

Invisible No More: AAPI Data Equity and Disaggregation

Coalition for Asian American Children and Families

The Leadership Conference October 24 Convening



CACF

Coalition For Asian American
Children+Families

The Nation's only pan-Asian children and families' advocacy organization bringing together youth, parents community organizations, and allies.



Our mission is to advocate for equity and opportunity for marginalized AAPI children and families

Our vision is for all children and families, including AAPIs, in New York to be safe, health, and able to reach their full potential in life

AAPI NEEDS, BY THE NUMBERS.

- **22%** or **1 in 5** AAPIs live in poverty in NYC - the highest poverty rate of all racial/ethnic groups
- **46%** of AAPI New Yorkers are linguistically isolated and have limited English proficiency
- **40%** of NYC AAPI youth are not college-ready upon graduating high school
- **21%** of AAPI New Yorkers are considered under-insured
- **40%** of AAPI New Yorkers are enrolled in Medicaid



OUR POLICY & ADVOCACY WORK

Language Access

Budget Equity

Education Equity

Data Disaggregation

Health Equity

Child Welfare

CACF is TRANSFORMING our communities for the better

To do this well, CACF is building a POWERFUL COMMUNITY

We have a coalition of almost 90 MEMBERS who are AAPI-led or -serving organizations

Adult Education (ESOL and Digital Literacy)

Anti Poverty

Anti-Violence/Hate Crime Response

Afterschool/Youth Services

Arts and Culture

Civic Engagement/Voting Rights

Community Development

Early Childhood Services

Food Insecurity

Gender-based Violence Intervention and Prevention

Health Services

Housing

Immigrant Services

Legal Services

LGBTQ Rights and Advocacy

Mental Health Services

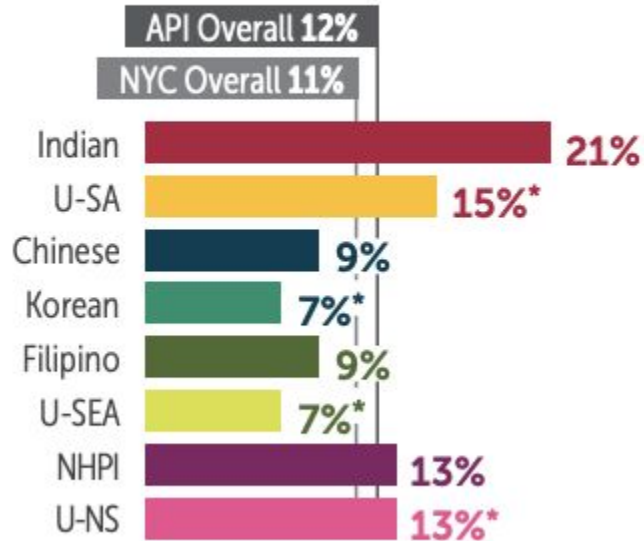
Small Business Services

Senior Services

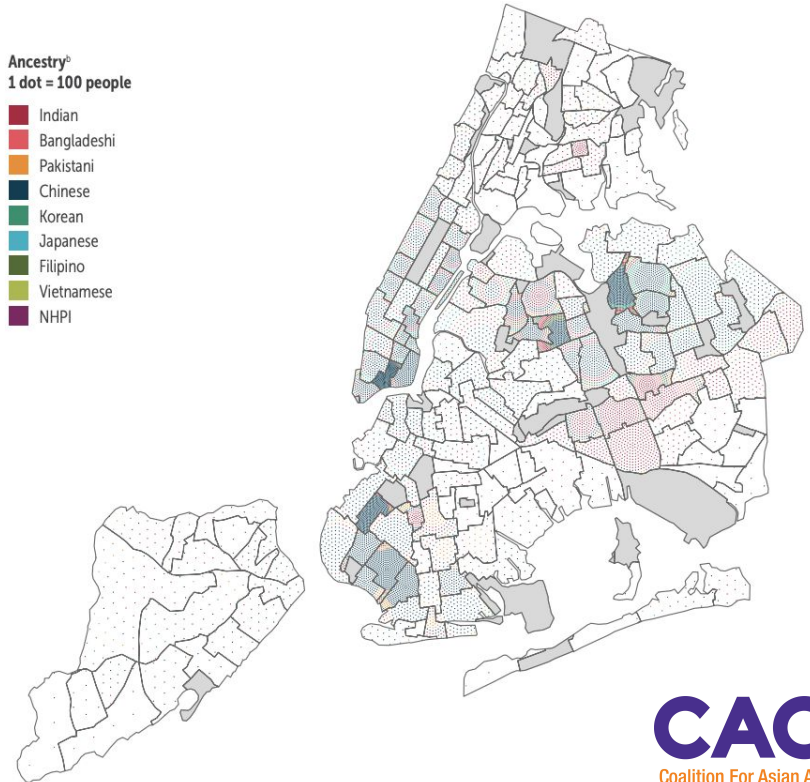
Workforce Development

Why is data disaggregation important?

Adults with diabetes^u

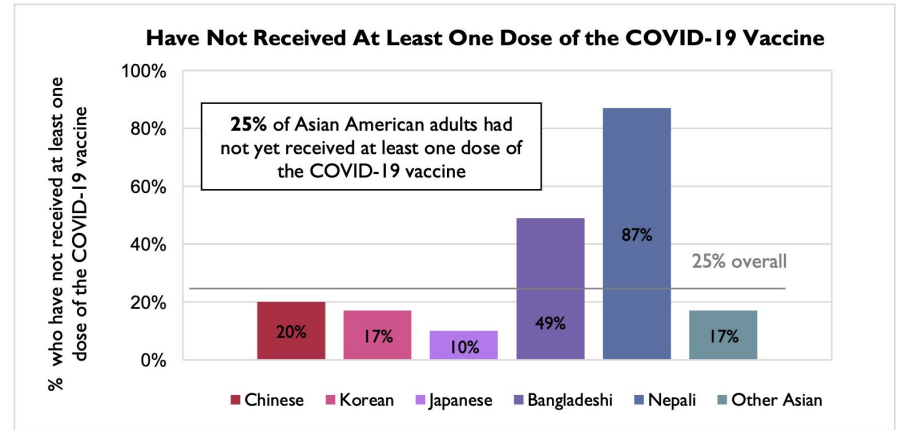
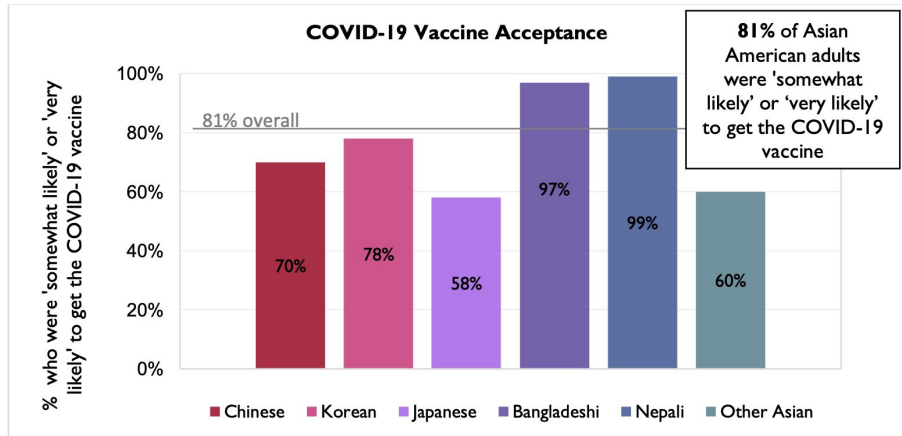


Ancestry^b
1 dot = 100 people



Source: [NYC DOHMH, Health of Asians and Pacific Islanders in New York City, 2021](#)

Why is data disaggregation important?



Source: NYU CSAAH, NYC COVID CHRNA Advance Findings

Invisible No More: Where Are We Now?

- **NYS:** AA and NH/PI Data disaggregation law passed and signed into law in 2021
 - For Top 10 Asian ethnic groups, Top 4 NH/PI ethnic groups by population
 - 2-year implementation timeline overall
- **NYC:** Data disaggregation laws for race and ethnicity, multiracial identity, and sexual orientation and gender identity passed and signed into law in 2016
 - Top 30 ancestry groups and languages spoken by population

What We Aim to Accomplish

- **NYS + NYC:** Ensure agencies collect extensive disaggregated data on AA and NH/PI New Yorkers and are not merely compliant with the law (community-centered implementation process)
- **NYC:** Craft new language and advocate for revision bill of existing data disaggregation laws
- Engage all stakeholders in issue of AAPI data equity for a comprehensive education campaign
- Compile lessons learned in NYS and NYC on AAPI data equity advocacy and implementation to advocates and stakeholders in other states

Lessons Learned in Implementing Data Equity Laws

- **Set the tone: build buy-in with key system stakeholders**
- **Incorporate community voice**
- **Understand the target system: protocol, practice, training, etc.**
 - **Assess costs and budget**
- **Accountability: build and leverage relationships**

Building buy-in with stakeholders (researchers)

Championing the 2021 New York State Law: A Step Toward Data Disaggregation on Asian Americans, Native Hawaiians, and Pacific Islanders

Anita Gundanna, PhD, Claudia M. Calhoun, DPH, Meeta Anand, JD, MA, Lloyd Feng, and Vanessa Leung, MA

ABOUT THE AUTHORS

Anita Gundanna, Lloyd Feng, and Vanessa Leung are with the Coalition for Asian American Children and Families, New York, NY. Claudia M. Calhoun is with the Department of Health and Human Performance, York College, City University of New York, New York. Meeta Anand is with The Leadership Conference on Civil and Human Rights, Washington, DC.

Racial and ethnic data aggregating Asian American and Native Hawaiian and Pacific Islander (AA and NH/PI) individuals into one or two categories do not provide an accurate picture of social needs or health outcomes among communities that identify as such.¹⁻⁴ Addressing these gaps in data is part of advancing data equity, which Lee et al. define as “a transparent, critically grounded approach to race and ethnicity data [dis]aggregation . . . necessary to document, understand, and address the health effects of racism.”^{5,6,24,25} Despite the longstanding acknowledgment of the gaps in AA and NH/PI population data, the passage of laws and changes in government data practices to correct these gaps have been slow.^{4,6} New York City and State have taken important steps in collecting better data on the full

range of AA and NH/PI populations. But the work to generate fully descriptive data that provide complete insights into health outcomes and social determinants and to support data equity remains incomplete.

In this article, we highlight the challenges of achieving data equity by advocating policies to fully disaggregate data, especially those that render invisible populations with heritage in Asia, Hawaii, and the Pacific Islands, through a detailed discussion of the Coalition for Asian American Children and Families (CACF) Invisible No More (INM) campaign in New York. Led by CACF, the decade-long INM campaign for AA and NH/PI data disaggregation led to the first-ever data disaggregation law in New York City in 2016, followed by the enactment of a New York State law in 2021. INM provides an important

template for how coalition-based advocacy can successfully push for the passage and implementation of laws that mandate better data collection and usage.

In the United States, 21 million people identifying as AA and NH/PI make up 6% of the population.⁷ Gaps in resources persist even though AA and NH/PI populations were the fastest-growing racial and ethnic minority group in the United States from 2000 to 2019.⁸ In New York State, AA and NH/PI populations together make up more than 17% of the overall population.⁹ Aggregated data on social determinants of health overstate the level of education, employment, and income among many populations that fall under this umbrella.¹⁰ Such data also mask health disparities requiring public health intervention and social services.¹⁰

For example, aggregated data on COVID-19's impact on communities indicated that Asian Americans were the racial group least affected by COVID-19.¹¹⁻¹³ But research by New York University's Center for the Study of Asian American Health showed that at the height of the pandemic in 2020, Chinese New Yorkers suffered from the highest COVID-19 mortality rate and that South Asian New Yorkers had the highest infection and hospitalization rates across all New Yorkers.¹¹ Subsequently, aggregated community estimates pointed to high rates of vaccine uptake among AA and NH/PI communities overall.¹⁴ Disaggregated data showed, however, that whereas vaccine acceptance among Nepali and Bangladeshi populations was high, vaccine uptake among these groups was relatively low, pointing to a missed opportunity for disease prevention.¹⁴

Building buy-in with stakeholders (electeds)

Frequently Asked Questions on NYS Law S7821/A8743: AA and NH/PI Data Disaggregation

The Coalition for Asian American Children and Families (CACF) knows that many community members have questions about the new data disaggregation law NYS [S7821/A8743](#) and why it matters. That's why we've created this list of **Frequently Asked Questions** about the new law to clarify what is in it — and what isn't. Here's why so many of the most prominent Asian American and Native Hawaiian/Pacific Islander (AA & NH/PI) groups in the state have been advocating for this new legislation for years.

What is data disaggregation?

You've probably heard the term "data disaggregation" a lot in recent months, but you might still have questions about what exactly that term means. Data disaggregation is simply the process by which a larger group is broken down into subcategories.

What data disaggregation isn't is a partisan issue. In fact, both Republicans and Democrats — including former President Obama and former President Trump — have called for the disaggregation of Asian American and Native Hawaiian/Pacific Islander data. This bipartisan support is proof that better data is key to better governing, and that treating the AA & NH/PI as a single group is not working.

Asian Americans and Native Hawaiian/Pacific Islanders are not a monolith, but have immense diversity and disparities between groups and within groups. This is especially true when it comes to ancestry, languages spoken and countries of origin. In New York City alone, there are [over 30 ethnic groups and 50 languages](#) represented in the AA and NH/PI community. Most current data collected, however, lumps all of our diverse groups together as a single entity, thereby masking substantial diversity (ancestry and language) and various disparities in our community. Data disaggregation breaks down the data into more granular ethnic and language subcategories that will help identify needs in our community that, for too long, have gone unseen and unaddressed by lawmakers and government agencies. We have been invisible and ignored for far too long.

Building buy-in with stakeholders (NYC + NYS)



Incorporating community voice



Shalanda Young
Office for Management and Budget
1650 17th Street N.W.
Washington, D.C. 20500

Bob Sivinski
Chair, Interagency Technical Working Group
on Race and Ethnicity Standards
1650 17th Street N.W.
Washington, D.C. 20500

April 27, 2023

Submitted via www.Regulations.gov by Lloyd Feng, CACF Special Projects Policy Coordinator

Re: Comments in Response to FR Document 2023-01635, Initial Proposals for Updating Race and Ethnicity Standards

Dear Director Young and Chair Sivinski,

The **Coalition for Asian American Children and Families (CACF)** is writing to respond to the Federal Register Notice published on January 27, 2023, requesting comments on the initial proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards to revise OMB's 1997 Statistical Policy Director No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15).

Successful budget advocacy

Understand the target system

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DEPARTMENT OF HEALTH

STATE OPERATIONS - REAPPROPRIATIONS 2022-23

1 ADMINISTRATION PROGRAM
2
3 General Fund
4 State Purposes Account - 10050
5
6 By chapter 50, section 1, of the laws of 2021:
7 Funds appropriated herein shall be made available to support any state
8 agency, board, or commission that directly or by contract collects
9 demographic data as to the ancestry or ethnic origin of residents of
10 the State of New York in separating demographic data collection
11 categories and tabulations for the following: (1) each major Asian
12 group, including, but not limited to, Chinese, Japanese, Filipino,
13 Korean, Vietnamese, Asian Indian, Laotian, Cambodian, Bangladeshi,
14 Hmong, Indonesian, Malaysian, Pakistani, Sri Lankan, Taiwanese,
15 Nepalese, Burmese, Tibetan, and Thai; (2) each major Pacific
16 Islander group, including, but not limited to, Hawaiian, Guamanian,
17 Samoan, Fijian and Tongan; or (3) other Asian or Pacific Island
18 Groups (59027).
19 Contractual services (51000) ... 3,000,000 (re. \$3,000,000)
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Successful budget advocacy, cont.

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DEPARTMENT OF HEALTH

STATE OPERATIONS 2022-23

1		
2	Contractual services (51000)	1,300,000
3		
4	Funds appropriated herein shall be made	
5	available to support any state agency,	
6	board, or commission that directly or by	
7	contract collects demographic data as to	
8	the ancestry or ethnic origin of residents	
9	of the State of New York in separating	
10	demographic data collection categories and	
11	tabulations for the following: (1) each	
12	major Asian group, including, but not	
13	limited to, Chinese, Japanese, Filipino,	
14	Korean, Vietnamese, Asian Indian, Laotian,	
15	Cambodian, Bangladeshi, Hmong, Indonesian,	
16	Malaysian, Pakistani, Sri Lankan,	
17	Taiwanese, Nepalese, Burmese, Tibetan, and	
18	Thai; (2) each major Pacific Islander	
19	group, including, but not limited to,	
20	Hawaiian, Guamanian, Samoan, Fijian and	
21	Tongan; or (3) other Asian or Pacific	
22	Island Groups.	
23		
24	Contractual services (51000)	1,004,000
25		-----
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Accountability



CONTACT

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