

AB 1726: A California Case Study on Disaggregating Public Health Data by Race and Ethnicity

Led by SEARAC, Empowering Pacific Islander Communities, and other partners, [Assembly Bill 1726](#) was passed in 2016 and requires the California Department of Public Health (CDPH) to collect and release disaggregated demographic data for an expanded set of Asian and Pacific Islander populations, in addition to those mandated by CA State Code 8310.5:

CA State Code - 8310.5 Categories

Asian

- Chinese
- Japanese
- Filipino
- Korean
- Vietnamese
- Asian Indian
- Laotian
- Cambodian

Pacific Islander

- Hawaiian
- Guamanian
- Samoan

AB 1726 Expansion - CA State Code 8310.7

Asian

- Bangladeshi
- Hmong
- Indonesian
- Malaysian
- Pakistani
- Sri Lankan
- Taiwanese
- Thai

Pacific Islander

- Fijian
- Tongan

Key health indicators for data disaggregation include major disease rates, birth and death rates, and leading causes of death. When AB 1726 went into effect July 1, 2022, SEARAC began meeting with stakeholders, including seven local health departments (LHDs). The goals of these meetings were to gauge understanding of AB 1726, learn more about the local impacts of its implementation, and listen for broader challenges to health data disaggregation.

Since these meetings with LHDs and CDPH last year, we know of two new data releases that include all the categories above: 2022 CA Comprehensive Master Death File (released Nov. 7, 2023) and 2021 Birth Cohort File (released Feb. 7, 2024). The actual files have not been easily accessible to us.

SEARAC and its community partners met with the following LHDs: Fresno, Sacramento, Los Angeles, Orange, Alameda, San Francisco, and Santa Clara.



KEY CHALLENGES TO AB 1726 IMPLEMENTATION

Data practices need greater standardization and coordination

Multiple LHDs desired increased state coordination for standardizing the collection of race and ethnicity data, including how to address technical and privacy concerns related to disaggregation. Standardization efforts within individual agencies are complicated by different guidance from larger bureaucracies, and are reliant on data from downstream parties such as hospitals and laboratories. Multiple LHDs indicated that **missing or inaccurate data at the provider level** was a key limitation. Race and ethnicity details can also get lost as data is reported from party to party. For example, one LHD mentioned Health Level 7, an international data standard that could force them to consolidate data into just seven ethnic categories, even if they had more detailed data to report.

Funding has also impacted race and ethnicity reporting and has created uncommon data standards. For example, LHDs operate under various grants with different data collection and reporting requirements, which can make standardization across different programs slow and cumbersome. There is **not one single data management system** that collects information from all health programs.

Moreover, LHDs had not received guidance from CDPH on AB 1726, and were not coordinating with each other on similar data efforts. We found that while data standards of practice may exist in some counties, it is **unclear who oversees compliance and accountability** at both the state and local levels.

Data systems and staff need further integration and investment

Multiple data systems are used for different types of health data. Each system may have varying race and ethnicity collection capacities and require unique technology updates. The interagency nature of these systems means any one change can create complex cascading effects. How data flow between agencies is not always automatic, and **systems are not always interoperable**. Race and ethnicity data quality often diminishes as data move from party to party. Several LHDs noted it is difficult to influence what state and federal forms ask for in these systems.

In addition to technology, **investments are needed to train health department staff and providers on data standards, and handling data limitations**. Every LHD interviewed named concerns that limit reporting of accurate data, including misidentifying ethnic backgrounds, not having enough data reported, or low population counts that risk confidentiality. However, smaller ethnic groups are often the ones with the most invisible needs. The erasure of communities deemed “too small” perpetuates inequities, prevents us from targeting resources effectively, and harms our ability to advance public health for all. Various technical approaches to balance privacy concerns exist, and may require cost and effort. However, distorting or blocking data for privacy reasons can further community misrepresentation and mistrust for future data collection.

Data disaggregation needs to be seen as critical for effective public health intervention

Disaggregating race and ethnicity data — and harnessing the insights it provides for strategic public health decision-making — is not yet the status quo. **Champions who know the power of disaggregated data can be missing in leadership roles within health institutions**, from agencies to providers. Many LHDs are actively trying to improve data practices, but a larger shift is needed to uplift success stories of how high-quality, disaggregated data helps us improve accuracy and reduce disparities. Such data can teach us how to improve service delivery and for whom, and thus make them more cost effective. For example, one LHD described how disaggregated data unearthed higher Covid-19 infection rates for Filipinos and higher mortality rates for Chinese in their region, ultimately providing a more accurate picture of local Covid-19 impact. Data from an aggregated “Asian” category would not have done the same.

RECOMMENDATIONS FOR CDPH

CDPH has agreed to form a separate workgroup focused on implementing disaggregated race and ethnicity data laws. The workgroup is a partnership between CDPH, community-based organizations (CBOs), researchers, data analysts, and data equity advocacy groups, and will begin in March 2024.

The workgroup should:

- **Begin its focus primarily on AB 1726 (CA State Code 8310.7) implementation progress and challenges, as a case study for improving data disaggregation across CDPH and for other demographic categories, such as other racial and ethnic groups, sexual orientation, and gender identity. AB 1088 (CA State Code 8310.5) can be addressed at the same time.**
- **Serve as a primary consultative body to CDPH on specific health indicator data that community based organizations (CBOs) and service providers may request or need to improve outcomes for underserved Asian American (AA) and Native Hawaiian and Pacific Islander (NHPI) subgroups.**
- **Directly notify participants immediately when data from the categories listed on the AB 1726 [webpage](#) is available (vital statistics, infectious diseases, chronic conditions, vaccinations, social determinants of health, and leading causes of death). The [webpage](#) should be updated after each instance new data is made available.**
- **Develop a process for community accessibility on available disaggregated data, in compliance with differential privacy policies.**
- **Include regular participation from technical experts working to address AB 1726-related data limitations, such as privacy concerns, small subgroup numbers, and third-party data sources.**
- **Include staff representative(s) from selected LHDs, ideally those with local decision-making authority or purview over data impacted by AB 1726. This is one of several potential ways to encourage partnerships with LHDs to create standardized data practices, ensure data reporting compliance, and develop a robust data pipeline.**
- **Provide updates at each meeting on broader data infrastructure projects impacting AB 1726, such as CalREDIE improvements, the [Data Exchange Framework](#), and OMB's SPD 15 revisions.**
- **Meet at a regular frequency agreed upon by CDPH and CBOs — ideally every month for 1.5 hours.**
- **Define a process for sharing meeting discussion points with CDPH leadership, including identifying who those leaders are.**

RECOMMENDATIONS FOR CDPH (Cont.)

CDPH should publicly provide an annual report or hold an annual webinar that has a summary of efforts to collect, analyze, and report data for categories required by AB 1726 (CA State Code 8310.7), including:

- A comprehensive list of forms required to collect this data, the level of compliance with AB 1726 data requirements for those forms, the forms exempt from these requirements, and the reasons for such exemptions.
- An assessment of current data sources at CDPH that are and are not disaggregated under AB 1726-required categories.
- The status of any improvement or replacement of CalREDIE.
- The outcomes of data analyses that CDPH has performed or has allowed other qualified researchers to perform using the disaggregated AA and NHPI data it has collected.
- The steps CDPH has taken or will take from learnings that year to improve services or program outcomes for underserved AA and NHPI populations.
- Regular evaluations of data quality, including measures and collection processes.

With these recommendations, this workgroup can model how CDPH and community partners can work together to implement legislation, and produce the disaggregated data needed to improve health outcomes for AA and NHPI subgroups and all other underserved communities.

RECOMMENDATIONS FOR HEALTH AGENCIES



Enhance community engagement

Establish workgroups and partnerships on data equity, where CBOs can be incorporated into efforts to improve data collection, ensure accurate terminology, learn how to communicate transparently about why race and ethnicity data is collected, help develop protections for privacy and security, and advise public health staff who collect data about the communities they serve. Such engagement by both agencies and community should be regular, long term, and committed. This could also include contracting with CBOs to support data investigations.



Invest in data systems and people

Create interoperable data systems or a statewide integrated data system for all health information. Train data collectors, agency staff, providers, and other stakeholders to use similar language and race/ethnicity information. If staff lack training or capacity, potential solutions include investing in electronic medical records technology or algorithms that can better pull data. Make standards of practice documents public and easily accessible online. Investments for systemic changes are needed to ensure that resources are effectively supporting communities in need and improving long-term health outcomes.



Balance the need for disaggregated data with technical data limitations

Concerns such as privacy, subgroup denominator size, and small data collection numbers are not sufficient reasons to avoid collecting and reporting disaggregated data. Methods already exist for addressing known data limitations (e.g. aggregating time series data for small groups, convenience sampling, setting up data use agreements with specific communities, partnering with community leaders to capture needs). Agencies exploring these methods should share their lessons learned and standards of practice with counterparts that need the technical assistance.



Include comprehensive accountability measures that support implementation in new efforts on data disaggregation

They can require:

- attached funding, including for upfront and maintenance costs (such as technology updates to data systems and forms);
- agency staff training on superseding data mandates and on data collection and reporting best practices;
- agencies to show how disaggregated data are used to improve services and address disparities;
- agencies to make data publicly available, rather than just its reporting.



Southeast Asia Resource Action Center (SEARAC) is a national civil rights organization that builds power with diverse communities from Cambodia, Laos, and Vietnam to create a socially just and equitable society. As representatives of the largest refugee community ever resettled in the United States, SEARAC stands together with other refugee communities, communities of color, and social justice movements in pursuit of social equity.

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