANGES TO THE LAW

Existing law:

- 1) Requires that a state agency, board, or commission that directly or by contract collects demographic data as to the ancestry or ethnic origin of Californians shall use separate collection categories and tabulations for the following:
 - a) Each major Asian group, including, but not limited to, Chinese, Japanese, Filipino, Korean, Vietnamese, Asian Indian, Laotian, and Cambodian.
 - b) Each major Pacific Islander group, including, but not limited to, Hawaiian, Guamanian, and Samoan. (Gov. Code § 8310.5(a).)
- 2) Provides that the above data shall be included in every demographic report on ancestry or ethnic origins of Californians by the state agency, board, or commission and shall be made available to the public in accordance with state and federal law, except for personal identifying information, which shall be deemed confidential. (Gov. Code § 8310.5(b).)
- 3) Establishes the Lesbian, Gay, Bisexual, and Transgender Disparities Reduction Act, which requires specified state entities, in the course of collecting demographic data directly or by contract as to the ancestry or ethnic origin of Californians, to also collect voluntary self-identification information pertaining to sexual orientation, gender identity, and intersexuality. The law provides various methods by which this requirement can be carried out. (Gov. Code § 8310.8.)
- 4) Applies the above obligation to the following entities:
 - a) The State Department of Health Care Services.
 - b) The State Department of Public Health.
 - c) The State Department of Social Services.
 - d) The California Department of Aging.
 - e) The State Department of Education and the Superintendent of Public Instruction, except this section shall not apply to the California Longitudinal Pupil Achievement Data System (CALPADS).
 - f) The Commission on Teacher Credentialing.
 - g) The Civil Rights Department.
 - h) The Labor and Workforce Development Agency.
 - i) The Department of Industrial Relations.
 - j) The Employment Training Panel.
 - k) The Employment Development Department, except this section shall not apply to the unemployment insurance program within the department.
 - l) The State Department of State Hospitals.
 - m) The Department of Rehabilitation.
 - n) The State Department of Developmental Services.

- o) The Department of Community Services and Development. (Gov. Code § 8310.8(a).)
- 5) Requires these state entities to report to the Legislature the data collected and the method used. They shall make the data available to the public in accordance with state and federal law, except for personal identifying information, which shall be deemed confidential and shall not be disclosed. (Gov. Code § 8310.8(c).)
- 6) Prohibits these state entities from reporting demographic data that would permit identification of individuals or would result in statistical unreliability. Demographic reports on data collected pursuant to this section, to prevent identification of individuals, may aggregate categories at a state, county, city, census tract, or ZIP Code level to facilitate comparisons and identify disparities. (Gov. Code § 8310.8(c).)
- 7) Limits the purposes for which these state entities can use this information, including demographic analysis, coordination of care, quality improvement of its services, conducting approved research, fulfilling reporting requirements, and guiding policy or funding decisions. All information about sexual orientation and gender identity collected shall be used only for the purposes specified. (Gov. Code § 8310.8(c).)
- 8) Permits local health officers (LHOs) to operate immunization information systems in conjunction with the Immunization Branch of CDPH. (Health & Saf. Code § 120440(b).)
- 9) Requires health care providers and specified agencies (such as schools, childcare facilities, and human services agencies), unless a refusal to permit record sharing is made, to disclose specified information to local health departments (LHDs) and CDPH. LHDs and CDPH are permitted to disclose this information to each other and, upon a request for information pertaining to a specific person, to specified service providers and government entities. The information includes basic identifying information about the patient/client and their immunization history. (Health & Saf. Code § 120440(c).)
- 10) Requires health care providers, LHDs, and CDPH to maintain the confidentiality of this information in the same manner as other medical record information with patient identification that they possess. The law subjects them to civil action and criminal penalties for the wrongful disclosure of this information. The law places use limitations on these data, as specified. (Health & Saf. Code § 120440(d).)

This bill:

- 1) Requires CDPH, as of July 1, 2026, to collect demographic data from third parties, including, but not limited to, local health jurisdictions, on any forms or electronic data systems, unless prohibited by federal or state law.
- 2) Includes a patient's or client's sexual orientation and gender identity (SOGI) data in the information that must be provided by health care providers and other agencies to CDPH and LHDs.
- 3) Requires CDPH to prepare and post publicly an annual report concerning SOGI data they have collected and submit it to the Legislature. The report must exclude any personally identifiable information. It must include all of the following information:
 - a) CDPH's efforts to collect, analyze, and report SOGI data, including a comprehensive list of forms through which the collection of SOGI data is required under existing law, the level of compliance with SOGI data collection requirements through those forms, the forms exempt from those requirements, and the reasons for those exemptions.
 - b) The status of any improvement or replacement of the California Reportable Disease Information Exchange (CalREDIE), CDPH's statewide database and surveillance system for reporting communicable diseases.
 - c) The outcomes of data analyses that CDPH has performed, or has allowed other qualified researchers to perform, using collected SOGI data.
 - d) The steps that CDPH has taken, or has caused to be taken, to improve services or program outcomes for underserved lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ) populations.
 - e) Until fully implemented, the progress CDPH has made in implementing recommendations set forth in a report by the California State Auditor's Office, dated April 27, 2023, and numbered 2022-102.

COMMENTS

1. A brief history of LGBT discrimination and exclusion

There is already clear evidence that the history of societal and institutional exclusion and discrimination against LGBTQ communities has resulted in disparities in health and other outcomes for those communities. Over the past decade, the specific struggles of the transgender and gender nonconforming communities have become part of the American zeitgeist, particularly as various media have explored the institutional challenges facing these communities. A 2011 National Transgender Discrimination Survey found that 90 percent of transgender people experienced mistreatment or

discrimination at work or took actions to avoid such discrimination.¹ Nearly 47 percent of those surveyed lost their jobs, were denied a promotion, or were denied a job as a direct result of discrimination because they were transgender. The transgender, gender-nonconforming, and intersex (TGI) community is experiencing alarming rates of marginalization and disenfranchisement.

A key tool in addressing these issues is more thoughtful and systematic data collection. As the Center for American Progress puts it:

Data collection is an indispensable tool to understand and address challenges facing LGBTQI+ and other sexual and gender-diverse communities. Although strides have been made in recent years, a persistent lack of routine data collection on sexual orientation, gender identity, and variations in sex characteristics (SOGISC) is still a substantial roadblock for policymakers, researchers, service providers, and advocates seeking to improve the health and well-being of LGBTQI+ people. More comprehensive and accurate point-in-time and longitudinal demographic data on SOGISC are crucial to:

- Advance research agendas
- Evaluate population trends
- Identify community-based needs
- Provide high-quality services
- Track and address discrimination
- Equitably distribute funding and other resources
- Shape evidence-based policy solutions to promote equity and reduce disparities faced by LGBTQI+ populations

As the size and diversity of LGBTQI+ populations in the United States continue to expand, particularly among youth and young adults, the importance of collecting data on these communities only continues to grow. Failing to collect these data can create harms by hindering the ability of researchers, policymakers, service providers, and advocates to understand the experiences of LGBTQI+ communities, identify disparities, generate policies that promote equity, and evaluate the effectiveness of those policies.²

¹ Jaime M. Grant et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey* (2011) National Center for Transgender Equality and National Gay and Lesbian Task Force, https://transequality.org/sites/default/files/docs/resources/NTDS_Report.pdf. All internet citations are current as of March 13, 2024.

² *Collecting Data About LGBTQI+ and Other Sexual and Gender-Diverse Communities* (May 24, 2022) Center for American Progress, <https://www.americanprogress.org/article/collecting-data-about-lgbtqi-and-other-sexual-and-gender-diverse-communities/>.

Despite the critical role this data collection plays, the number of federally funded surveys that include questions to identify LGBTQI+ respondents is limited. Here in California, many agencies that provide vital services do not offer an option for the TGI community to identify themselves on public-use forms.

2. Responding to the lack of adequate data collection

To begin to address these issues, AB 959 (Chiu, Ch. 565, Stats. 2015) enacted the Lesbian, Gay, Bisexual, and Transgender Disparities Reduction Act. The Act requires specified state departments to collect voluntary self-identification information pertaining to sexual orientation and gender identity in the course of collecting other demographic data directly or by contract. The Act provides some possible methods for carrying out this data collection. Initially, only four state departments were included. After multiple expansions, 15 departments are now subject to the Act.

The departments are required to report the data collected and the method used to collect that data to the Legislature. They are further required to make the data available to the public in accordance with state and federal law. To ensure the privacy of the individuals involved, the Act specifically prohibits personal identifying information from being disclosed. The departments are further prohibited from reporting any demographic data that would permit identification of individuals or would result in statistical unreliability. The Act provides that demographic reports on data collected may aggregate categories to prevent identification of individuals. This can be done at a state, county, city, census tract, or zip code level to facilitate comparisons and identify disparities.

To provide an additional layer of privacy protection, the state departments are only authorized to use information voluntarily provided about sexual orientation and gender identity for specified purposes, namely demographic analysis, coordination of care, quality improvement of its services, conducting approved research, fulfilling reporting requirements, and guiding policy or funding decisions.

3. Responding to the State Auditor's Report

In 2023, the California State Auditor conducted an audit of CDPH and its role in collecting, reporting, and using SOGI data. The audit found that:

[CDPH] has been slow to adopt and enforce standardized guidelines to ensure the consistent collection and reporting of SOGI data, which has limited its ability to identify and address health disparities among those in the lesbian, gay, bisexual, transgender, and queer or questioning population.

Public Health collects health-related demographic data using a variety of reporting forms, questionnaires, and surveys (forms), but the department has not had clear and consistent policies regarding how such forms should collect SOGI data. Of the 129 forms we reviewed, 105 were exempt from the requirement to collect SOGI data but were not prohibited from doing so, and only 17 of the remaining 24 forms collect complete SOGI data. The lack of consistent SOGI data collection procedures, and ultimately the low number of Public Health forms that currently collect SOGI data, indicate that changes to state law may be warranted to compel more consistent and useful SOGI data collection practices.³

The audit laid out a series of recommendations to address these shortfalls, including the following, directed at the Legislature:

To ensure that Public Health's branches use the SOGI data it collects to identify and address disparities in health outcomes, and to provide Public Health with an efficient mechanism to fulfill its current reporting requirements, the Legislature should require Public Health to provide an annual report to the public and to the Legislature that includes descriptions of the following:

- Public Health's efforts to collect, analyze, and report SOGI data, including a comprehensive list of forms that are required to collect SOGI data, the level of compliance with SOGI data requirements for those forms, the forms exempt from these requirements, and the reasons for such exemptions.
- The status of any improvement or replacement of CalREDIE—Public Health's database used for statewide reporting of communicable diseases.
- The outcomes of data analyses that Public Health has performed or has allowed other qualified researchers to perform using the SOGI data it has collected.
- The steps Public Health has taken or has caused to be taken to improve services or program outcomes for underserved LGBTQ populations.
- Until fully implemented, the progress Public Health has made in implementing recommendations from this audit report.

To ensure that Public Health collects sufficient data to effectively implement and deliver critical services, the Legislature should amend the

³ Grant Parks, *California Department of Public Health: It Has Missed Opportunities to Collect and Report Sexual Orientation and Gender Identity Data* (April 2023) California State Auditor, <https://auditor.ca.gov/pdfs/reports/2022-102.pdf>.

SOGI data collection law to require Public Health to collect SOGI data from third-party entities, including local health jurisdictions, on any forms or electronic data systems unless prohibited by federal or state law.

The Legislature should amend state law to allow voluntarily provided sexual orientation and gender identity data to be included with the immunization data that is reported to Public Health.⁴

This bill implements these recommendations. First, it requires CDPH to prepare, publicly report, and submit to the Legislature, an annual report on its SOGI data collection and its progress on the metrics laid out above by the Auditor's report.

The bill also implements the data collection piece by amending the Act to require CDPH to collect SOGI data from third party entities, such as local health departments.

Finally, the bill carries out the final recommendation by amending existing law that requires health providers and other agencies to report specified data to CDPH. The law currently requires sharing of basic patient/client identifying information and immunization data. The bill adds SOGI data to that reporting requirement.

According to the author:

SB 957 implements the recommendations from last year's State Auditor report that found that the California Department of Public Health (CDPH) is failing to adequately assess health disparities faced by the LGBTQ community. California is still not collecting adequate data to understand the unique health challenges faced by LGBTQ people. It is egregious that during the COVID-19 pandemic, no data was being collected, leaving the LGBTQ community with limited resources. Senate Bill 957 requires the CDPH to collect sexual orientation and gender identity (SOGI) data from third-party entities, including local health jurisdictions, on any forms or electronic data systems. Last year, the State Auditor released a report on CDPH and found that they had failed to collect SOGI data, impacting their ability to measure LGBTQ health outcomes. The MPX outbreak of 2022 showed once again the danger of leaving LGBTQ health invisible to the public health system. By forcing CDPH to finally collect SOGI Data, SB 957 takes us one step closer to health equity.

4. Stakeholder positions

Equality California, San Francisco AIDS Foundation, and California LGBTQ Health & Human Services Network, co-sponsors of the bill, explain the need for the bill:

⁴ *Ibid.*

According to the Williams Institute at the UCLA School of Law, California's overall population is made up of approximately 5.3% of people that self-identify as LGBTQ+. Collecting accurate SOGI data is essential to understanding the extent to which LGBTQ+ people in California are experiencing disparities in health and well-being and whether government programs are reaching LGBTQ+ people in need of care and assistance. Failing to collect accurate SOGI data makes the LGBTQ+ community invisible and undermines opportunities to ensure that all Californians receive the care and services they need. This oversight can have significant consequences for LGBTQ+ people, including increased stigma, misinformation, ineffective service provision, and a delayed response to public health emergencies like COVID-19 and the recent mpox outbreak.

A wide coalition of groups in support, including the Sacramento LGBT Community Center, writes:

The Legislature has acknowledged the importance of collecting accurate and comprehensive SOGI data to fully comprehend the challenges facing the LGBTQ+ community and applying that data to improve public services for LGBTQ+ Californians. SB 957 ensures that our state has access to the complete data required to tackle public health issues facing LGBTQ+ people and uplift California's most vulnerable communities.

SUPPORT

California LGBTQ Health and Human Services Network (co-sponsor)

Equality California (co-sponsor)

San Francisco Aids Foundation (co-sponsor)

AARP

ABD/skywatchers

Amador County Arts Council

Bienestar Human Services

California Legislative LGBTQ Caucus

Children Now

Courage California

El/la Para Translatinas

Fresno, California State University

Glide

Harvey Milk LGBTQ Democratic Club

Health Access California

Healthright 360

Justice in Aging

LGBTQ+ Collaborative

Los Angeles LGBT Center
Lyon-martin Community Health Services
Our Family Coalition
PRC Baker Places
Radiant Health Centers
Rainbow Pride Youth Alliance
Sacramento LGBT Community Center
San Diego Pride
San Francisco Pretrial Diversion Project
SF LGBT Center
Somos Familia
The Source LGBT+ Center
Transgender Resource, Advocacy & Network Service
Viet Rainbow of Orange County

OPPOSITION

None received

RELATED LEGISLATION

Pending Legislation: None known.

Prior Legislation:

AB 1163 (Luz Rivas, Ch. 832, Stats. 2023) expanded the data collection obligations of the Act to three additional agencies.

AB 1797 (Weber, Ch. 582, Stats. 2022) required, rather than permitted, health care providers and specified agencies that have access to immunization information to disclose certain information from a patient medical record or a client record to CDPH and local health departments. It added “patient’s or client’s race and ethnicity” to the list of information collected for purposes of immunization information and reminder systems.

SB 932 (Wiener, Ch. 183, Stats. 2020) required any electronic tool used by LHOs for the purpose of reporting cases of communicable disease to CDPH to include the capacity to collect and report SOGI data of individuals who are diagnosed with a reportable disease, and requires health care providers who are in attendance on a case of a reportable disease to report the patient’s sexual orientation and gender identity, if known.

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AB 2677 (Chiu, Ch. 744, Stats. 2017) also expanded the list of state entities to which the Act applies.

AB 532 (McCarty, Ch. 433, Stats. 2015) required any state agency, board, or commission that collects demographic data to provide forms that offer respondents the option of identifying as multiracial and selecting one or more ethnic or racial designations.

AB 959 (Chiu, Ch. 565, Stats. 2015) *See* Comment 2.

AB 1088 (Eng, Ch. 689, Stats. 2011) required certain state agencies to collect and tabulate data for additional major Asian groups, as listed, in order to better reflect the diversity of Asian American, Hawaiian, and Pacific Islander communities in California.

PRIOR VOTES:

Senate Health Committee (Ayes 9, Noes 2)
