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SENATOR SCOTT WIENER 威善高 ELEVENTH SENATE DISTRICT



May 2, 2022

The Honorable Rudy Salas Chair, Joint Legislative Audit Committee 1020 N Street, Room 107 Sacramento, CA 95831

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Dear Chair Salas and Members:

We respectfully request that the Joint Legislative Audit Committee approve an audit to examine the California Department of Public Health's (CDPH) procedures to collect, report and utilize data relating to the sexual orientation and gender identity (SOGI) of California residents.

According to the Williams Institute based out of the UCLA School of Law, utilizing Gallup Tracking survey data, California's overall population is made up of approximately 5.3% of people that self-identify as lesbian, gay, transgender, or queer/questioning (LGBTQ). However, noting the history of discrimination against people on the basis of their sexual orientation or gender identity, the stigma that is associated with identifying as LGBTQ has led many in this community to a life of invisibility. This has subsequently led the state to not have an accurate picture of how many people identify as LGBTQ and therefore has led to a neglecting of SOGI data collection.

The SOGI data that we are able to collect is pivotal in helping us to adequately respond to the unique needs of the LGBTQ community. From research, we know that LGBTQ people everywhere experience disparities as it relates to all aspects of their health. In a 2017 article on the National Center for Biotechnology Information's website regarding healthcare disparities among LGBTQ youth, it is cited that LGBTQ youth are at a higher risk for substance use, sexually transmitted diseases, cancers, cardiovascular diseases, anxiety, depression, and suicide as compared to the general population. LGBTQ people generally are also known to receive poor quality of care due to stigma, lack of healthcare providers' awareness, and insensitivity to the unique needs of this community.

Since the passage of Assembly Bill 959 (Chiu, Chapter 565 of the Statutes of 2015), CDPH is required to collect voluntarily provided information about sexual orientation and gender identity in the regular course of collecting other types of demographic data. AB 959 required that the aggregated SOGI data that is intended to act as indicators of disparities be reported to the Legislature and made publicly available. However, since the passage of AB 959, elected officials and advocates have had difficulty obtaining any relevant SOGI data.

Each program within CDPH set its own path for purposes of implementing AB 959. In 2020, sponsors of this legislation learned that CDPH has provided guidance on which questions and measures should be used to collect SOGI data. However, it is up to each program to actually implement these measures, update forms, inform frontline workers, provide translations, and to communicate with contractors. In recognizing the lack of publicly available data since the passage of this legislation, the potential for variability in implementation is troubling. While sponsors of AB 959 received information about the SOGI measures the Department was using in fall of 2019, there has not been much clarity in regard to follow-up with the programs to ensure that the guidance was consistently being followed.

Years since the passage of AB 959, the urgency behind collecting SOGI data has been exacerbated by the COVID-19 pandemic. According to a research brief published on March 20, 2020 from the Human Rights Campaign (HRC), those in the LGBTQ community are particularly vulnerable to the impacts of COVID-19. HRC found that LGBTQ people are more likely to work in jobs in highly affected industries, often with more exposure and/or higher economic sensitivity to the COVID-19 crisis.

LGBTQ people are also more likely than the general population to experience homelessness; this is particularly true among LGBTQ youth. People experiencing homelessness are at heightened risk of contracting and experiencing severe illness from the novel coronavirus. Additionally, members of the LGBTQ community are also more likely to be immunocompromised, because of HIV/AIDS and other health issues that are prevalent in higher rates amongst LGBTQ individuals. These health concerns, in addition to the economic concerns detailed above, mean that the LGBTQ community is uniquely susceptible to the impacts of COVID-19. According to the California Office of AIDS, while the impact of the novel coronavirus on people living with HIV is unknown, research suggests that those with chronic conditions are at higher risk of serious illness associated with COVID-19.

Out of the recognition of these inequalities and of the fact that the state was not requiring healthcare providers to collect SOGI data in the course of their COVID-19 testing efforts, the legislature passed an urgency measure, Senate Bill 932 (Wiener, Chapter 183 of the Statutes of 2020). This bill required that all electronic disease tools used in California by local health officers, for the purpose of reporting data on cases of communicable diseases to the Department of Public Health, include the capacity to collect and report data relating to SOGI. This legislation also added SOGI fields to the demographic information that healthcare providers are required to include in their reports of communicable diseases, if that information is known.

Unfortunately, CDPH has not made public any SOGI data around COVID-19 as it has with other demographic data fields like race and ethnicity. After various conversations with CDPH since the passage of SB 932, it has become abundantly clear that there are glaring issues related to the collecting and reporting of SOGI data both within the Department and among the providers and labs they work with.

We are very concerned with the lack of data and information that the California Department of Public Health has been able to provide since the passage of the aforementioned legislation and now with administration of the COVID-19 vaccine. LGBTQ people face additional barriers that non-LGBTQ people do not, and it is incumbent upon those crafting public policy to identify these barriers and work to fix them accordingly.

We know that the Department of Public Health alone cannot solve each of the issues experienced by LGBTQ Californians. However, we believe an audit would help to shed light on why research continues to indicate that LGBTQ experience negative health outcomes, and would also help identify the primary barriers our state experiences when attempting to identify these disparities. We hope the audit will also identify best practices and successful strategies for the Department to use in providing support for some of the most vulnerable people in our state and in order to inform our public policy decisions.

## SCOPE OF AUDIT

We request that an audit examine all of the programs within the California Department of Public Health that collect demographic data and examine compliance with Assembly Bill 959 (Chiu, Chapter 565 of the Statutes of 2015 and Senate Bill 932 (Wiener, Chapter 183 of the Statutes of 2020). Additionally, we request that this audit identify the procedures that the Department has in place to ensure and facilitate the process of soliciting SOGI data from healthcare providers and laboratories. Lastly, we request the audit examine the relationships with entities that CDPH contracts with and that this audit be prioritized over other audits unrelated to the COVID-19 pandemic.

## Audit Questions:

- 1. What programs within CDPH are actively collecting SOGI data at this time?
- 2. For the CDPH programs that are collecting SOGI data, who advises them on how to collect this data and is there any follow-up to ensure that the data is being properly collected?
- 3. How many entities does CDPH have contracts with that are collecting or have previously collected SOGI data and how are these contracts negotiated?
- 4. Are there particular processes in place within CDPH to monitor SOGI data collection with contracted entities?
- 5. How are changes in law relating to SOGI data collection communicated with entities that CDPH contracts with?
- 6. What barriers does the state experience when attempting to get SOGI data on communicable diseases from providers and labs?
- 7. What measures does CDPH take to ensure that all healthcare providers are actually collecting SOGI data and reporting it to the state in compliance with SB 932? How can these measures be improved?
- 8. What are the different methods that healthcare providers are using to collect SOGI data from patients with reportable communicable diseases? Can these methods be improved?

- 9. How does CDPH interact with labs that receive SOGI data from providers? Are there challenges present in this relationship related to gathering data? If so, how can these challenges be addressed?
- 10. How does CDPH interact with drive-through/pop-up COVID-19 testing sites that collect SOGI data? Are there challenges present in this relationship related to gathering this data and, if so, how can these challenges be addressed?
- 11. Has CDPH provided any specific guidance to laboratories on what to do once they receive SOGI data from providers? If they haven't, why not?
- 12. What are the current limitations and/or deficiencies related to SOGI data collection within electronic disease reporting systems used by both providers and labs? Are there any ways that these systems can be improved to allow for better SOGI data collection?
- 13. Are there any efforts being taken to begin collecting SOGI data information for COVID-19 vaccine administration? If not, why is CDPH not ensuring this data is being collected?
- 14. Are there any similar difficulties identified between the collection of data on race and ethnicity in comparison to SOGI?
- 15. Are there major differences identified when attempting to collect SOGI data between rural versus urban areas? If so, what are they?
- 16. Do any local health jurisdictions report SOGI data to CDPH particularly well? If so, are there any practices within these LHJs that can be adopted elsewhere?
- 17. What programs within CDPH are conducting SOGI data collection particularly well?
- 18. Was there a quantifiable difference in SOGI data retained after the passage of AB 959 (Chiu, 2015)?
- *19. Do different teams or programs within CDPH have different methodologies for collecting and tracking SOGI data?*
- 20. Is there unified guidance coming from any source within or outside of CDPH that could be used as a model for the entities required to collect SOGI data under current law?
- 21. Has CDPH provided any guidance to local county health departments, labs, or contractors on the collection of SOGI data? If so, what guidance -- and if not, why?
- 22. AB 959 (Chiu, 2015) specified that CDPH may only use SOGI data for demographic analysis, coordination of care, quality improvement of its services, conducting approved research, fulfilling reporting requirements, and guiding policy or funding decisions. If a program or team within CDPH has successfully collected SOGI data along with other demographic data, how has it been used?

Thank you for your consideration of our audit request. Given the emergency need for this information during this pandemic, we respectfully request that this audit be prioritized in advance of other requests unrelated to the pandemic. If you have any questions, please do not hesitate to contact us.

Sincerely,



ALEX LEE

Assemblymember, 25th District