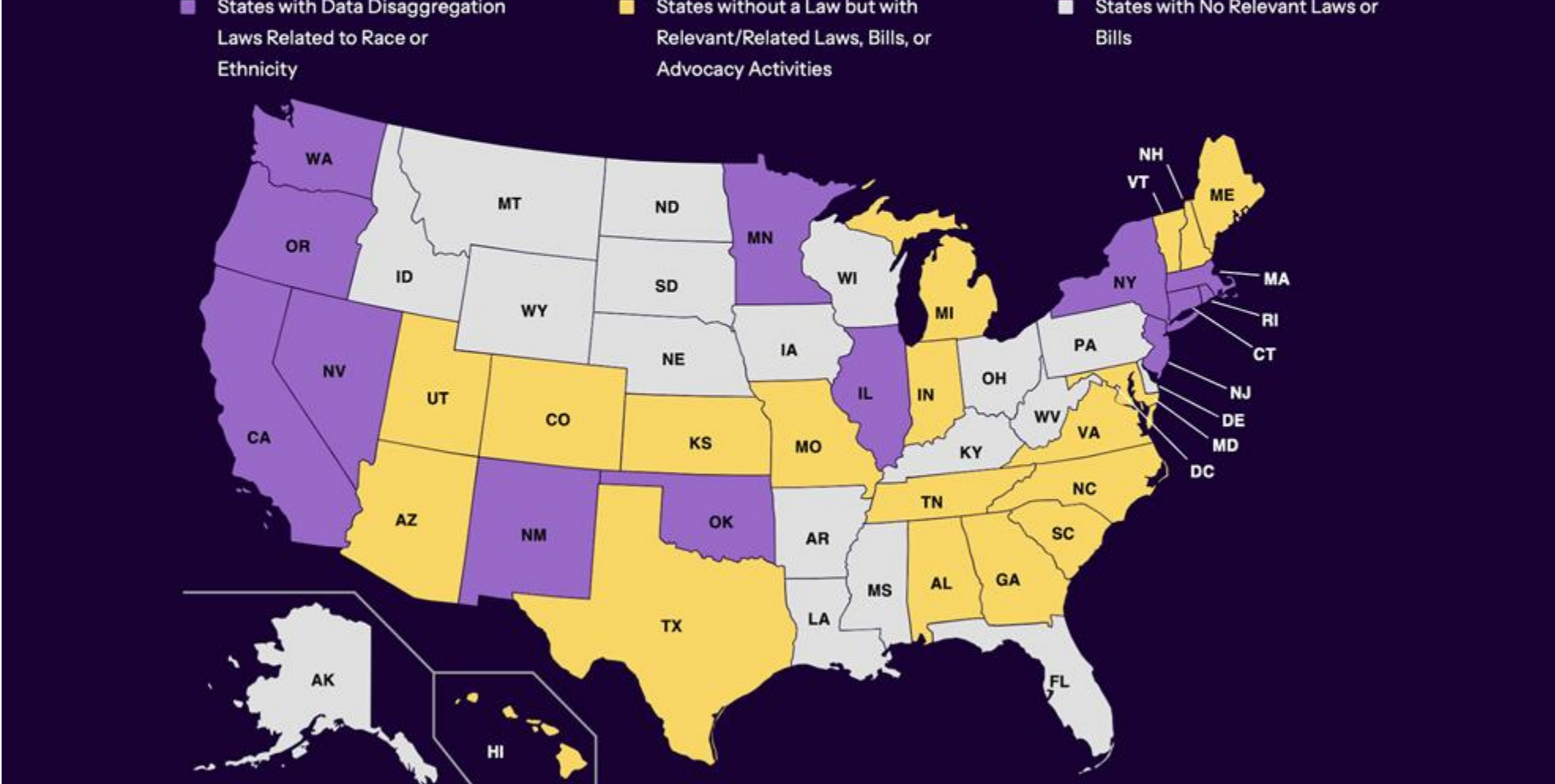


Disaggregating Public Health Data by Race and Ethnicity to Improve Public Health

Hover over each state to see its current data disaggregation policy. For states with laws, bills, and other related activity, click through to learn more.



The Data Disaggregation Action Network

Amy Vertal, Senior Program Manager for Census & Data Equity
The Leadership Conference on Civil and Human Rights

Why is Data Disaggregation Important?

“Although the collection of race, ethnicity and language data does not necessarily result in actions that will reduce disparities and improve care, **the absence of the data guarantees that none of that will occur.**”

Source: IOM (Institute of Medicine). 2009. Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. Washington, D.C.

Why is Data Disaggregation Important?

Aggregated and disaggregated health outcomes of AANHPIs

Figure 4



Source: [Community Counts](#): Assessing Social Drivers of Health among Asian American, Native Hawaiian, and Pacific Islanders. Change in Sight.

The Leadership Conference Education Fund's

Data Disaggregation Action Network (D-DAN)

We are a growing action network seeking partners in all 50 states, Washington, D.C., and U.S. territories.

**Our Data Disaggregation Action Network
Partners Are Working To Advance Data Equity
Every Day.**



Who we are:

Launched in 2022, D-DAN is a network of state and national nonprofit organizations working to improve race and ethnicity data collection and advance data equity.

What we do:

- Our D-DAN partners work to advance federal and state policies to collect and publish more detailed (or “disaggregated”) race and ethnicity data, particularly in the health field.
- We do this by engaging stakeholders, policymakers, and communities on the need for disaggregated data and mobilizing them to advocate for better data policies.
- The Leadership Conference supports this work through funding, technical assistance, convenings, and other resources and connections for D-DAN partners.

Data Disaggregation Action Network (D-DAN)

9 National Partners

15 State Partners

2 Cohorts

Listserv: 350+ contacts in 39 states!

TARGET STATES:

- California
- Maryland
- Michigan
- New Mexico
- New York
- Illinois

MILESTONES:

- Updated federal race/ethnicity data standards in 2024
- New state policies and progress on implementation
- Growth of the wider D-DAN network



Advancing NHPI Visibility: EPIC's Updated Blueprint And Data Profiles Support Federal Policy Reform

Categories: Partner Spotlight | Tags: Current Cohort, National



BRC Engages Black Communities Across Illinois On Race Data Categories And Representation

Categories: Partner Spotlight | Tags: Current Cohort, Illinois



SEARAC Advances Implementation Of California's AANHPI Health Data Disaggregation Law

Categories: Partner Spotlight | Tags: California, Current Cohort



NALEO Works To Ensure Latino Communities Are Fully Reflected In Federal Data

Categories: Partner Spotlight | Tags: Current Cohort, National



Malikah Leads Statewide Efforts To Implement NY's New MENA Disaggregation Law

Categories: Partner Spotlight | Tags: Current Cohort, New York



Johnson Center Builds Momentum For Equitable Data Through "Do You See Us?" Campaign

Categories: Partner Spotlight | Tags: Current Cohort, Michigan



AltaMed Mobilizes To Advance Data Equity For Latino And Indigenous Communities

Categories: Partner Spotlight | Tags: California, Current Cohort

Federal race/ethnicity data standards:

What is SPD15?

- The U.S. Office of Management and Budget (OMB)'s **Statistical Policy Directive No. 15 (SPD15)** defines the **minimum set of categories** that federal agencies must use when they collect race and ethnicity data.
- Until 2024, **the last time SPD15 had been updated was 1997(!)**. Many organizations and coalitions (including D-DAN!) advocated for years for updated standards that would better **reflect the growing diversity of the nation's population and allow more communities to be visible in federal data**.
- **In March 2024, OMB finally revised SPD15**. The updated standards include several improvements that advocates called for, including **requiring agencies to disaggregate race and ethnicity data beyond the major categories**.
- Agencies must implement the new standards by **March 2029**, and publish their implementation plans by **September 2025**. Learn more at spd15revision.gov.



Remember 1997?



D-DAN in Action!



1997 SPD15 Standards:

- Separate race and ethnicity questions
- No Middle Eastern/North African (MENA) Category
- Agencies encouraged (but not required) to collect disaggregated data for detailed subgroups

Is this person of Hispanic, Latino, or Spanish origin?

☐ No, not of Hispanic, Latino, or Spanish origin

☐ Yes, Mexican, Mexican Am., Chicano

☐ Yes, Puerto Rican

☐ Yes, Cuban

☐ Yes, another Hispanic, Latino, or Spanish origin – *Print, for example, Salvadoran, Dominican, Colombian, Guatemalan, Spaniard, Ecuadorian, etc.* ↴

What is this person's race?

Mark ☒ one or more boxes **AND** print origins.

☐ White – *Print, for example, German, Irish, English, Italian, Lebanese, Egyptian, etc.* ↴

☐ Black or African Am. – *Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.* ↴

☐ American Indian or Alaska Native – *Print name of enrolled or principal tribe(s), for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, etc.* ↴

<input type="checkbox"/> Chinese	<input type="checkbox"/> Vietnamese	<input type="checkbox"/> Native Hawaiian
<input type="checkbox"/> Filipino	<input type="checkbox"/> Korean	<input type="checkbox"/> Samoan
<input type="checkbox"/> Asian Indian	<input type="checkbox"/> Japanese	<input type="checkbox"/> Chamorro
<input type="checkbox"/> Other Asian – <i>Print, for example, Pakistani, Cambodian, Hmong, etc.</i> ↴	<input type="checkbox"/> Other Pacific Islander – <i>Print, for example, Tongan, Fijian, Marshallese, etc.</i> ↴	

☐ Some other race – *Print race or origin.* ↴

2024 SPD15 Standards:

- ✓ Single combined race/ethnicity question
- ✓ Middle Eastern/North African (MENA) category
- ✓ Requires collection of disaggregated data *by default*

Challenges ahead:

- Uncertain future for implementation of 2024 SPD15 in the current federal environment
- Need to educate communities about changes
- Broader concerns about threats to federal data and potential for misuse
- **In this landscape, state-level data are more important than ever!**

What is your race and/or ethnicity?
Select all that apply and enter additional details in the spaces below.

☐ **American Indian or Alaska Native** – Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.

☐ **Asian** – Provide details below.

☐ Chinese ☐ Asian Indian ☐ Filipino
☐ Vietnamese ☐ Korean ☐ Japanese
Enter, for example, Pakistani, Hmong, Afghan, etc.

☐ **Black or African American** – Provide details below.

☐ African American ☐ Jamaican ☐ Haitian
☐ Nigerian ☐ Ethiopian ☐ Somali
Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.

☐ **Hispanic or Latino** – Provide details below.

☐ Mexican ☐ Puerto Rican ☐ Salvadoran
☐ Cuban ☐ Dominican ☐ Guatemalan
Enter, for example, Colombian, Honduran, Spaniard, etc.

☐ **Middle Eastern or North African** – Provide details below.

☐ Lebanese ☐ Iranian ☐ Egyptian
☐ Syrian ☐ Iraqi ☐ Israeli
Enter, for example, Moroccan, Yemeni, Kurdish, etc.

☐ **Native Hawaiian or Pacific Islander** – Provide details below.

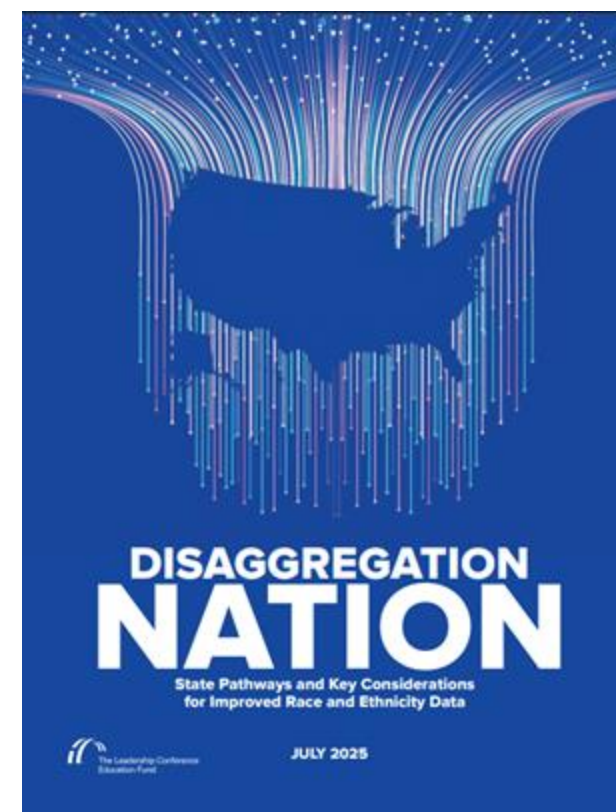
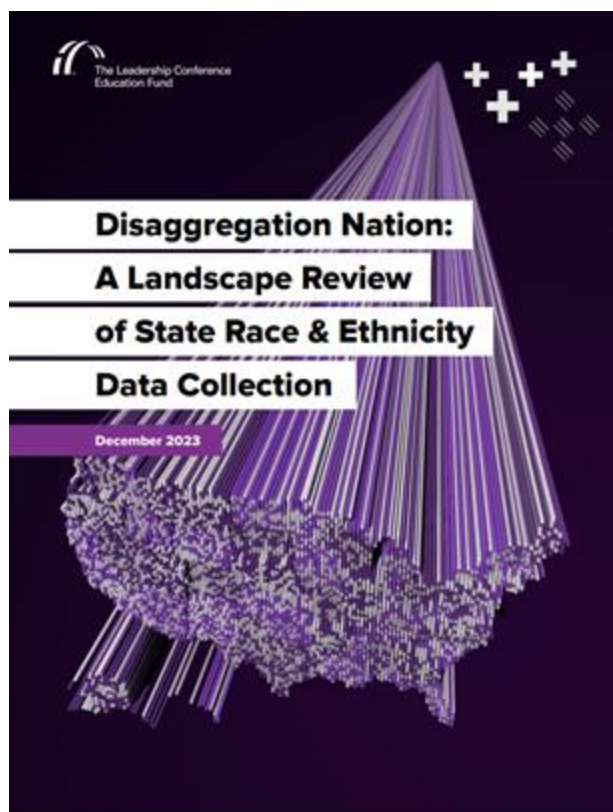
☐ Native Hawaiian ☐ Samoan ☐ Chamorro
☐ Tongan ☐ Fijian ☐ Marshallese
Enter, for example, Chuukese, Palauan, Tahitian, etc.

☐ **White** – Provide details below.

☐ English ☐ German ☐ Irish
☐ Italian ☐ Polish ☐ Scottish
Enter, for example, French, Swedish, Norwegian, etc.

Disaggregation Nation:

Our ongoing analysis of state standards for race and ethnicity data



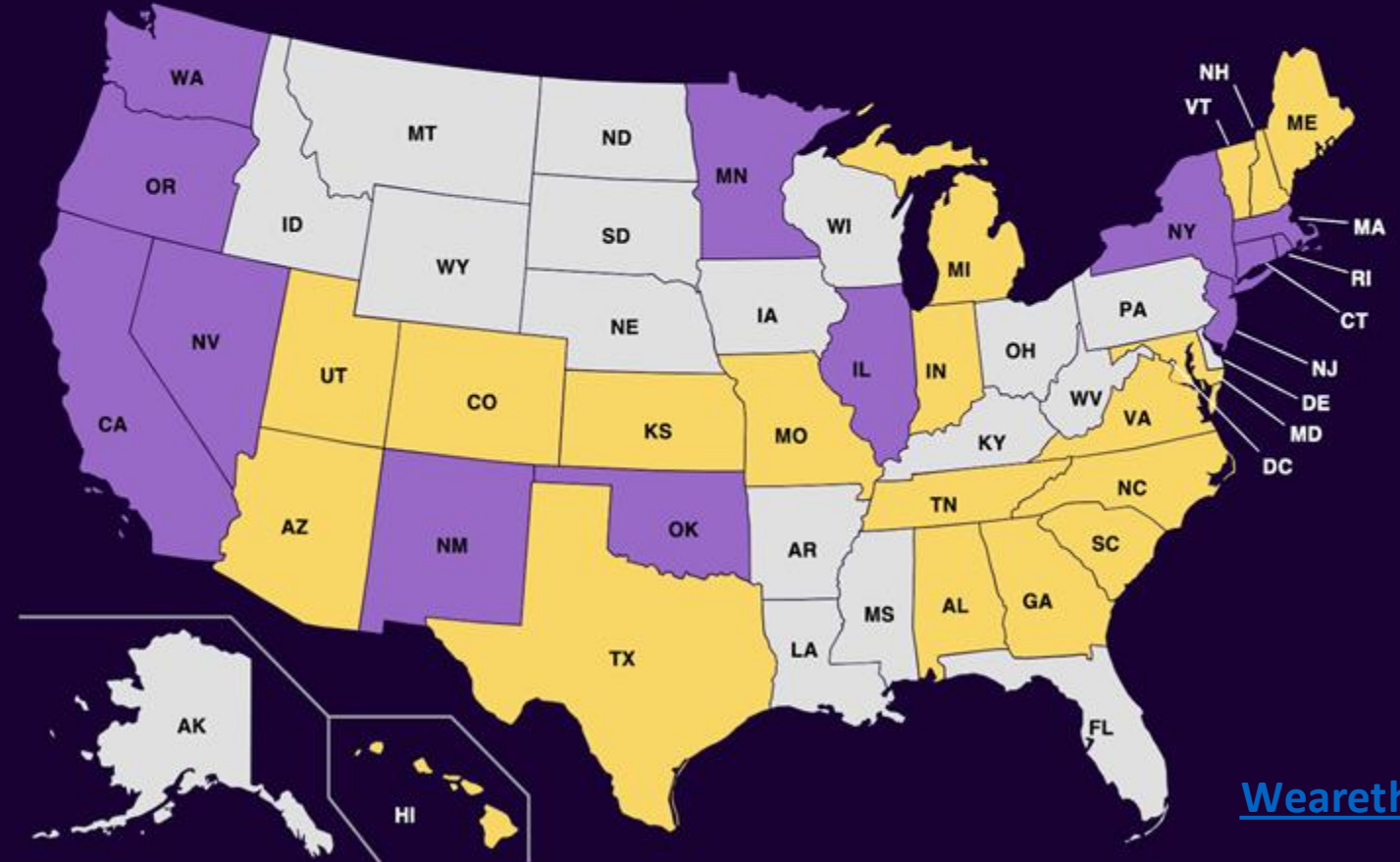
Check out our D-DAN website here to view the interactive map and other resources:



Interactive Map: Does Your State Have Data Disaggregation Policy In Place?

Hover over each state to see its current data disaggregation policy. For states with laws, bills, and other related activity, click through to learn more.

- States with Data Disaggregation Laws Related to Race or Ethnicity
- States without a Law but with Relevant/Related Laws, Bills, or Advocacy Activities
- States with No Relevant Laws or Bills



[Wearethedata.us](https://wearethedata.us)

At A Glance: Current Progress Toward Data Disaggregation Nationwide

13

States require data disaggregation of race and ethnicity beyond federal standards.

9

States require collection of disaggregated data for Asian and/or Pacific Islander groups: CA, CT, MA, MN, NJ, NY, OR, RI, and WA

6

States require collection of disaggregated data for Black or African groups: CA, CT, MA, MN, OR, and WA

6

States require collection of disaggregated data for Hispanic/Latino groups: CA, CT, MA, MN, OR, and WA

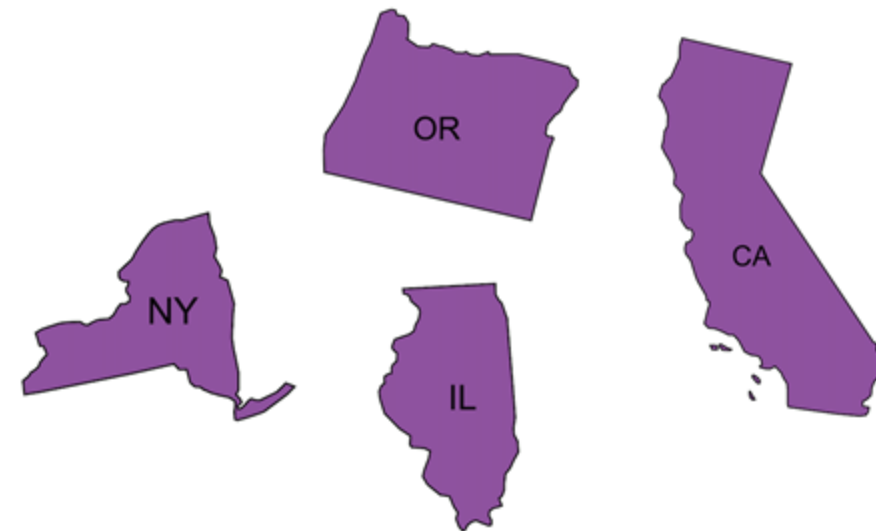
7

States require collection of disaggregated data for Middle Eastern and/or North African data: CT, IL, NJ, NV, NY, OR, and WA

5

States require collection of some disaggregated tribal data: CT, MN, NM, OK, and OR

State Pathways and Key Considerations for Improved Race and Ethnicity Data



Case studies from CA, OR, IL, and NY examining:

- Advocacy and education behind the policy
- Scope of the policy and how it evolved
- Implementation progress and considerations





[Home](#)

[About D-DAN](#) ▾

[State Progress](#) ▾

[Reports](#)

[Resources](#) ▾

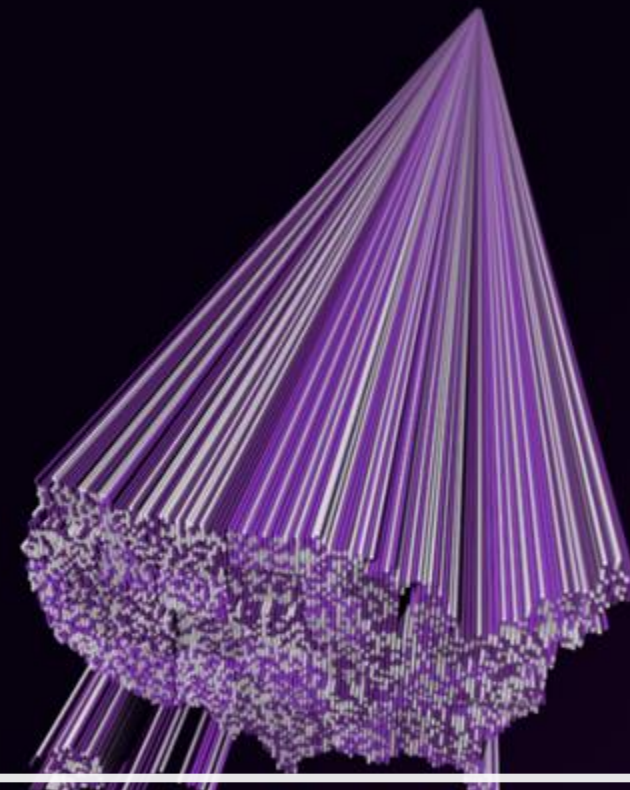
[Sign Up](#)

We are the data, and the data are diverse.

What is data disaggregation?

Breaking down government data into the building blocks of equity across all 50 states.

[Our State-by-State Analysis](#)



Join us! Learn more and sign up for D-DAN updates at: wearethedata.us

CACF Invisible No More Campaign

Lloyd Feng, Senior Data Policy Coordinator
Coalition for Asian American Children and Families (CACF)

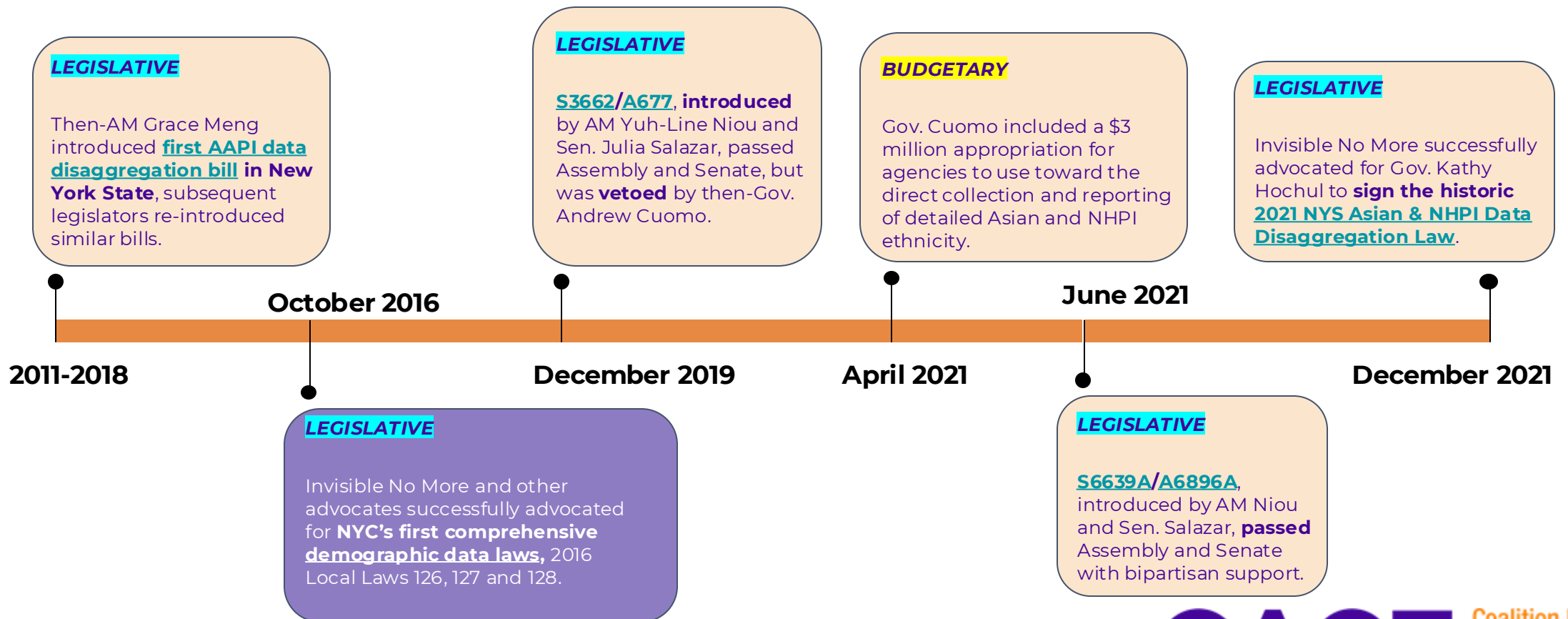
CACF's **Invisible No More Campaign** has been fighting for 15 years to ensure that our New York City and New York State governments collect accurate data and information - **disaggregated data** - about our diverse Asian and Native Hawaiian Pacific Islander communities.



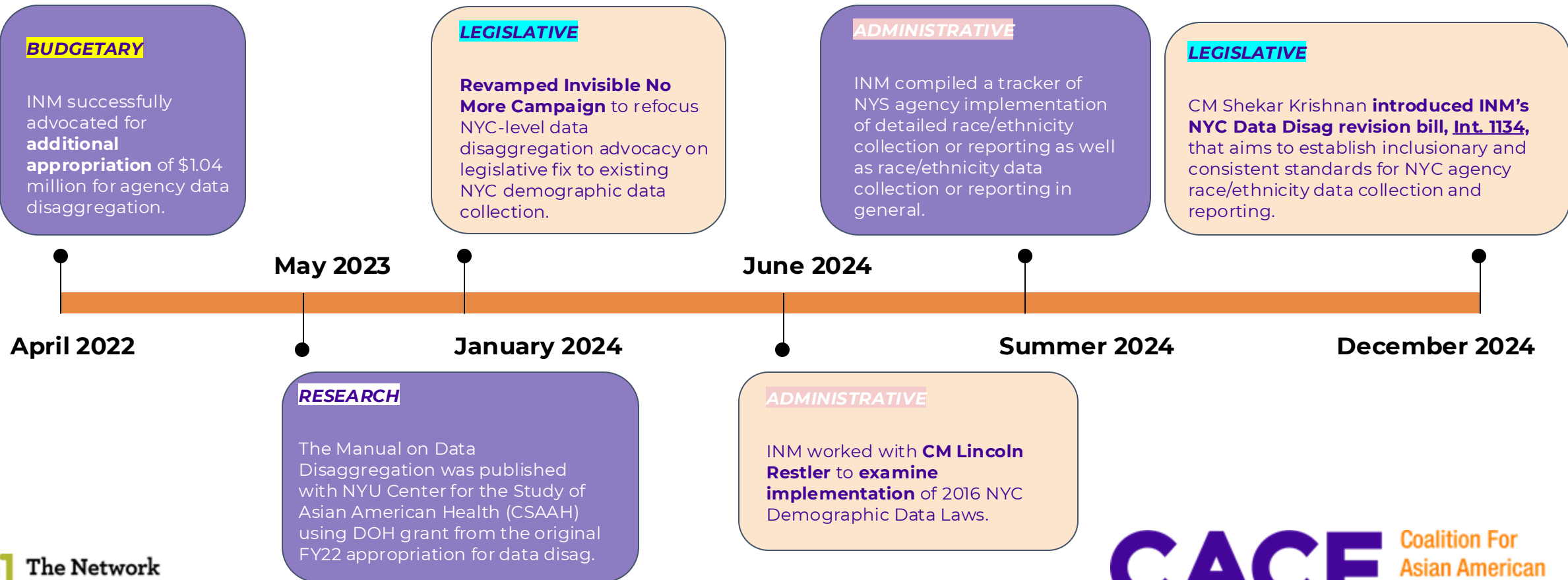
Our **mission** is to advocate for AAPI data disaggregation in NYC and NYS

Our **vision** is for community members, advocates, and legislators to use disaggregated data to develop policy solutions to address needs of marginalized Asian and NHPI communities

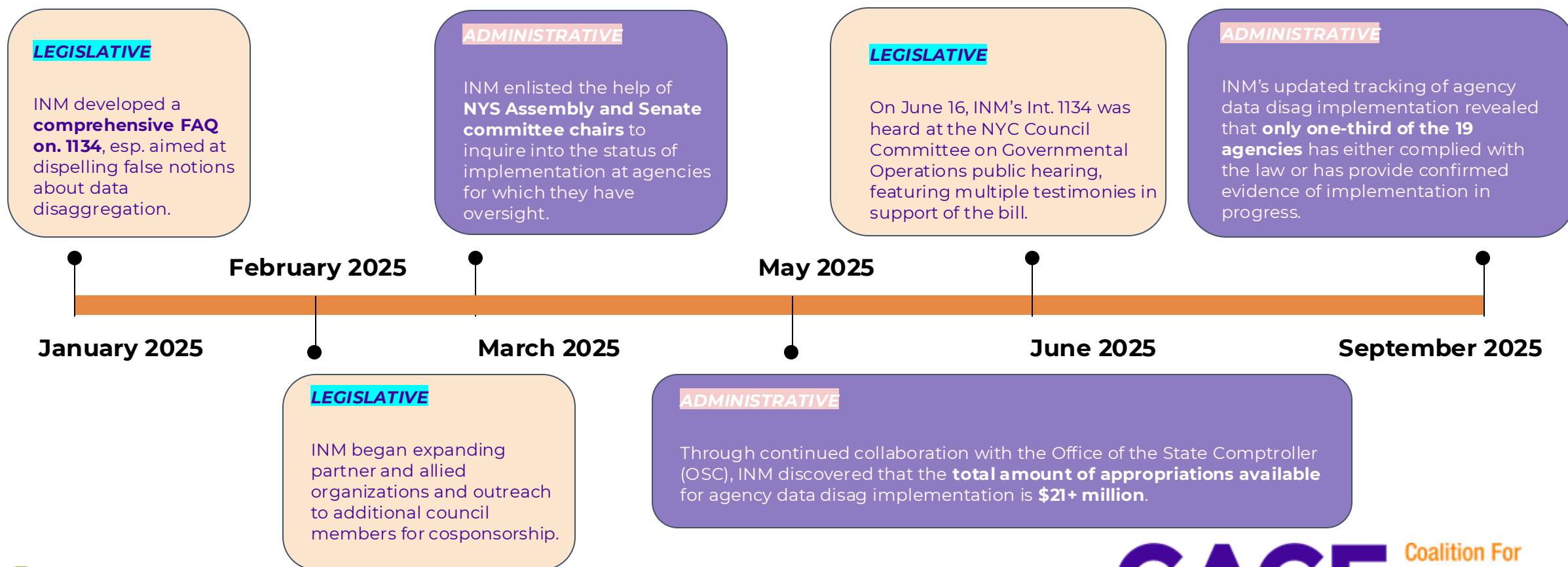
Campaign Timeline: 2011-2021



Campaign Timeline: 2022-2024



Campaign Timeline: 2025



INM Legislative Wins

NYS

- **2021 NYS Asian and NHPI Data Disaggregation Law (Exec Law 170-e*2)**
 - Requires all state agencies, offices, boards, and commissions that collect demographic information related to ancestry or ethnic origin to collect and report information for the ten most populous Asian subgroups and the three most populous NHPI subgroups based on the U.S. Census Bureau data.
 - Any agency that does not publish such information in its reports that include race/ethnicity demographic information must include a public explanation.
 - In practice, it specifically applies to 19 agencies overseen by the Executive Chamber to collect and report detailed Asian and NHPI demographic information.

NYC

- **2016 Demographic Data Laws**
 - Requires seven city agencies to collect and report information on the 30 most populous ancestry groups in NYC using a voluntary survey form.
 - Requires the Mayor's Office of Operations to conduct an annual form review.
 - Requires data collected by the seven agencies using the survey form to be published on a regular basis on the NYC OpenData platform.
 - Successful June 16 hearing in the Gov Ops Committee

Ongoing Advocacy

NYS

- **Implementation of 2021 NYS Asian and NHPI Data Disaggregation Law (Exec Law 170-e*2)**
 - As of September 2025, only ⅓ of the 19 agencies identified by Executive Chamber as required to comply with the law have demonstrated concrete evidence that they have either:
 - published data collected using the detailed categories
 - updated forms to include the detailed categories
 - in the process of updating systems to include the new categories for data collection.
 - As of September 2025, there is over \$21 million available for NYS agencies to use in implementing the law.

NYC

- **Int. 1134 (Revision Bill)**
 - Requires all NYC agencies to use the same unified race/ethnicity data collection standards:
 - adopt 2024 SPD 15'S minimum categories
 - collect and report data for at least 10/12 subgroups within each minimum category
 - Requires Ops and MOIA to manage a public webpage listing all race and ethnicity categories and hierarchies (**NYC race and ethnicity code list**)
 - Requires agencies to publish information on the **specific forms and number of forms** eligible for updating to include the detailed categories
 - Requires agencies to **publish information identifying the specific agency personnel** managing implementation of the law and the agency's implementation plan in one place
 - Requires Ops and MOIA to develop the **standardized forms**
 - Requires Ops to **publish annual data** collected from agencies in a single webpage accessible to the public

Example Demographic Form

2024
SPD 15

What is your race and/or ethnicity?
Select all that apply and enter additional details in the spaces below.

☐ **American Indian or Alaska Native** – Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.

☐ **Asian** – Provide details below.
☐ Chinese ☐ Asian Indian ☐ Filipino
☐ Vietnamese ☐ Korean ☐ Japanese
Enter, for example, Pakistani, Hmong, Afghan, etc.

☐ **Black or African American** – Provide details below.
☐ African American ☐ Jamaican ☐ Haitian
☐ Nigerian ☐ Ethiopian ☐ Somali
Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.

☐ **Hispanic or Latino** – Provide details below.
☐ Mexican ☐ Puerto Rican ☐ Salvadoran
☐ Cuban ☐ Dominican ☐ Guatemalan
Enter, for example, Colombian, Honduran, Spaniard, etc.

☐ **Middle Eastern or North African** – Provide details below.
☐ Lebanese ☐ Iranian ☐ Egyptian
☐ Syrian ☐ Iraqi ☐ Israeli
Enter, for example, Moroccan, Yemeni, Kurdish, etc.

☐ **Native Hawaiian or Pacific Islander** – Provide details below.
☐ Native Hawaiian ☐ Samoan ☐ Chamorro
☐ Tongan ☐ Fijian ☐ Marshallese
Enter, for example, Chuukese, Palauan, Tahitian, etc.

☐ **White** – Provide details below.
☐ English ☐ German ☐ Irish
☐ Italian ☐ Polish ☐ Scottish
Enter, for example, French, Swedish, Norwegian, etc.

Int. 1134: Example Demographic Data Form

This illustrates how standardized race/ethnicity data collection might appear under Int. 1134, which would require NYC agencies to use consistent reporting formats. This sample reflects CACF's vision for implementation and is not an officially adopted agency form. The legislation requires including minimum categories, top subgroups, and write-in options.

What is your race and/or ethnicity?

Select all that apply and enter additional details in the space below

☐ **American Indian or Alaska Native** - Provide details below
☐ Aztec ☐ Taino ☐ Maya ☐ Cherokee ☐ Blackfeet Tribe of the Black Indian Reservation of Montana
☐ Inca ☐ Mixtec ☐ Navajo Nation ☐ Mohawk ☐ Arawak
Enter, for example, Choctaw, Shinnecock Indian Nation, Nome Eskimo Community, etc.

☐ **Asian** - Provide details below
☐ Chinese ☐ Asian Indian ☐ Bangladeshi ☐ Filipino ☐ Korean
☐ Pakistani ☐ Japanese ☐ Vietnamese ☐ Uzbek ☐ Taiwanese
Enter, for example, Thai, Afghan, Guyanese, etc.

☐ **Black or African American** - Provide details below
☐ African American ☐ Jamaican ☐ Haitian ☐ Guyanese ☐ Trinidadian & Tobagonian
☐ Nigerian ☐ West Indian ☐ Ghanaian ☐ Senegalese ☐ Ethiopian
Enter, for example, Somali, Congolese, Barbadian, etc.

☐ **Hispanic or Latino** - Provide details below
☐ Dominican ☐ Puerto Rican ☐ Mexican ☐ Ecuadorian ☐ Colombian
☐ Salvadoran ☐ Honduran ☐ Peruvian ☐ Guatemalan ☐ Cuban
Enter, for example, Panamanian, Argentinian, Venezuelan, etc.

☐ **Middle Eastern or North African** - Provide details below
☐ Egyptian ☐ Turkish ☐ Israeli ☐ Lebanese ☐ Iranian
☐ Moroccan ☐ Syrian ☐ Palestinian ☐ Yemeni ☐ Armenian
Enter, for example, Iraqi, Jordanian, Amazigh, etc.

☐ **Native Hawaiian or Pacific Islander** - Provide details below
☐ Native Hawaiian ☐ Samoan ☐ Chamorro ☐ Fijian ☐ Tongan
☐ Maori ☐ Guamanian ☐ Marshallese ☐ Papua New Guinean ☐ Tahitian
Enter, for example, Palauan, I-Kiribati, Chuukese, etc.

☐ **White** - Provide details below
☐ Italian ☐ Irish ☐ German ☐ Polish ☐ English
☐ Russian ☐ Ukrainian ☐ French ☐ Greek ☐ Hungarian
Enter, for example, Albanian, Romanian, Australian, etc.

☐ **Other Race and/or Ethnicity** - Provide details below

NYC Int. 1134
(one
hypothetical
example of the
form that
agencies could
adopt)

Int. 1134: FAQ for Community Education

Understanding Int. 1134

Frequently Asked Questions about Int. 1134
from CACF's Invisible No More Campaign

CACF

Coalition For Asian American
Children+Families

What is Int. 1134?

Int. 1134 is a bill introduced in the NYC Council by CM Shekar Krishnan to improve New York City's race and ethnicity data collection and reporting process for New Yorkers accessing city services.

This bill would require all NYC agencies collecting demographic information to collect and report detailed ethnicity data on our communities.

Why Int. 1134 for NYC?

There is currently no uniform standard for race and ethnicity data collection and reporting across NYC agencies.

At the moment, agency data leave out the diversity of NYC communities despite NYC being home to hundreds of ethnicities, heritages, and languages spoken.

What does Int. 1134 do?

- Require all city agencies to use the same standards when collecting race and ethnicity data.
- Require more detailed options beyond broad categories like "Asian," "Black," and "Hispanic," but instead "Indian," "Nigerian," and "Cuban."
- Require agencies to publish the data collected on an annual basis and information on which agency team is responsible for implementation.
- Provide agencies with critical, high-quality data in order to make policy decisions and deliver services truly responsive to the unique needs of all communities.

What is Data Disaggregation?

Data disaggregation is simply the process of breaking down a large group into smaller, more specific groups.



Data disaggregation offers a more precise picture of NYC communities and their needs.

Who would Int. 1134 impact?

This bill impacts all New Yorkers who use city services. All New Yorkers will also benefit.



Int. 1134 would allow a person filling out NYC forms to provide more accurate race/ethnicity information and enable agencies to collect such granular race/ethnicity data that would ultimately help make NYC's demographic data better and more accurate than ever before.

Does Int. 1134 require the collection of immigration status?

Int. 1134 does **NOT** require NYC agencies to collect any information about immigration status.

This bill only focuses on improving how the city collects race and ethnicity data. It is not related at all to immigration status.

For more information about Data Policy or Int. 1134, contact jcha@cacf.org and lfeng@cacf.org.

Understanding Int. 1134

Frequently Asked Questions about Int. 1134
from CACF's Invisible No More Campaign

CACF

Coalition For Asian American
Children+Families

Will my privacy be protected?

Privacy protection is critically important to CACF INM. According to Int. 1134, NYC agencies collecting race and ethnicity data would:

Adhere to all federal, state, and local privacy laws.

Not affect a person's eligibility for services such as SNAP and Cash Assistance.

Be entirely voluntary.

Use such data to enhance services to better meet New Yorkers' needs.

How can our communities benefit from Int. 1134?

Community organizations can show the specific needs in their communities when applying for funding or resources.

NYC agencies can see which services are reaching communities and target them more strategically, esp. for communities overlooked in the past.

NYC Legislators can craft legislation with a clearer understanding of impacts on NYC communities.

For more information about Data Policy or Int. 1134, contact jcha@cacf.org and lfeng@cacf.org.

Why isn't language data enough for agencies to understand NYC's diversity?

Language data alone doesn't tell the full story of a community's needs, esp. when it comes to communities as complex as Asian communities, making ethnicity data crucial in filling the gaps.

- Many second or third-generation Americans identify strongly with their ethnic heritage, but primarily speak English.
- Relying on language alone would neglect these community members' needs completely.
- Different ethnic groups may speak the same language, but also have very different needs.

Why do our communities need disaggregated ethnicity data?

Disaggregated ethnicity data is essential to address each community's needs. APIs show an overall diabetes rate of 11%, below NYC's 12% average, but Indian New Yorkers face a much higher rate of 21%. Without detailed data, disparities like this stay hidden.



Source: 2021 NYC DOHMH report, *Health of Asians and Pacific Islanders in New York City*

Challenges and Lessons Learned

Challenges

- **Implementation of 2021 NYS Asian and NHPI Data Disaggregation Law (Exec Law 170-e*2)**
 - Relationship-building with the appropriate agency officials not only familiar with the data management systems, but also, officials with political will to prioritize data disaggregation implementation
 - Despite there being millions of dollars available in funding theoretically to support any agency in its efforts to implement Asian and NHPI disaggregated data collection and reporting, agencies have not known and/or not been able to access the funding.
 - More concerted efforts focused on ethnicity-based disaggregation of education data

Lessons Learned

- **Int. 1134 (Revision Bill)**
 - Community concerns about robustness of NYC agency data privacy protections and protections against data sharing with federal government entities, particularly federal law enforcement agencies
 - Could/Will data disag be used against 'us'?
 - Talking points attuned to legislators' and community partners' different political priorities and policy needs
 - Importance of clear messaging and use cases specifically what kinds of policy questions/plans of action for which data disaggregation by ethnicity would be useful

Additional information

NYS

- 2021 NYS Asian and NHPI Data Disaggregation Law ([NYS Exec Law 170-e*2](#))
- FY22-FY26 NYS [Appropriations](#) for Data Disaggregation

NYC

- [Int. 1134-2024](#)
 - [FAQ](#)
 - [Example Form](#)
- 2016 Local Laws [126](#), [127](#), and [128](#)

The Latine and Indigenous Disparities Reduction Act

Mar Velez, Director of Policy
Latino Coalition for a Healthy California

Latino Coalition for a Healthy California

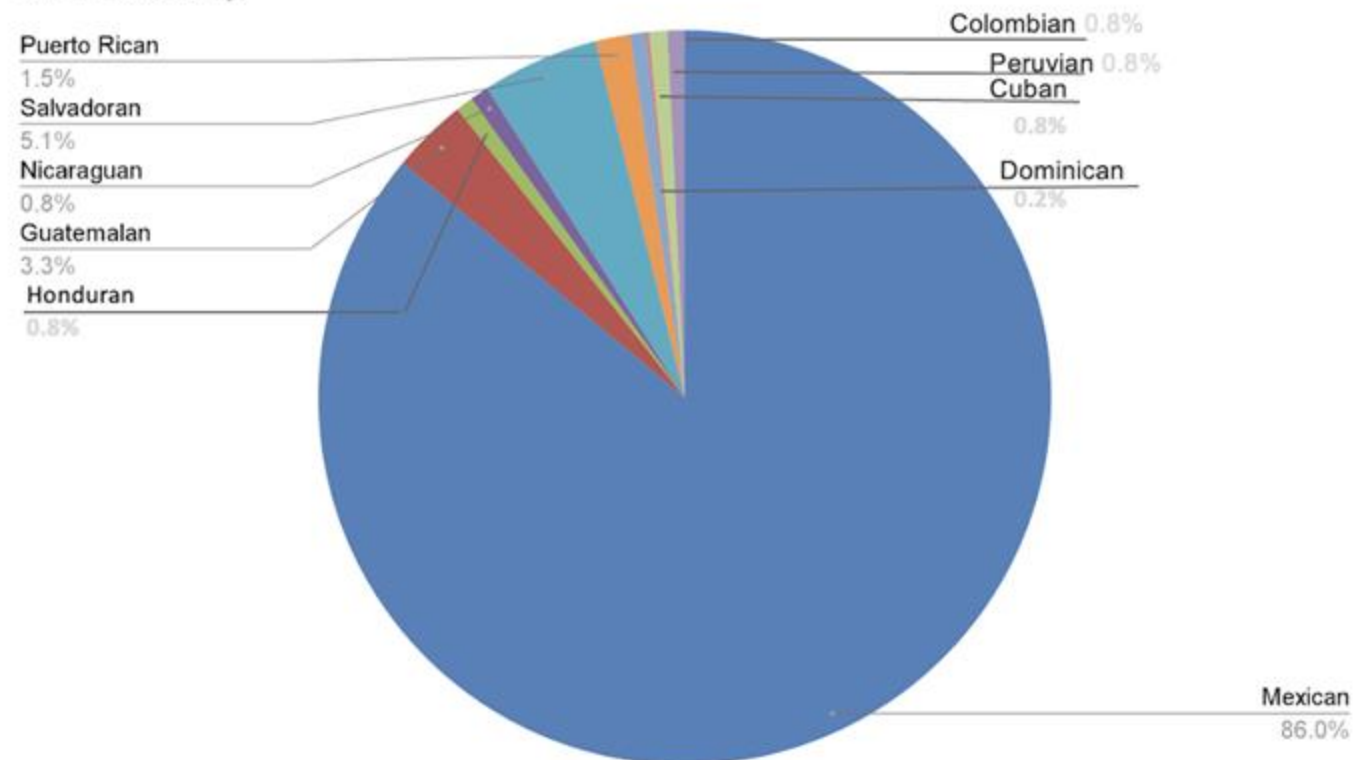


The Latino Coalition for a Healthy California, or LCHC, is the only statewide policy and advocacy organization led by Latine leaders that is dedicated to protecting and promoting health equity for Latine communities. We are a diverse, cross-sector alliance of community leaders, advocates, policy experts, administrators, and healthcare providers—brought together by a shared commitment to advancing health equity. Our efforts focus on community-driven programs, impactful policy advocacy, and strategic communications

Overview of Latine Diversity within California

- Latines make up 40% of California population.
- Latine children make-up half of the children under 5 in California.
- Latine makeup 40% of the workforce in 2021.
- Latine older adults make up 20% of the 65+ population in California.

SB 1016 Latine Groups



Source: U.S. Census Bureau, ACS 5-Year Estimates Detailed Tables

Indigenous identity outside of the Latine label

- According to the U.S. Census Bureau, almost **20,000 Indigenous language speakers** from Meso and Latin America reside in the United States and California has one of the largest Indigenous Mesoamerican populations in the country.^{1,2}
- Many Indigenous migrants do not speak Spanish or English. This creates a barrier to access services and navigate community resources.
- Decades of resilience against a system attempting to restrict culture and language.



SB 1016 the Latine and Indigenous Disparities Reduction Act

Requires the California Department of Public Health (CDPH) to publish a report to include disaggregated data for the following health indicators: birth rates, death rates, major diseases, leading causes of death per demographic, pregnancy, housing, and mental health rates for Latine groups and Mesoamerican Indigenous Nations.

Mesoamerican Indigenous Nations: Maya, Aztec, Mixteco, Zapoteco, and Triqui
Preferred language data for: Mixteco, Triqui, Zapoteco, K'iche, Mam, and Kanjobal.

Latine Groups: Mexican, Guatemalan, Salvadoran, Honduran, Nicaraguan, Puerto Rican, Dominican, Cuban, Colombian, and Peruvian.

Threats to SB 1016 Implementation

#Health4All 

Frequently Asked Questions:
Medicaid Information Sharing with
Immigration Enforcement

What occurred with the information of people enrolled in Medi-Cal?

- On June 10, 2025, the Centers for Medicare and Medicaid Services (CMS)—an agency of the U.S. Department of Health and Human Services (HHS)—shared personal information of people enrolled in Medi-Cal with the U.S. Department of Homeland Security (DHS).
- The information shared includes the personal and sensitive medical information of all Medi-Cal members: citizens, immigrants with satisfactory immigration status, immigrants with unsatisfactory status, and people who have accessed only emergency services through Medi-Cal.
- Additionally on July 14, 2025, CMS signed an agreement with DHS so that federal immigration officials can directly access the private information of people who have Medi-Cal. The agreement allows immigration enforcement to access the names, addresses, birth dates, ethnic and racial information, as well as Social Security numbers and the types of health care received for over 79 million Medicaid members, including everyone enrolled in Medi-Cal. The agreement allows immigration enforcement to access a database with this information every day from Monday through Friday from 9-5pm until September 9, 2025.
- Current federal and state laws protect the privacy of personal information about Medi-Cal members. This is a departure from the longstanding laws and policies that limit using a Medi-Cal/Medicaid recipient's personal information for purposes directly related to the program. Allowing immigration enforcement to access these private data undermines the Medicaid program's goals and the privacy guarantees from both the federal and state governments that consumers have relied on for decades.

- California expanded Medi-Cal/Medicaid to all income-eligible Californians, regardless of immigration status
- Recently the Trump Administration ordered HHS to hand over Medicaid beneficiary data to DHS for the purposes of deportation
- The CA Health4All Coalition has been providing information on what was included in the data share including names, dates of birth, immigration status, and addresses.

Implementation and Data Privacy

LCHC and Indigenous SB 1016 cosponsors are working with CDPH to implement the law. Although new SPD 15 regulations were approved under the Biden Administration, the new federal administration is posing unforeseen challenges to policy implementation.

- **Data sharing:** Recent agreements and transfers of Medi-Cal/Medicaid data for purposes of deportation have caused a lot of anxiety and mistrust among immigrant/Latine/Indigenous Mesoamerican communities that may make it more challenging for them to share demographic data with government agencies
- **Reductions in public health funding:** CDPH staff have shared that implementation timelines, although they are still on track, may have to be adjusted given the reductions in funding by the Trump Administration.

THANK YOU

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Leslie Zellers

Public Health Policy
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Questions & Discussion

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