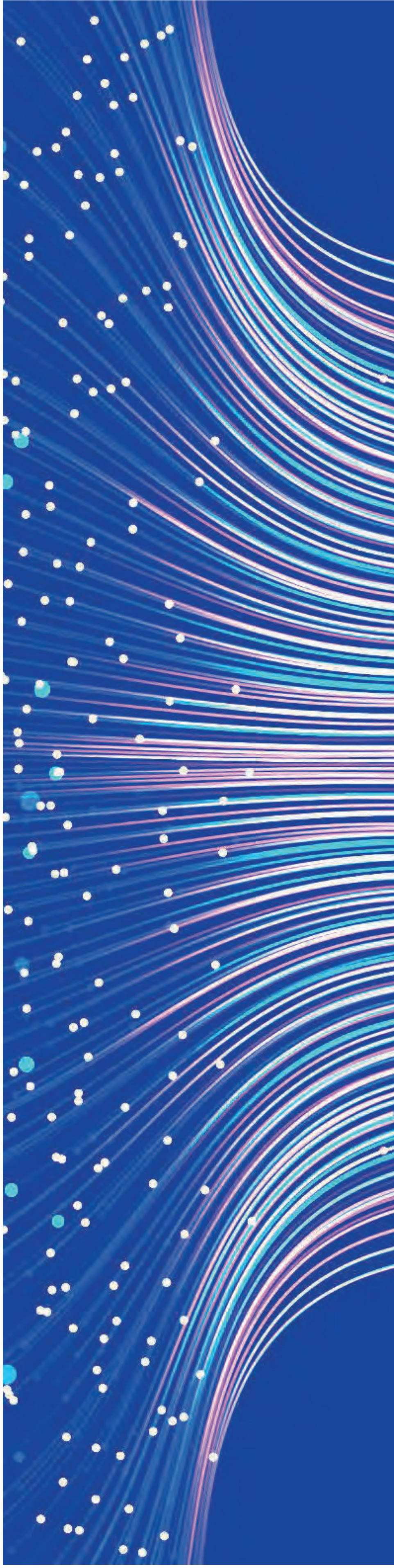
DISAGGREGATION NATION

State Pathways and Key Considerations for Improved Race and Ethnicity Data

JULY 2025

The Leadership Conference
Education Fund

Acknowledgments



“Disaggregation Nation: State Pathways and Key Considerations for Improved Race and Ethnicity Data” is a project of The Leadership Conference Education Fund. The Education Fund was founded in 1969 as the education and research arm of The Leadership Conference on Civil and Human Rights, the nation’s oldest and largest civil and human rights coalition of more than 240 national organizations. For more than five decades, The Education Fund has served as a force multiplier and has amplified the call for a just, inclusive, and fair democracy.

We would like to thank interviewees in the four case study states — California, Illinois, New York, and Oregon — for generously sharing their time, insights, and wisdom regarding data disaggregation laws based on race and ethnicity. A full list of interviewees is provided in Appendix 1.

We also thank Leslie Zellers, JD, and Brianne Schell, JD, MPH, who conducted the interviews and research for this report and were its principal authors. We are also grateful to The Education Fund’s staff, including Meeta Anand, Rachel Hooper, Patrick McNeil, and Amy Vertal. The report was designed by Christian Madison. The author and publisher are solely responsible for the accuracy of statements and interpretations contained in this publication.

Support for this work was provided by the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.

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Introduction

Disaggregation of race and ethnicity data is essential to identify the needs and challenges faced by different subgroups within a population. When these subgroups become visible in the data, it is possible to address disparities, identify systemic inequalities, and monitor progress toward goals.

Race and ethnicity data collection at the federal level is governed by the Office of Management and Budget's (OMB) revised Statistical Policy Directive 15 (SPD 15), issued in March 2024. OMB and federal agencies are required to develop and file plans by September 2025 as to how the new standards will be fully implemented — no later than March 2029. However, implementation of the federal requirements is uncertain given the change in administration.
States may collect race and ethnicity data that are at least as detailed and comprehensive — if not more so — than that required of federal agencies. That is to say, SPD 15 is a floor and not a ceiling. As of May 2025, 13 states have passed laws to require disaggregation of race and ethnicity data beyond the requirements of the 1997 version of SPD 15, when it had previously last been updated. These state laws are summarized in a report from The Education Fund — "Disaggregation Nation: A Landscape Review of State Race and Ethnicity Data Collection" (December 2023) — and a mid-year update released in July 2024.

Since the Disaggregation Nation reports were issued, Illinois adopted a law requiring collection of Middle Eastern and North African (MENA) data, bringing the total number of state laws requiring data disaggregation of race and ethnicity data to 13.

Three other states — California, New York, and Oregon — have expanded their laws requiring collection of additional race and ethnicity data. Current information on state laws with respect to disaggregated race and ethnicity data collection is available on The Education Fund's Data Disaggregation Action Network (D-DAN) website.

The existence of these laws — while a success — does not shed much light on how collection of race and ethnicity data is playing out in state agencies. Therefore, The Education Fund sought to learn more about the experience of four states — California, Illinois, Oregon, and New York — in adopting and implementing data disaggregation laws. These states have approached data disaggregation requirements in different ways, based on the demographics of their population, political will, and commitment by state agencies. We provide brief case studies on these four states, as well as a list of key considerations for states that are considering adopting or updating their data disaggregation laws.

Overall, we found that:

- The four state laws reflect a broad commitment in those states to the collection and analysis of disaggregated race and ethnicity data.
- Even with that commitment, updating data collection systems takes time, resources, and sustained oversight.
- States are collecting data that are critical to learning more about their populations, especially as we await SPD 15 implementation at the federal level and face threats to federal data collection more broadly.

Key Considerations

Data disaggregation advocates are seeking preferred practices for policies requiring disaggregation of data by race and ethnicity. Unfortunately, it is not yet possible to offer universal recommendations, due in part to the small number of laws and the state-specific context in which each policy was developed. However, based on our review of laws in 13 states and our interviews with four states, we provide questions for consideration in three areas: (1) advocacy and education around the policy; (2) the scope of the policy; and (3) implementation and enforcement. The four profiled states adopted laws to change their data disaggregation requirements. Other paths exist to expand race and ethnicity data collection, including policies adopted by a state agency, rules issued by a state, and/or changes in data collection practices by non-governmental actors, such as health care providers.

Advocacy and Education Efforts

Adopting a data disaggregation policy at the state level requires traditional efforts that include building a coalition, identifying a champion, generating political support, educating elected officials, and more. (See resources available from Community Commons.) In addition to these strategies, there are considerations specific to advocacy and education for a policy requiring disaggregation of data by race and ethnicity. Key considerations include:

- **How will community stories be leveraged** to educate policymakers? The experiences of all four states profiled in this report show that effective education includes telling stories by those most affected — or rendered invisible — as a result of current data collection practices. These include the Indigenous community in California and the MENA community in New York and Illinois.
- **How should community and elected officials be educated** about the value of disaggregated race and ethnicity data? For example, advocates in some states are shifting their talking points from health equity to ensuring the availability of high-quality data on subgroups. Groups such as Arab American Family Services in Illinois spent more than two decades developing relationships with the community and legislators, long before a specific bill was introduced.
- **How will state agencies be educated** about the responsibilities that will be assigned to them under the policy? Is it possible for legislators and/or the governor to meet with agencies to hear their concerns prior to the law's enactment?
- **What concessions are acceptable** to ensure the policy's passage? Political compromises were made in the passage of data disaggregation bills in California and New York. In these two states, bills were introduced in multiple legislative sessions before becoming law.

"**Championing the 2021 New York State Law: A Step Toward Data Disaggregation on Asian Americans, Native Hawaiians, and Pacific Islanders**" offers additional recommendations, including: moving beyond a scarcity mindset (a fear that data disaggregation might lead to a diffusion of political power by creating divisions among Asian American and Native Hawaiian / Pacific Islander populations), addressing concerns around data privacy, and working in coalition with other populations interested in data equity.

Scope of the Policy

When deciding on the scope of the data disaggregation policy, consider the following questions:

- **What subpopulations should be included in the policy?** The revised SPD 15 provides a model for the minimum standards included in a state law or policy. However, the policy also should be customized to the state's population, with consideration for political feasibility and implementation. For example, Oregon's REALD law includes 72 race and ethnicity subgroups. The Illinois law only added a MENA category.

- **Should the data collection requirements apply to all state agencies or to a subset** of agencies? For example, the California laws regarding additional AA and NH/PI and Latino and Indigenous populations apply only to the California Department of Public Health. In contrast, the New York AA and NH/PI and MENA laws, and the Illinois MENA law, apply to all agencies.

- **How long are agencies given to comply** with the policy? Are certain agencies exempted or provided with additional time for implementation? Additionally, are organizations that contract with state agencies required to comply with the data collection requirements? The New York AA and NH/PI and MENA laws exclude these entities.

- **Does the policy provide requirements that could help in implementation or in monitoring compliance?** For example, does the policy require:
  - A report (or webinar) from affected agencies on their progress implementing the law or policy — either as a one-time report/webinar at a designated time or annual reports.
  - A legislative hearing on progress in implementing the law or policy (for example, a year after the effective date of the law or annually).
  - Establishment of a workgroup composed of groups with an interest in the law, including state agency representatives, community-based organizations, researchers, community members, advocates, and others.
  - Incentives to implementing agencies, such as funding, technical assistance, or training.

Implementation

Even a strong and comprehensive policy is only a roadmap until agencies actually begin to collect data that will provide information about differences among sub-populations. There is no single path recommended for effective implementation of data disaggregation policies, and the suggestions offered are not mutually exclusive. The probability of success may be improved by pursuing multiple paths in parallel. Key considerations include:

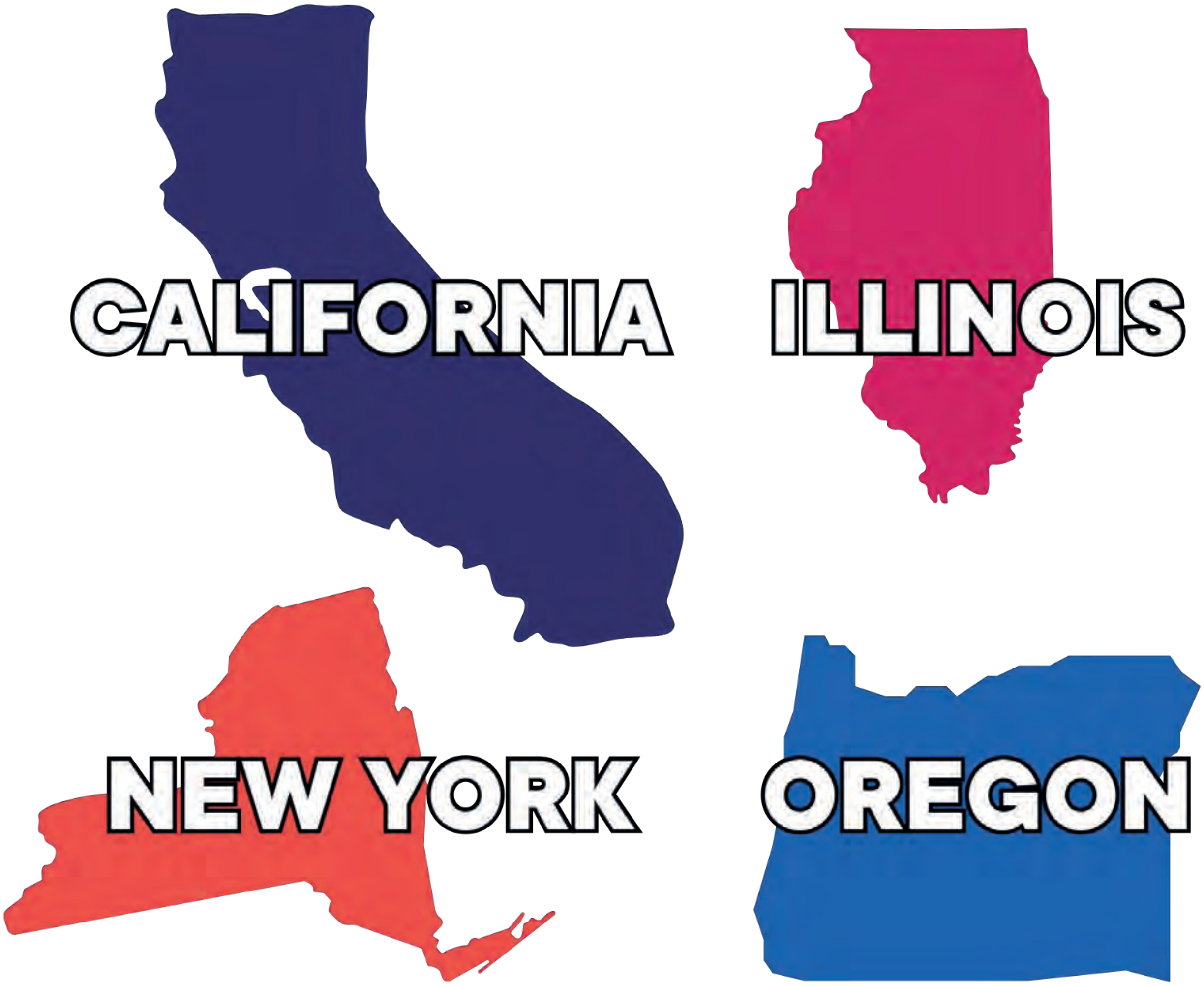
- **Is funding provided** to implement the policy? Updating computer systems is resource intensive. It requires specialized staff to change data collection practices, translate self-reported data, and analyze the data. Additionally, agencies need staff to shepherd and monitor changes in data collection practices and in agency priorities.
- **Are multiple actors engaged to exert pressure** on the agencies/departments that are responsible for implementing the policy? For example, strategies used in some states include:
    - Developing relationships with agency personnel who are tasked with implementing the policy (ideally before the law or policy is passed).
    - Working with the legislative sponsors of the original bill — as a conduit to state agencies — to monitor progress and signal to agencies that active oversight is being provided.
    - Working with elected officials/committees who oversee different agencies to update them on implementation and ask for follow-up with the agencies for updates.
    - Asking elected officials to hold a hearing on agencies' progress in implementing the law.
    - Working with the executive branch — i.e., the governor's office — to encourage agency/departmental compliance.
    - If funding has been allocated, working with the state comptroller or state auditor (or equivalent agency) to track whether and how funding has been spent.
- **Are the requirements in the policy being followed?** For example, are forms being updated, are agencies providing reports as required, and are agencies stating why they are not complying with the law?

- To the extent not already specified in the policy, **should additional requirements be imposed on agencies** through regulation or through voluntary compliance by state agencies? These may include:
    - Regular (perhaps annual) reports and/or webinars on implementation progress
    - A workgroup that includes community members and data disaggregation advocates
- **Are legislative or administrative improvements needed** to improve the collection of race and ethnicity data? If so, has consideration been given to introducing a follow-up bill or regulation to clarify or improve any of the original legislative requirements?
- **Are incentives other than funding** provided to encourage compliance? These could include training, learning collaboratives, and community working groups. Based on our interviews, respondents believed that incentives would be more productive than penalties for noncompliance with the policy.

Case Studies

To learn more about the adoption and implementation of data disaggregation laws, The Education Fund chose four states to profile. The states were chosen based on the diversity of their laws, which cover different race and ethnicity categories and apply to different state agencies, as well as geographic diversity and varying dates of adoption. For each case study, The Education Fund reviewed the state's laws and interviewed at least two key informants in the state government or advocacy community. See Appendix 1 for a list of key informants.

The case studies provide (1) an overview of the state's law(s); (2) information about the adoption of the law(s); and (3) successes and challenges in implementation of the law(s). The goal of the case studies is to guide other states on important factors to consider in their efforts to advance policies requiring collection and disaggregation of detailed race and ethnicity data.



California

Overview of California Law

California has adopted five laws requiring data disaggregation by race and ethnicity. Two laws require state agencies to collect disaggregated data for Asian American, Native Hawaiian, and Pacific Islander (AA and NH/PI) groups (CA Government Code §§ 8310.5 and 8310.7).

A first-of-its kind law requires collection of data for state job applicants that includes categories for African Americans who are descendants of persons who were enslaved and Black people who are not descendants of persons who were enslaved (CA Government Code § 8310.6).

The most recent law, passed in 2024, requires collection of data for Latino groups and Mesoamerican Indigenous nations as of January 1, 2028 (CA Health & Safety Code § 131250).

Another law requires the state Department of Corrections to collect and publish self-reported race and ethnicity information on people admitted, in custody, and released and paroled using 37 specified race and ethnicity categories (California Penal Code § 2068). Additional information about the California data disaggregation laws is available on the D-DAN website.

As of May 2025, the California legislature is considering a bill to require state agencies that collect demographic data on ancestry or ethnic origin to include separate categories for Middle Eastern and North African (MENA) groups (CA AB 91). Another bill being considered in 2025 would require a specified number of detailed categories in each of the minimum race and ethnicity categories collected by state agencies and provide a write-in option to allow for additional self-identification (CA AB 1186).

Table 1: California Laws Requiring Data Disaggregation by Race and Ethnicity[1]

Asian		Pacific Islander		Latino	Mesoamerican Indigenous Nation	Black or African American
All state agencies	Department of Public Health[2]	*All state agencies*	Department of Public Health[3]	Department of Public Health	Department of Public Health	State Controller's Office and Department of Human Resources[4]
Each major Asian group, including but not limited to:	Additional major Asian groups, including but not limited to:	Each major Pacific Islander group, including but not limited to:	Additional Native Hawaiian and other Pacific Islander groups, including, but not limited to:	Each major Latino group, including but not limited to:[5]	Each major Mesoamerican Indigenous nation, including but not limited to:[6]	Additional collection categories and tabulations for Black or African American groups, including, but not limited to:
Chinese Japanese Filipino Korean Vietnamese Asian Indian Laotian Cambodian	Bangladeshi Hmong Indonesian Malaysian Pakistani Sri Lankan Taiwanese Thai	Hawaiian Guamanian Samoan	Fijian Torgen	Mexican Guatemalan Salvadorian Honduran Nicaraguan Puerto Rican Dominican Cuban Colombian Peruvian	Maya Aztec Mixteco Zapoteco Triqui	African Americans who are descendants of persons who were enslaved in the U.S. Black people who are not descendants of persons who were enslaved in the U.S., including but not limited to, African Black people, Caribbean Black people, and other Black people

Adoption

California has made great strides in requiring data disaggregation based on race and ethnicity. However, the path has been long. The first AA and NH/PI data disaggregation law, adopted in 2011, applied to all state agencies and included 11 total categories (eight Asian and three Pacific Islander — see Table 1). Below we describe the paths to adoption of two laws expanding these requirements to (1) additional AA and NH/PI groups and (2) Latino and Indigenous groups. Both laws were introduced in multiple legislative sessions before being passed into law, and both were amended during the legislative process. Though the final versions of both bills were a political compromise and did not go as far as advocates had hoped, each law represents a significant step toward inclusive race and ethnicity data collection in the state of California.

I. The Accounting for Health and Education in API Demographics (AHEAD) Act

A 2016 law, the Accounting for Health and Education in API Demographics (AHEAD) Act, expanded data collection requirements to include additional major Asian groups and additional major Native Hawaiian and other Pacific Islander groups (AB 1726, codified as CA Government Code § 8310.7). See Table 1. The law applies to the state Department of Public Health.

A similar bill was previously introduced in 2014 as AB 176. The bill passed the legislature — rather uneventfully — but was vetoed by then-Governor Jerry Brown, who called the bill "unnecessary, or at least premature." AB 176 would have applied to the Department of Managed Care, California community colleges, California State University, and the University of California.

In 2016, then-Assemblymember Rob Bonta agreed to reintroduce the bill as AB 1726. Cosponsors of the bill and AM Bonta engaged in a strategy to raise the profile of the campaign and to proactively address the governor's concerns. The Southeast Asia Resource Action Center (SEARAC) led many of the advocacy efforts, including social media, an online petition, sign-on postcards, and a rally at the state capitol.

Ultimately, AB 1726 was amended to remove requirements for public higher education institutions and the Department of Health Care Services (DHCS). However, since the law's adoption, the University of California and California State University have agreed to provide the disaggregated data that were originally requested in AB 1726. Additionally, although DHCS was removed from the bill, cosponsors agreed to pursue an administrative process for revising forms used to collect racial and ethnic data for Medi-Cal, which is managed by DHCS.

AB 1726 expanded on decades of work by AA and NH/PI advocates for data equity. After AB 1726 was signed, the Asian & Pacific Islander American Health Forum, the California Pan-Ethnic Health Network, Empowering Pacific Islander Communities, and SEARAC issued a joint statement saying, in part: "Better data on the different needs of our communities translates to more effective public health strategies that save lives." The bill's sponsor, Assemblymember Rob Bonta, stated:

> **"AB 1726 will give us a clearer pathway to formulate policy focused on positive outcomes for our specific API communities."**

II. The Latino and Indigenous Disparities Reduction Act

In 2024, the California legislature adopted the Latino and Indigenous Disparities Reduction Act, which requires the California Department of Public Health (CDPH) to collect data for Latino groups, Mesoamerican Indigenous nations, and preferred Indigenous languages as of January 1, 2028 (CA Health & Safety Code § 131250).

The bill was first introduced in 2023 (SB 435). Advocates from the Latino Coalition for a Healthy California (LCHC) — and other community groups — educated members of the legislature about data disaggregation and how Latino and Indigenous community members felt invisibilized. LCHC was encouraged by the initial conversations with legislators, who saw the bill as a way to address the needs of communities in their district. The 2023 version of the Latino and Indigenous Disparities Reduction Act passed the legislature but was vetoed Governor Gavin Newsom, who claimed that the bill was premature since it predated OMB's final revision to SPD 15.

> **Data disaggregation is not telling people how to identify, LCHC reported; instead, it is providing more options for self-identification, which is especially important given the changing demographics of California's population.**

When the bill was reintroduced in 2024 (SB 1016), the legislature was again supportive, and the Latino Caucus prioritized the bill. As a result, the education strategy focused primarily on the governor. Strategies included tabling at community celebrations featuring Zapotec traditions and collecting almost 500 postcards in support of the bill. The postcards were delivered to the governor in Sacramento and Los Angeles with some supporters pinning postcards to the traditional dress, such as those used in birthing ceremonies. This process humanized and put a face on the people who deserve to be counted.

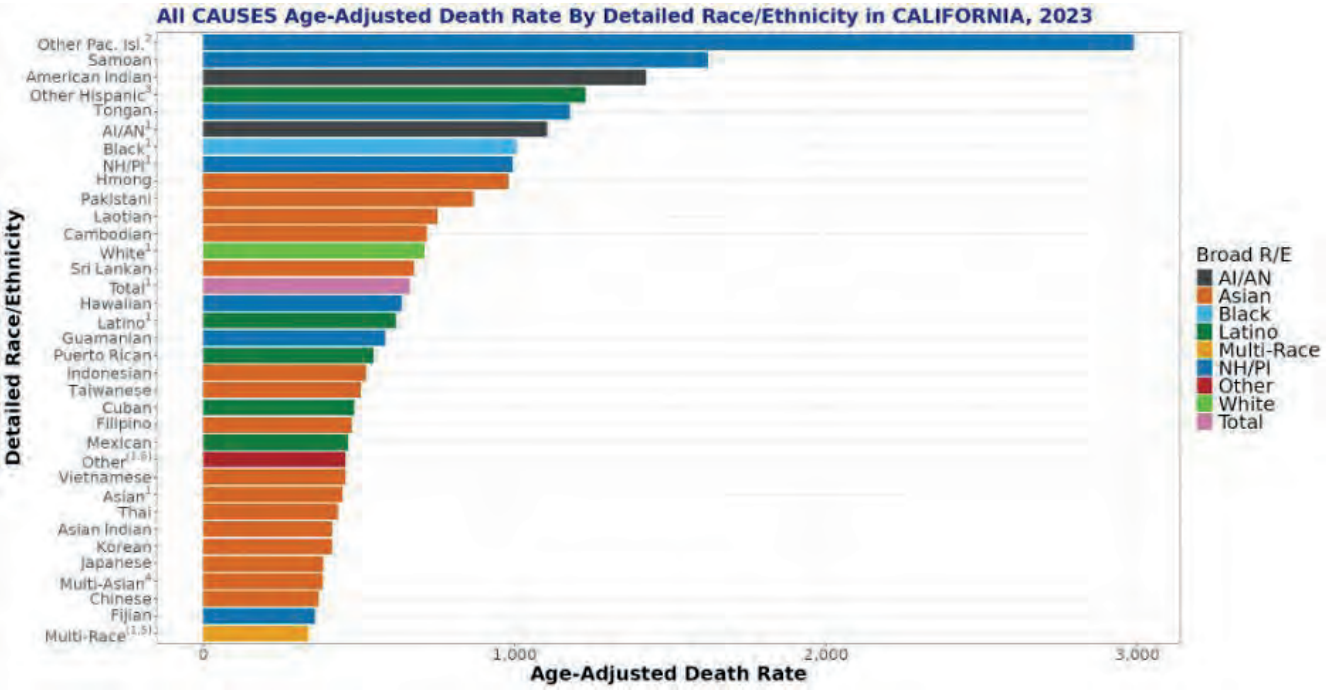
Political compromises were necessary to ensure adoption of the law. For example, the first version of the Latino and Indigenous Disparities Reduction Act would have applied to multiple agencies. Ultimately, the final bill enacted in 2024 applies only to CDPH. Additionally, the number of Latino and Indigenous groups was narrowed during the legislative process based on feedback from CDPH.

Implementation

AB 1726 — requiring data collection for additional AA and NH/PI groups — took effect in June 2022. Three years later, CDPH and advocacy groups continue to work on implementing the law.

The state of California maintains a webpage with information about implementation of the law including reports with disaggregated data, including data on death rates (see Figure 1) and tuberculosis (data includes birth country). Although disaggregated data are available for some data sets, implementation is ongoing.

Figure 1[7]



Source: California Department of Public Health, available at https://skylab.cdph.ca.gov/communityBurden/?tab=detailedrace.

SEARAC produced a policy brief on implementation of AB 1726, which offers several challenges and recommendations, including creating a workgroup focused on implementing disaggregated race and ethnicity data laws. Following sustained advocacy by SEARAC and its coalition partners, CDPH created a workgroup that began meeting in March 2024 and continues to meet monthly. The workgroup is a partnership between CDPH, community-based organizations, researchers, data analysts, and data advocacy groups.

The workgroup seeks to help agencies integrate various standards, address implementation challenges all California data disaggregation laws will face, and think holistically about disaggregation as a key practice of broader data modernization. Through the workgroup process, SEARAC has learned that:

- There is an aspiration across state entities to comply with the law, but coordination costs across state governments are huge. Agencies are subject to many data requirements, which are cumulatively difficult to implement.
- Participants must acknowledge and address challenges that may be difficult or out of the agency's control. These include incompatible data systems, privacy risks, different reporting requirements based on different funding streams, and lack of data quality downstream.
- For a workgroup to be effective, participants must be operating in good faith. In addition, it is advisable to:
    - Limit the number of preliminary objectives, for example, to no more than three.
    - Focus on the workgroup's composition to ensure that it includes representatives from the state, community organizations, researchers, and relevant parties involved in the journey from data collection to processing to reporting (such as providers and county public health departments), etc.
    - Be explicit about workgroup roles. For example, SEARAC staff acts as a liaison between the workgroup and CDPH.
    - Ideally, allocate funding for the workgroup so it is sustainable.
    - Include an evaluator or independent participant to monitor what the workgroup is actually producing, compiling, and synthesizing.
    - Include opportunities to check in with the agency between meetings, such as regular debriefs and/or a mid-point check in.

Based on the implementation of AB 1726, SEARAC recommends that agencies receive information about the law prior to adoption to ensure that they have the capacity to implement the requirements.

The Latino and Indigenous Disparities Reduction Act data collection requirements take effect on January 1, 2028. Groups such as the LCHC are coordinating on its implementation with groups such as SEARAC and participating in the workgroup with CDPH.

Illinois

Overview of Illinois Law

Illinois enacted a law in 2023 (effective January 1, 2024[8]) requiring all state agencies that collect data on race and ethnicity to include a "Middle Eastern or North African" (MENA) classification (HB3768, amending 20 ILCS 50/5).

Before Illinois passed its MENA law, it passed the "Data Governance and Organization to Support Equity and Racial Justice Act," known as "ERJA" (20 ILCS 65), effective in 2021. The ERJA law, an initiative of the LGBTQ+ community, requires a pilot group of six state agencies to collect information about race, ethnicity, age, sex, disability status, sexual orientation, gender identity, and language from participants of a selection of programs.

Illinois was the first state in the nation to require a MENA category.

Enactment

The campaign to adopt the Illinois MENA law was led by Arab American Family Services of Illinois (AAFS). AAFS educated legislators — with whom it has long-established relationships — about how MENA groups appear invisible in the data because they are categorized as white. AAFS raised the challenges with legislators about access to funding and services for MENA communities without data. For example, during the COVID-19 pandemic, Arab American groups struggled to show health officials how MENA communities were disproportionately impacted due to a lack of data.

AAFS and other groups worked to add a MENA category to the 2020 Census. After that effort was halted by the first Trump administration, the groups pushing for the change set their sights on making progress at the state level.

In 2022, the state elected its first Arab legislator, Representative Abdelnasser Rashid, who became the champion for the initiative in the legislature. Rep. Rashid was the primary sponsor of the MENA bill (HB 3768); the first Muslim woman elected to the state legislature, Representative Nabeela Syed, was one of its many cosponsors.

AAFS credits the bill's success, in part, to the positive relationships it has built with elected officials over more than two decades. AAFS also convened a group of leading Arab American institutions, each with its own network, who helped drive the process and mobilize support when needed. Additionally, AAFS sought input from the Latino community's efforts to collect race and ethnicity data in order to inform their campaign to include a MENA category.

Implementation

The Illinois MENA law took effect for most agencies on January 1, 2024, and implementation to date has been relatively smooth. Since state agencies are already required to collect data on other racial and ethnic groups (e.g., Asian, Hispanic and Latino), adding a MENA category has been a modest change.

The bill's legislative champion made it a priority to engage relevant state agencies early in the process. The agencies provided crucial input to understand what implementation would realistically require and how to align with existing systems. To date, the MENA category has begun to be included in areas such as health care, education, and public services. Additional implementation will happen incrementally. Agencies will need to update forms, train staff, and ensure that MENA is integrated consistently across systems.

AAFS acknowledges the growing hesitancy around disclosing race and ethnicity information, especially in marginalized communities. The group stressed the importance of building public trust, including being transparent about why the data are being collected, how they will be used, and what protections are in place.

The ERJA law instructs the Department of Human Services to establish demographic classifications for each category via administrative rulemaking. The office of the governor is required to establish a team to oversee implementation of the law, and the Department of Innovation and Technology is required to advise on technological processes involved in implementation.

Although the Illinois ERJA law was designed as a pilot project and includes defined responsibilities for implementation and oversight, implementation still has been slow. The office of the governor has primary oversight authority. The office supports the implementation of the ERJA law with a dedicated team, but it is still a challenge to manage the implementation across the different agencies with all their particularities, programmatic specifics, etc. The Department of Human Rights — which is helping to implement the law — believes that regulatory rules will help bolster agencies' data collection.

Adoption of new information systems can require significant time and resources. For example, an online case management system the department has been working to adopt for discrimination cases has been in development for eight years. Although there are obvious drawbacks to the fact that information system changes will likely be slow, the department pointed out that it could be a benefit that once the changes are made they will be difficult to change back in the event of a political shift and/or decreased dedication to racial equity.

The election of Rep. Rashid was critical to their success, as he could educate other legislators directly and have a greater level of influence on them than coalition members could.

AA and NH/PI Data Disaggregation

In addition to advocating for policies such as ERJA and the MENA law, community organizations also can improve data disaggregation outside the statehouse, especially when state policies have not yet expanded to their demographic of interest. The Chinese American Service League (CASL), based in Chicago, launched the Change InSight initiative in 2022 to help other community organizations collect disaggregated data on Asian Americans, Native Hawaiians, and Pacific Islanders (AA and NH/PI).

Change InSight is a national movement that started with just six community partners in Chicago and has grown to include more than 30 partners across the country. Community organizations that provide services directly to individuals collect the data in the form of a social drivers of health assessment from their clients — either formally as part of their intake or via a separate process — and send it to CASL to analyze and create a visualization of the data. CASL then shares the data analysis with the community organizations, along with the visualization of the data, who can use it to inform decision-making and resource allocation based on their organization's goals.

CASL believes the analyses based on disaggregated data help the community organizations get a better grasp of their communities' needs. The organizations often have an anecdotal understanding, but having the data deepens the understanding and gives the organization a better basis for advocating for policy change and/or additional funding. CASL hopes the improved data collection and analyses will help address the general lack of knowledge around the differences between AA and NH/PI immigrant groups and the importance of those differences when it comes to health status and needs.

Although CASL has been fairly successful in collecting and analyzing the data thus far (see the 2024 Change InSight Report), they are continually working with their community organizations to improve data collection processes, expanding their network of organizations, and refining their methods for analysis. They also hope to help introduce a bill in the legislature to expand disaggregated AA and NH/PI data collection to state agencies as part of their advocacy agenda, but they are taking time to evaluate when and how it would be best to approach such legislation.

New York

Overview of New York State Law

New York state has adopted two laws requiring collection and disaggregation of (1) Asian American, Native Hawaiian, and Pacific Islander groups; and (2) Middle Eastern and North African (MENA) groups. The AA and NH/PI law was adopted in 2021 (with requirements on state agencies as of December 1, 2023), and the MENA law was adopted in 2024 and will take effect on July 1, 2026.

Both laws apply to all state agencies and departments that collect demographic data as to the ancestry or ethnic origin of New York state residents. The AA and NH/PI law provides a two-year grace period on implementation by the Department of Labor, the Division of Criminal Justice Services, the Office of Mental Health, and the Office of Temporary and Disability Assistance. Laws of New York, Chapter 18 sec. 170-E*2 (AA and NH/PI) and Laws of New York, Chapter 18, § 170-h (MENA). Additional information about the New York laws is available on the D-DAN website.

Table 2: New York Laws Requiring Data Disaggregation by Race and Ethnicity

Asian American and Pacific Islander		**Middle Eastern and North African**	
Each major Asian group shall include:	Each major Pacific Islander group shall include:	Each major North African (NA) group shall include:	Each major Middle Eastern (ME) group shall include:
Chinese Japanese Filipino Korean Vietnamese Asian Indian Bangladeshi Pakistani[9] Other Asian or Pacific Islander group	Native Hawaiian Guamanian and Chamorro Samoan Other Asian or Pacific Islander group	Egyptian Moroccan Algerian Sudanese Tunisian Libyan Other Middle Eastern or North African groups	Yemeni Iranian Palestinian Iraqi Lebanese Israeli Jordanian Syrian Armenian Saudi Other Middle Eastern or North African groups

Adoption

Adoption of the historic AA and NH/PI data disaggregation law took many years, multiple versions, and two different administrations to finally achieve success. The first data disaggregation law related to AA and NH/PI groups was introduced in 2009. A 2019 bill that was passed by both houses of the legislature was vetoed by then-Governor Andrew Cuomo. Increased anti-Asian violence in 2020 and 2021 led groups such as the Coalition for Asian American Children and Families (CACF) to redouble their efforts to elevate data equity as a critical component of addressing health, wellness, and safety for AA and NH/PI communities. The state law ultimately was signed in 2021.

> **CACF's Invisible No More campaign has been working for nearly 15 years to ensure accurate data on the diverse Asian American and Pacific Islander communities in New York state.**

After the AA and NH/PI bill passed the legislature in 2021, additional concessions were required for Governor Kathy Hochul to sign the bill. These concessions included reducing the number of AA and NH/PI categories included in the law and removing the requirement that contractors of state agencies be subject to the data collection requirements. The latter requirement primarily affects the vendors who provide the data collection technology to state agencies. For additional information about lessons learned in the adoption of the New York AA and NH/PI law, see the article on "Championing the 2021 New York State Law: A Step Toward Data Disaggregation on Asian Americans, Native Hawaiians, and Pacific Islanders," published in the American Journal of Public Health.

The AA and NH/PI data disaggregation law in New York paved the way for the 2024 law on disaggregation of Middle Eastern and North African populations. A bill to require disaggregation of MENA groups was introduced in 2023, but it failed to pass the legislature. The following year, the community advocacy campaign ramped up. Malikah, an anti-violence organization in New York, worked with community members who were able to engage their elected officials to share their experience and stories.

> **For many elected officials, it felt straightforward that MENA should be a separate category rather than being lost in "white."**

The MENA bill passed the New York legislature in 2024. Getting the bill signed by Governor Kathy Hochul was a further challenge, requiring negotiation on elements such as the effective date, whether residents could check multiple ethnicity categories, and community input into the implementation of the law.

Implementation

Despite the admirable success of advocates in passing a state law requiring collection of detailed data on AA and NH/PI populations, data are only now starting to be collected, more than three years after the law was adopted.

Because the New York AA and NH/PI law applies to all New York agencies, one challenge has been for advocates to develop relationships with multiple agencies simultaneously. The Coalition for Asian American Children and Families (CACF), which is working closely on implementation of the law, has prioritized agencies such as the Department of Health, the Department of Labor, the Office of Mental Health, and the Office for the Aging because of the populations served by these agencies. CACF noted that it would be more efficient if the law required agencies to provide designated contacts.

Although the slow pace and limited access to data are frustrating to advocates, some agencies are now beginning to update their forms and collect data on AA and NH/PI subgroups, including the Office of Victims Services, the Office of Mental Health, and the Department of Health. Other agencies that have not begun collecting AA and NH/PI data also have not provided a reason, despite the law's requirement that agencies state if the data quality is insufficient for publication.

CACF believes that an annual report on implementation of the law by agencies would be helpful to monitor the progress of data collection, how to access the data, and the reasons why certain data sets were or were not included. It also would be helpful if agencies provide more transparency about how they are using detailed ethnicity data internally — either in changes to services and programs or in decision-making. Agency implementation plans with timelines and benchmarks for measuring progress would also be useful.

Some agencies have taken the position that the law does not apply to them — or that the agency itself is not collecting the data.[10] According to CACF, greater accountability may be possible if the law names specific agencies and addresses instances where a separate entity is collecting the data.

Among the challenges and lessons New York learned are that funding is necessary but not sufficient. As part of the law's passage, the state allocated $3 million to assist with implementation. However, for reasons that have been unclear, agencies have not been able to access that funding. CACF is asking for a state audit of the funds to uncover barriers to accessing the money.

Oregon

Overview of Oregon Law

Oregon's "Race, Ethnicity, Language, and Disability Demographic Data Collection Standards" (REALD) law (OAR 950-030) requires the Oregon Health Authority (OHA) and the Oregon Department of Health Services (ODHS) to ask questions about race, ethnicity, tribal affiliation, and sexual orientation and gender identity (SOGI) in surveys that include demographic data (e.g., an application for SNAP benefits). The requirements also apply to health care providers who contract with and/or report data to OHA. For example, health care providers who are subject to the law must ask open-ended questions about race and ethnicity of patients, clients, and members.

The first version of the law, passed in 2013 (HB 2134), included 39 race and ethnicity subgroups. An update (EID 2-2024) was issued in 2024 based on the revised SPD 15 as well as on input from residents. The update expands the race and ethnicity subgroups to 72. The full list of subgroups is available on the D-DAN website.

Adoption

Oregon was an early adopter of race and ethnicity data disaggregation, passing its first version of the REALD law a decade before OMB released the revised SPD 15. The impetus for adopting REALD in 2013, and one of the reasons it applies only to state health agencies and their partners, was a focus on health equity. Because demographic data are being collected in the context of health care, OHA could use the data to identify and address inequities and inform decision-making. In fact, the OHA Strategic Plan for 2024-2027 set a goal to eliminate health disparities in the state by 2030. Collecting disaggregated race and ethnicity data would not only help OHA reach its goal, but it would also contribute to tracking progress toward that goal.

Community groups working on health equity pushed for the REALD law, with leadership from the Asian Pacific American Network of Oregon and the Oregon Health Equity Alliance.

The updates to the REALD law in 2024 followed OMB's updates to SPD 15, which disaggregate existing categories and add a MENA category. While the first version of the REALD law included options for Middle Eastern and North African, it did not disaggregate those options further (e.g., Egyptian, Lebanese, Syrian, etc.). The update added further disaggregated options under the MENA category, as well as additional options in other existing categories.

Implementation

The REALD law is designed as a partnership between OHA and ODHS.

> To collect, analyze and utilize disaggregated data to serve their populations, both agencies have sought to create a change-management process aligned with the agencies' cultures and community needs.

Elements include a robust effort to tell the story of why having disaggregated data is vital to the agencies' work, training of data collection and analysis staff, partnership with executive and IT leaders, early incorporation of community and tribal voices, plans for how the data will be used to adjust agency policy and programming, and an ongoing assessment and improvement plan.

Interviews with both OHA and ODHS included discussions of similar roadblocks, suggestions for improvements, and considerations moving forward. The main issue with implementation for both agencies has been the technical aspect — both the difficulty of updating data collection and reporting systems and the number of resources those updates have diverted from other aspects of implementation. ODHS relies on up to two dozen different systems for data collection. These systems all interact with each other, so changing one variable in one system can throw off communication between all the other systems. Smaller systems don't have the infrastructure to handle significant change.

OHA maintains a team of full-time staff dedicated to implementation of the REALD and SOGI law, funded by the state's general fund. To date, the agency has been successful in integrating a data collection process into the state's eligibility system for Medicaid and has begun receiving data from applicants. While implementation of disaggregated data standards in state systems is a necessary step in this process, the agencies note that it is not sufficient to achieve improved service for all in the state.

The OHA team has also been working on developing a case for health care providers to adopt electronic health record (EHR) modifications to support broad participation in data collection. In pursuit of this, they have been providing training to support health care entities and providers in implementing EHR changes. Although OHA does not currently have the resources to provide incentives (e.g., funding) to providers to encourage adoption of EHR updates, it does employ a provider engagement team that is working to understand what support providers might require outside of training.

Because of the focus on facilitating the collection of data and the complicated technical aspects, OHA has not yet been able to conduct any extensive analysis of the data it has collected thus far. The REALD and SOGI team plans to eventually hire a data manager to conduct analyses to identify disparities and inequities.

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Although reporting the data remains voluntary for providers until OHA develops a more comprehensive and accessible system for collection, the team has seen increasing rates of race and ethnicity data completion and improvements in all other REALD domains. This may be due, in part, to OHA's awarding of grants to community organizations to facilitate education about the importance of detailed data collection and its benefits.

The ODHS has had a much different experience with implementation of the REALD and SOGI law than OHA. While OHA works more in the health care realm (i.e., with health care providers and Medicaid recipients), ODHS works with individuals applying for other benefits and human services (i.e., food and cash benefits and disability services). ODHS has only one employee dedicated to implementation and does not have access to any additional dedicated funding.
Even with limited capacity, ODHS has been able to develop a script to assist its employees in asking the questions required by the REALD and SOGI law, and most patients have felt comfortable answering the questions.

OHA has thus far had more capacity to make needed technical improvements, but it still does not have a centralized and simplified system in place. Oregon law also requires that the REALD and SOGI categories be updated periodically, requiring the complex process of updating data collection and reporting systems to be repeated every few years. To address these technical challenges, states can ensure they are providing adequate resources throughout the implementation process. After the REALD law first passed in 2013, the agencies received an influx of funding, which has not been sustained over the years.

To reduce the burden on EHRs, OHA also has tried collecting data more directly and informally for more flexibility by providing patients with a survey via QR code, allowing them to collect the data without reconfiguring EHR systems. In the long-term, both agencies would benefit from the creation of a centralized data collection and processing system that would cut down on many of the complexities and resource shortages.

ODHS noted that although the two agencies are happy to work together toward the shared goal of improved data collection and gaining a better understanding of community needs, the partnership in itself can be a challenge for implementation — as is evidenced by the agencies' differing experiences with implementation. Different agencies have different budgets, capacities, priorities, and policy contexts, making alignment on one particular goal or project difficult.

Another implementation challenge lies in data collection and security: Some individuals are hesitant to provide specific information about their race, ethnicity, nationality, sexual orientation, and/or gender identity to providers, and recent federal government actions have raised doubts about the security of government data. OHA and ODHS suggested that continued efforts to educate the community on the importance of good data collection and its impact on health equity, as well as increased dedication to and vigilance regarding data security and privacy, could help ease the discomfort and hesitation.

Other recommendations based on Oregon's experience include annual reporting, training, and learning collaboratives, in addition to community working groups. Requiring annual reports from agencies tasked with implementing data disaggregation laws can help the legislature and the agencies identify areas for improvement and needed support and track progress. Training and learning collaboratives can help organizations adapt to the new data collection requirements and any changes in technology, and community working groups can bring community input into the process, help spread information to members of the community, and make them feel more comfortable providing their own data.

Conclusion

Conclusion

Detailed data on race and ethnicity is vital to support data equity and provide insights into health outcomes. Collection of race and ethnicity data at that state level is more important than ever given significant cuts to federal data collection efforts in 2025. States have the potential to require the collection and disaggregation of race and ethnicity data to make informed decisions about services and funding that reflect their specific populations. Thirteen states have adopted laws in this area. Although the laws represent a tremendous success reflecting the education and advocacy of many groups, the laws are only a starting point. To ensure that the laws are implemented — that forms are updated, that data are collected and analyzed, and that programs or services are changed — requires an ongoing and long-term commitment. This report provides deeper information about four of these states as well as key considerations for states that wish to support policies to increase collection of detailed race and ethnicity data.

Appendices

APPENDIX 1 - Case Study Interviewees

California

Andrew C. Lee, California Policy Manager, Southeast Asia Resource Action Center (SEARAC)
Mar Velez, Director of Policy, Latino Coalition for a Healthy California (LCHC)

- *Note: We contacted staff at the Office of Health Equity, California Department of Public Health, but they were not able to respond in time for their views to be included in this report.*

Illinois

Jason Rosensweig, PhD, Senior Policy Advisor, Illinois Department of Human Rights
Nareman Taha, Co-founder, Arab American Family Services of Illinois
Dr. Dilara Sayeed, Educator and President, Muslim Civic Coalition
Amina Barhumi, Advocacy and Policy Lead, Muslim Civic Coalition
Abbey Eusebio, Manager, Anti-Hate Action Center, Chinese American Service League (CASL)
Thy Nguyen, Vice President, Impact and Advocacy, Chinese American Service League (CASL)

New York

Lloyd Feng, Senior Data Policy Coordinator, Coalition for Asian American Children and Families (CACF)
Rana Abdelhamid, MPP, Founder and President, Malikah

Oregon

Kweku Wilson, REALD & SOGI Data Analytics Manager, Equity & Inclusion Division, Oregon Health Authority
Matthew Friesen, PhD, REALD Manager, Office of Equity and Multicultural Services, Oregon Department of Human Services

APPENDIX 2 - State Laws and Related Resources

Nationwide

- D-DAN website

California

California Laws:

- Asian, Native Hawaiian, and other Pacific Islander groups: CA Government Code § 8310.5
- Additional Asian, Native Hawaiian, and other Pacific Islander groups: CA Government Code § 8310.7
- Data disaggregation for Black and African American groups: CA Government Code § 8310.6
- Latino and Indigenous Disparities Reduction Act: CA Health & Safety Code § 131250
- Department of Corrections race and ethnicity requirements: California Penal Code § 2068)

California Resources:

- "AB 1726: A California Case Study on Disaggregating Public Health Data by Race and Ethnicity" policy brief, SEARAC
- AB 1726 Asian and Pacific Islander Data Disaggregation, California Department of Public Health
- Latine and Indigenous Disparities Reduction Act, CA Data Justice

Illinois

Illinois Laws:

- Uniform Racial Classification Act, Amended to add Middle Eastern and North African (MENA) (all state agencies): HB3768, amending 20 ILCS 50/5
- Data Governance and Organization to Support Equity and Racial Justice Act (ERJA): 20 ILCS 65/20

Illinois Resources:

- 2024 Change InSight Report, Chinese American Service League

APPENDIX 2 - State Laws and Related Resources

New York

New York Laws:

- Data collection for Asian and Pacific Islander groups: Laws of New York, Chapter 18 sec. 170-E*2
- Data collection for Middle Eastern and North African groups starting: Laws of New York, Chapter 18, § 170-h

New York Resources:

- Championing the 2021 New York State Law: A Step Toward Data Disaggregation on Asian Americans, Native Hawaiians, and Pacific Islanders, AJPH 113,1296_1300, https://doi.org/10.2105/AJPH.2023.307428 by Anita Gundanna, Claudia M. Calhoon, Meeta Anand, Lloyd Feng, and Vanessa Leung

Oregon

Oregon Laws:

- The "Race, Ethnicity, Language, and Disability Demographic Data Collection Standards" (REALD) law: Oregon Administrative Rules 950-030
- REALD and SOGI Permanent Rules (7/2/24)

Oregon Resources:

- Oregon Health Authority information on the REALD law, including FAQs and legislative reports
- Community Organizing to Influence Policy Change in Oregon for Disaggregated Data Collection, *Progress in Community Health Partnerships: Research, Education, and Action 12*(3), 341-352, https://dx.doi.org/10.1353/cpr.2018.0058 by Nguyen-Truong, C.K.Y., Hsiao, C., & Demchak, V. (2018).

Endnotes

ENDNOTES

[1] For additional information about California's race and ethnicity data collection requirements in comparison to SPD 15, please see this table created by SEARAC.

[2] The Asian and Pacific Islander data collection requirements also apply to the Department of Industrial Relations and the Civil Rights Department.

[3] The Asian and Pacific Islander data collection requirements also apply to the Department of Industrial Relations and the Civil Rights Department.

[4] When collecting demographic information from applicants.

[5] Followed by a blank space to fill in additional groups.

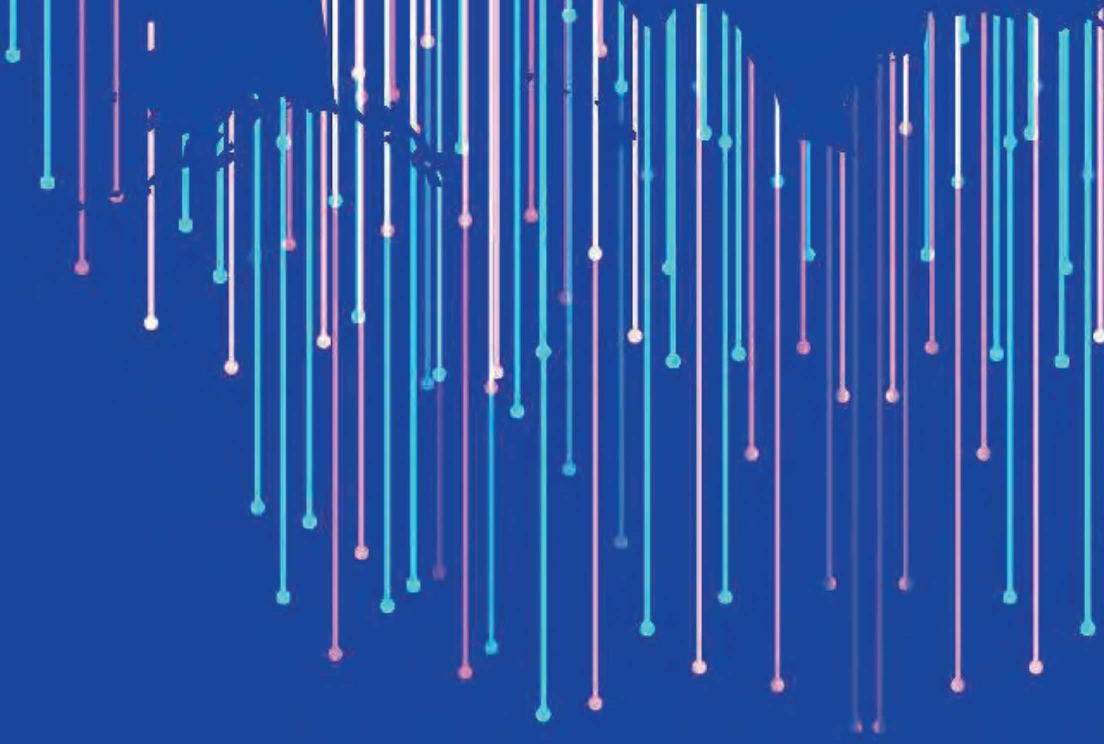
[6] Followed by a blank space to fill in additional nations. When collecting the preferred language of program participants, the department shall include Mixteco, Triqui, Zapoteco, K'iche, Mam, and Kanjobal, followed by a blank space to fill in additional languages (CA Health & Safety Code § 131250).

[7] "Age-adjusted death rate" refers to an adjustment for differences in age distributions when comparing death rates; the goal is to make fairer comparisons by removing the effect of age on mortality.

[8] The MENA category is not required for workforce or hiring data until July 1, 2025.

[9] . . . and all of the 10 most populous Asian groups in the most recent five-year American Community Survey published by the U.S. Census Bureau.

[10] For example, the State Education Department (SED) has taken the position that the law does not apply to them because: "(1) SED does not directly collect data through local school districts; and (2) SED does not collect or report any ancestry data." Memo from the SED to the governor, March 29, 2022. Negotiations are ongoing between the SED and the state to resolve this issue.



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