



A Profile of Data Availability

On American Indians &
Alaska Natives in California

*Prepared for the State of California Department
of Health Care Services Epidemiological Workgroup by:*
California Consortium for Urban Indian Health



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The California Consortium for Urban Indian Health, Inc. (CCUIH) is an alliance of Indian Health Service funded Urban Indian Health Programs that supports health promotion and access for American Indians living in cities in California. CCUIH provides centralized management of community health organizing, training and technical assistance, public education and civic engagement, and policy advocacy for UIHPs in California. Our advocacy includes the illumination and improvement of data capacity issues which limit our understanding of issues affecting urban American Indians and Alaska Natives (AIAN).

Despite having the largest population of AIAN in the United States, with 1 in 7 AIAN statewide and 1 in 9 AIAN nationwide living in a California city, our state government has done little to employ epidemiologists or other public health officials to address long-standing and well known racial disparities in health, which continue to be poorly articulated and defined due to racial misclassification, under-sampling and other data capacity issues, particularly among AIAN in urban areas. Additionally, the California Department of Health Care Services (DHCS) State Epidemiological Workgroup (SEW) has not undertaken specific projects related to AIAN data capacity issues even though mis- and under-identification of urban youth substance use issues are leading to under-funding of prevention and intervention services and causing harm to AIAN youth throughout the state.

This brief report articulates these challenges and outlines several proposed recommendations to the DHCS SEW to improve the quality of AIAN substance use data in California such that we are able to effectively partner to plan and respond to this serious issue. We welcome discussion and collaboration with the SEW to respond effectively to improvements discussed herein.

Sincerely,

A handwritten signature in dark ink, appearing to read "V Hedrick", with a long horizontal flourish extending to the right.

Virginia Hedrick, (Yurok) Executive Director
California Consortium for Urban Indian Health

Section 1

Brief Introduction to AIAN Data Capacity Issues

Problems with Historical and Current Data

Public health literature have extensively documented data capacity issues which under-report health conditions and causes of death among American Indians and Alaska Natives (AIAN).^{1,2,3,4,5} Nationwide and particularly in California, AIAN experience the most racial misclassification of any racial/ethnic group, with between 30-60% of health conditions and causes of death for AIAN misclassified as non-AIAN in funding equations and public health policy discussions.^{2,3,6,7} In numerous data sources, AIAN are “invisible” because public health researchers use varying methodologies and definitions to describe individuals who identify as AIAN or AIAN in combination with another race as “other” or “multiple races.”^{4,8} This invisibility is intensified when standard epidemiological practices are employed, such as omission of data due to small numbers, in statewide and national surveys reports and data interfaces. This practice results in a failure to establish reliable measures of public health risk factors and behaviors, including substance use, particularly for AIAN populations.^{4,5} In California’s urban centers where AIAN are often multi-race and “look” like other ethnic groups, racial misclassification and data invisibility of AIAN are particularly problematic.^{2,3,5,6,7,9,10}

There is also limited collaboration and consultation between public health researchers and AIAN data capacity experts.^{7,10,11} Therefore, Urban Indian Health Organizations and Tribal Epidemiology Centers, including the Urban Indian Health Institute, with staff that know how to analyze and adjust for misclassification in AIAN data do not have access to data needed to calculate substance use by urban geographic area.^{7,9,10,11}

¹ National Congress of American Indians (2018). *The state of Tribal data capacity in Indian Country: Key findings from the Survey of Tribal Data Practices*. http://www.ncai.org/policy-research-center/research-data/prc-publications/Tribal_Data_Capacity_Survey_FINAL_10_2018.pdf

² Jim et al. (2014). *Racial misclassification of AIAN by Indian Health Service Contract Health Service Delivery Area*, *American Journal of Public Health*, 104, S295-S302.

³ Jacobs-Wingo et al. (2016). *Causes and disparities in death rates among urban AIAN populations, 1999-2009*, *American Journal of Public Health*, 106, 906-914.

⁴ Urban Indian Health Commission. (2007). *Invisible Tribes: Urban Indians and Their Health in a Changing World*. Seattle: Urban Indian Health Commission. <https://www2.census.gov/cac/nac/meetings/2015-10-13/invisible-tribes.pdf>

⁵ Support Services, International. (1996). *Adjusting for Miscoding of Indian Race on State Death Certificates*.

⁶ Fiscella & Meldrum, 2008. *Race and ethnicity coding agreement between hospitals and between hospital and death data*. *Medical Science Monitor*, 14, SR9-13

⁷ Dankovchik, J. (2014). *Improving AIAN Injury Statistics: Using record linkage to Correct Racial Misclassification in a State Trauma Registry*. *IHS Provider*, 125-130.

⁸ Substance Abuse and Mental Health Services Administration (2012). *Comparing and evaluating youth substance use estimates from the NSDUH and other surveys*. HHS Publication No. SMA 12-472, Methodology Series M-9. Rockville, MD: SAMHSA.

⁹ Duke, Hendrix, & Reaves (2019). *Improving Tribal Nation-specific Mortality Numerators in the South and Eastern Tribes*, *JPHMP*, 25, S44-S47.

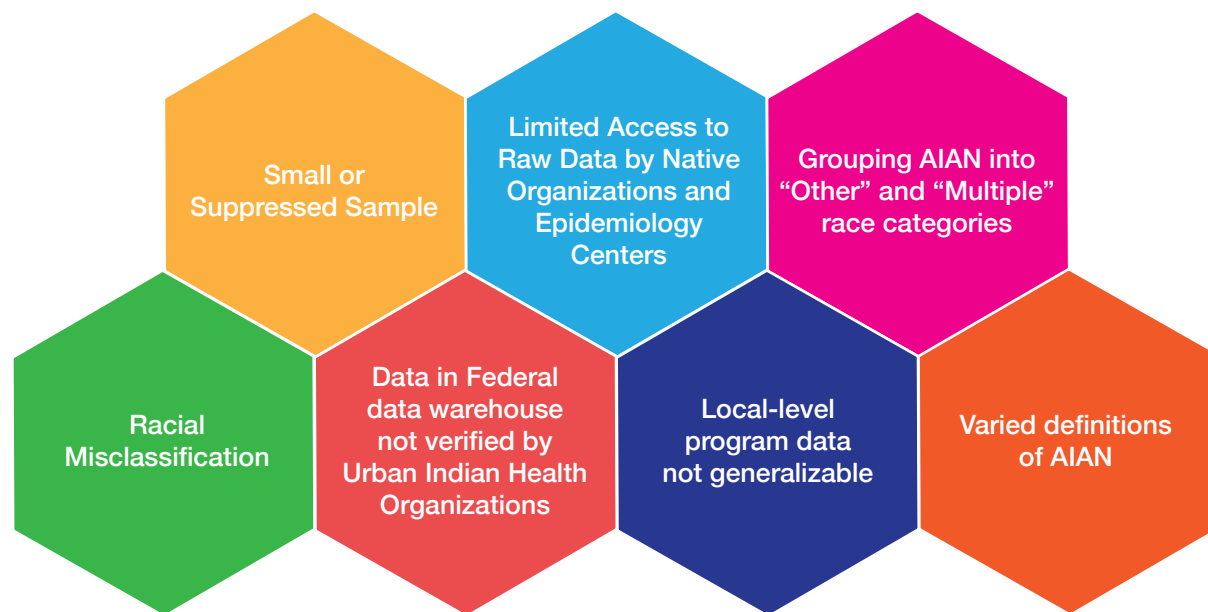
¹⁰ Dominguez & James (n.d.) *Rethinking our approach for urban Indian research*. Washington State Public Health Association: Olympia, WA. <https://www.wspha.org/blog-rethinking-our-approach-for-urban-indian-research>

¹¹ Urban Indian Health Institute. *Community Health Profile: National Aggregate of Urban Indian Health Organization Service Areas*. (2016). http://www.uihi.org/wp-content/uploads/2017/08/UIHI_CHP_2016_Electronic_20170825.pdf

Access to datasets to establish this information comes at a price that must be shouldered by individual organizations working in this area, instead of emphasized as a legitimate need to address health disparities under public health mandate.

Local-level data, including from programs that are funded to conduct needs assessments specific to youth substance use, provide valuable insight into regional youth substance use behaviors and deaths. For example, Substance Abuse Mental Health Services Administration (SAMHSA)-funded Strategic Prevention Framework, Circles and Systems of Care federal grant programs offer Urban Indian Organizations the opportunity to build capacity and partnerships in collecting, analyzing, and disseminating youth substance use data.^{12,13} However, these data are not typically referenced when making statewide data collection, program funding, and policy decisions due to limitations in generalizability.¹⁴ See Figure 1.

Figure 1. Well-Documented AIAN Data Capacity Issues
Barriers to utilization



¹² Systems of Care: <https://www.samhsa.gov/grants/grant-announcements/sm-14-002>

¹³ Circles of Care: <https://www.samhsa.gov/tribal-ttac/circles-care>

¹⁴ PolicyLink (2018). Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health. <https://www.policylink.org/resources-tools/counting-a-diverse-nation>

Section 2






Methods for Gathering Consensus on AIAN Data Capacity Issues and Proposed Recommendations for Practice and Policy

Based on the problems gathering current data to write a county-level Needs Assessment, a California-based Urban Indian Health Program and current SAMHSA Strategic Prevention Framework grantee engaged a consultant to develop and conduct open-ended key informant interviews to assess and gather consensus on AIAN data capacity issues and proposed solutions for practice and policy. A total of nine experts on California AIAN data capacity issues participated in 30-minute interviews about specific data sources and potential practice and policy-based recommendations for improving those data sources so that they can more effectively inform data and intervention focus in AIAN communities. Participants in stakeholder interviews included those from the Centers for Disease Control and Prevention, State of California, national and California-based Urban Indian Health Organizations, and experts in AIAN public health research.

Capacity Issues within Specific Data Sources

An additional layer of AIAN data capacity issues relates to specific state and national data sources and significant variations in barriers to data utilization. Nine experts in California AIAN data capacity issues were interviewed about specific data sources for this brief report. Each data source was discussed in its applicability to AIAN urban youth and substance use. Findings from these discussions are presented in Table 1.

Table 1. Data Sources, Barriers to Utilization, and Potential Solutions

Data Source	Barriers to Utilization	Potential Solutions
Adoption and Foster Care Analysis and Reporting System (AFCARS) data	 <p>May be used to identify children of Indian Ancestry, but data are not related to urban youth substance use.</p>	Utilize AFCARS only for data linkage studies.
California Health Interview Survey	 <p>Small AIAN sample size in years when AIAN were not oversampled, so data may be suppressed/unstable.</p> <p>Telephone interview methodology limits participation.</p> <p>Cannot analyze data by urban area; for some counties AIAN cell sizes require multi-county analysis.</p>	Increase sample size, potentially by oversampling AIAN, conduct in-person or paper-based data collection.
California Healthy Kids Survey	   <p>Schools opt-in to survey; it is not mandatory. AIAN classification or “2 or more races,” meaning AIAN plus other race(s) are invisible in data.</p> <p>Drug use questions are only in the core module and/or Alcohol or Other Drug Modules, and modules are selected at school district’s discretion so there is no comprehensive statewide dataset.</p> <p>Small AIAN sample size so data may be suppressed/unstable. AIAN data cannot be stratified to urban areas.</p>	<p>Increase sample size by requiring schools to participate in data collection.</p> <p>Include substance use questions in all modules.</p> <p>Do not aggregate multiple or other races; allow for stratification by researchers.</p>
California Tribal Behavior Risk Factor Community Survey	   <p>Only measures adult AIAN data; youth data have not yet been released.</p> <p>Sampling methodology not as stringent as Behavioral Risk Factor Surveillance System.</p> <p>The dataset is not available for download or manipulation.</p>	<p>Collect youth substance use and health behavior data.</p> <p>Employ rigorous sampling methodology, including statistically representative sampling across urban and rural geographic areas.</p> <p>Ensure dataset is publicly available for download.</p>
Emergency Department Data	  <p>Racial misclassification high in emergency department data.</p> <p>Race by age data not publicly available, nor are toxicology indicators; must obtain by request.</p>	<p>Conduct data linkages to identify racial misclassification rates and provide adjustment factors calculations for those utilizing the dataset.</p> <p>Ensure datasets are publicly available for analysis.</p>
Indian Health Service Epi Data Mart	  <p>Code of Federal Regulations 42 prohibits health data granted to Tribes and Urban Indian Health Organizations from containing substance use data.</p> <p>Other health data are not verified by Urban Indian Health Organizations and are known to be inaccurate in the field.</p>	Provide verified, accurate substance use data to Urban Indian Health Organizations for analysis and data linkage to Indian Health Service Epi Data Mart data.

Data Source	Barriers to Utilization	Potential Solutions
Local-level Circles of Care and Systems of Care Grant and Program Data	 <p>In-depth local-level information about strengths, needs, and risk factors for AIAN youth substance use.</p> <p>Not generalizable to state and national urban AIAN populations.</p>	<p>Ensure grantees are collecting some consistent open-ended and needs assessment-related data to assist with generalizability of regional and national findings.</p>
Maternal Infant Health Assessment	  <p>AIAN determined by mother's reported race only.</p> <p>No drug statistics, only alcohol and smoking before and after pregnancy.</p> <p>Cannot stratify by both AIAN and age to identify youth mothers in sample.</p>	<p>Determine AIAN by either mother's or father's race.</p> <p>Allow for stratification by both AIAN and age to ensure identification of young mothers in sample.</p>
National Behavioral Risk Factor Surveillance System	  <p>Small AIAN sample size so data may be suppressed/unstable.</p> <p>Definitions of AIAN vary from other national surveys.</p>	<p>Increase sample size or oversample AIAN.</p> <p>Standardize definition of AIAN with consideration of definition(s) of Indian ancestry from AFCARS data.</p>
National Health Interview Survey	  <p>No substance use data. No smoking or drinking data for those under 18 years old, cell suppression due to small AIAN sample size.</p> <p>Definitions of AIAN vary from other national surveys.</p>	<p>Include substance use data in instruments.</p> <p>Increase sample size.</p> <p>Standardize definition of AIAN with consideration of definition(s) of Indian ancestry from AFCARS data.</p>
National Survey on Drug Use and Health	 <p>Small AIAN sample size so data may be suppressed or unstable.</p> <p>In public data sources, cannot reduce to state level by AIAN.</p>	<p>Increase sample size to allow for stratification by state.</p>
National Vital Statistics (death records, mortality data, injury statistics)	  <p>Too few cells to draw comparisons/trends.</p> <p>Extensive AIAN racial misclassification as non-AIAN in datasets and on death records.</p> <p>Cannot stratify data to urban areas.</p>	<p>Require training on race classification for funeral directors and medical examiners.</p> <p>Conduct data linkages to identify racial misclassification rates and provide adjustment factors calculations for those utilizing dataset.</p> <p>Increase sample size to allow for stratification by urban area</p>



Section 3

Proposal for California Department of Health Care Services (DHCS) State Epidemiological Workgroup (SEW)

Overview of SEW

The purpose of the SEW is to “enhance statewide analytical capacity by functioning as an expert data advisory group that recognizes the importance of regular statewide evaluations to monitor and track outcomes.”¹⁵ The SEW is made up of experts in substance use and mental health from DHCS and other state departments, as well as researchers and evaluators from academic and community organizations. Beyond providing guidance on county strategic prevention plans, the SEW is charged with reviewing, analyzing, and reporting trends in substance use and mental health issues that cause harm. The SEW also solicits editorial feedback to the DHCS on the California Healthy Kids Survey, one of the data sources with limitations in AIAN data described above.

Scope of Problem and Proposed Action Steps for SEW

Despite having the largest AIAN population of any state, California has done little to employ epidemiologists or other public health officials to address racial misclassification and other AIAN data capacity issues. To date the SEW has not undertaken specific projects related to AIAN data capacity issues, however, racial misclassification and other data capacity issues could be addressed by the SEW because mis- and under-identification of urban youth substance use issues are leading to under-funding of prevention and intervention services and causing harm to AIAN youth throughout the state. Furthermore, the SEW has access to the developers of the California Healthy Kids Survey and could use its position to advocate for practice and policy changes to statewide, school-based collection of AIAN substance use data.

There are several action steps that the SEW should take to improve the quality of AIAN Data in California:

Changes to SEW

- Make AIAN data capacity issues a focus of the SEW.

- Include representatives from Urban Indian Health Organizations, Tribal Epidemiology Centers, and other Native-serving organizations on the SEW.

- Review existing local-level and grant-funded programmatic data to better understand AIAN youth culture, resiliency, and substance use. Advocate that similar data be included in statewide surveys.

- Require collaboration with Tribes or AIAN organizations in county strategic prevention plans.

¹⁵ <https://www.dhcs.ca.gov/services/MH/Pages/Operations-Branch.aspx>

SEW Requests to DHCS

Request that DHCS formalize partnerships with other state agencies and AIAN data capacity experts to standardized AIAN definitions and data collection methodologies. This should include conferring with the California Department of Social Services about legal definitions of Indian Ancestry utilized in the Indian Child Welfare Act and within Adoption and Foster Care Analysis and Reporting System (AFCARS) data. Discussions should center on self-identification of race and ethnicity across more than 1 category, not collapsing AIAN with other or multiple races, and ensuring Tribally and non-Tribally enrolled AIAN are reflected in all state datasets.

After broadening race categories, have DHCS ask the state superintendent to support for the California Healthy Kids Survey surveying diverse communities and families.

Ensure that DHCS conducts data linkages about racial misclassification in AIAN substance use data and publishes findings and race adjustment factors for DHCS datasets.

Ensure that DHCS funds Urban Indian Health Organizations, Tribal Epidemiology Centers, and/or AIAN researchers to collect statewide survey data from AIAN to increase sample sizes.

Request that DHCS release raw substance use data to Urban Indian Health Organizations, Tribal Epidemiology Centers, and AIAN researchers for public health planning and racial misclassification data analysis projects.

SEW Requests to Other State Departments and Agencies

Publicize standardized AIAN definitions on state websites to promote utilization by non-government (academics, community) organizations.

Ensure dashboards for state surveys include query systems so that people can view data by “Any mention of AIAN” rather than AIAN alone.

Advocate for funding to oversample AIAN and across urban and rural areas throughout California; ensure that oversampling methods for surveys (e.g., California Healthy Kids Survey, California Health Interview Survey) include telephone and in-person interviews.

Ask policy advocates to pass legislation requiring California funeral directors to obtain knowledge and continue education/training about identifying race, Tribal affiliation, and Hispanic status on death records.

Request funding for Tribal organizations to job aides about AIAN people and data; require that state employees receive training about job aides.

Conclusion

This brief report articulates challenges and outlines several proposed recommendations to the DHCS SEW to improve the quality of AIAN substance use data in California. Engagement in ongoing discussion and collaboration with Native-serving organizations will help the SEW to respond effectively to AIAN data capacity challenges and reduce health inequities to AIAN populations across the state. Improvements to the health of AIAN will ultimately lift the health of all Californians, and we challenge the SEW to implement these recommendations immediately.

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