



# Disaggregating American Indian & Alaska Native Data: A Review of Literature



*A Report of the National Congress of American Indians to the Robert Wood Johnson Foundation  
July 2016*

**Abstract:** This report focuses on disaggregation of American Indian and Alaska Native (AI/AN) data and synthesizes academic, policy, tribal, news, and other resources to assess the potential and possibility of disaggregating AI/AN data to improve health outcomes. A literature review and annotated bibliography were conducted and three primary issues of concern emerged affecting efforts to promote AI/AN data disaggregation:

1. Ongoing data quality challenges constrain accurate data disaggregation;
2. Multiple “definitions of Indian” in use by federal agencies impact the utility of disaggregated data; and
3. There are some priority types of disaggregation emphasized in the literature and an emerging set being considered.

**Recommendations** from this review include:

1. Amend existing policies and reporting practices that inhibit disaggregation of AI/AN data;
2. Assess the potential for and impact of federal agency coordination to develop standards for AI/AN data collection and reporting;
3. Equip regional intertribal entities to support the development of tribal data capacity and increase data disaggregation where appropriate; and
4. Invest in tribal data capacity.

**How to Use This Document:** This document is meant to inform community and policy discussions designed to improve the appropriate disaggregation of data to improve AI/AN health outcomes. This report can be used in planning disaggregation policy and coordination.

**Suggested Citation:** NCAI Policy Research Center. (2016). Disaggregating American Indian & Alaska Native data: A review of literature. Washington DC: National Congress of American Indians.

## Introduction

Access to meaningful, quality data continues to be a challenge for American Indian and Alaska Native (AI/AN) communities. Data are essential for developing effective policy and initiatives to generate improved health and other outcomes. One strategy to equip AI/AN communities with better data is to explore the current universe of existing data and to determine whether promoting specific disaggregation could increase access to meaningful, quality data. Disaggregated data are:

“[N]umerical or non-numerical information that has been (1) collected from multiple sources and/or on multiple measures, variables, or individuals; (2) compiled into aggregate data—i.e., summaries of data—typically for the purposes of public reporting or statistical analysis; and then (3) broken down in component parts or smaller units of data”<sup>1</sup>

Data are disaggregated when information is reported for subgroups from a larger aggregate group (e.g., disaggregating a national rate to rates for the 50 states; disaggregating within a state to rates for the counties within that state; disaggregating a national total for racial/ethnic subpopulation estimates). For example, disaggregating national AI/AN data on health outcomes to state-level reports for the 10 states with the largest AI/AN population would provide key insights on strengths and disparities obscured in national reports. Typically, data are disaggregated for a population with distinct status (e.g., racial/ethnic status, disability status), for a language group, or by geography.

With regard to AI/AN people and communities, it may be important to disaggregate data in the following ways:

- **By tribal nation**, to explore cultural and political uniqueness and equip tribal leaders in their planning efforts;
- **By geography**, to explore intra and intergroup differences with regard to statistical areas such as on- and off-reservation, county, state, or region;
- **By demographic characteristics**, to explore differences by age and gender, for instance; and
- **By status**, to explore the impact of group membership such as enrolled or non-enrolled tribal member or Native language speaker or non-speaker.

---

<sup>1</sup> The Glossary of Education Reform, (7/23/2015), Great Schools Partnership. Available at: <http://edglossary.org/disaggregated-data/>.

In some instances, disaggregation can increase access to existing data without much cost as it does not always require new data collection, only new approaches to reporting and sharing existing data in different ways to equip users to conduct more meaningful analyses. In other instances, however, there may be additional costs as new data may need to be collected through various strategies, such as additional questions on surveys, data sharing agreements, and/or tribal permissions to access and use tribal-level data to enable further levels and types of disaggregation.

## **Methods**

The National Congress of American Indians (NCAI) Policy Research Center conducted a literature review of academic, policy, tribal, news, and other source on data disaggregation with American Indian/Alaska Native populations. The literature review focused on six questions:

- 1. What has been published in the academic and policy literature on data disaggregation with American Indian/Alaska Native people?**
- 2. What are the priority issues of concern with disaggregating American Indian/Alaska Native data as stated in academic and policy literature? Are these issues unique to American Indian/Alaska Native people?**
- 3. What demographic or other variables that impact health outcomes are important to collect related to aspects of the American Indian/Alaska Native experience (e.g., generation)?**
- 4. What is the potential and importance of disaggregating data among American Indian or Alaska Native groups, or further within each group, for understanding health outcomes?**
- 5. What are the potential benefits to tribal and American Indian/Alaska Native communities as a result of disaggregating American Indian/Alaska Native data?**
- 6. What organizations could lead and inform work on data disaggregation with American Indian/Alaska Native people?**

The literature review was conducted through an online search of Arizona State University's online library database that includes several online and print resources including books, newspapers, journal articles, dissertations, government documents, and reports. Search terms were used to review relevant literature and "American Indian" and "Alaska Native" was used with the following search terms: data disagg\*(n=1,426 AI; n=468 AN); data aggreg\* (n=733 AI; n=162 AN); and data quality (n=1,072,346 AI; n=223,933 AN). Titles and abstracts with relevance to our six questions were reviewed. The bibliographic references of the top 100 resources selected for analysis were mined to identify other resources. Google and Google Scholar were used to search with the same terms to assure that any major resources available

in the broader universe were not missed. We ultimately compiled a list of 19 academic, 23 policy, and seven media literature resources which are detailed in the attached annotated bibliography. Past work on data quality and improvement at NCAI were reviewed including key policy reports, academic materials, and media literature. Lastly, the draft literature review was distributed to academic, policy, tribal, and data experts familiar with AI/AN data to identify other key resources for inclusion.

## Findings

The literature review findings on disaggregating AI/AN data are summarized for each question posed during the review.

### **1. What has been published in the academic and policy literature on data disaggregation with American Indian/Alaska Native people?**

An annotated bibliography is included as an appendix to this review to summarize seminal texts on data disaggregation and related topics with American Indian/Alaska Native people. While only a few resources were located that were specific to the topic of data disaggregation, a range of others resources were included that provide insights into the possibilities and challenges of producing disaggregated data as a strategy for improving health and other outcomes with Native people. In order to supplement the review of published academic and policy literature, media articles were reviewed and 20 experts were invited to review a draft report to ensure all key resources and highlighted priority topics were included.

### **2. What are the priority issues of concern with disaggregating American Indian/Alaska Native data as stated in academic and policy literature? Are these issues unique to American Indian/Alaska Native people?**

Three primary issues of concern were found to affect efforts to promote AI/AN data disaggregation. These issues are of particular relevance to AI/AN people who are usually considered to be from small populations, who may belong to tribes that have special political status in addition to being from racial/ethnic groups, and for which the inherent relationships between people and land in defining AI/AN populations is important. The three issues of concern found in the literature review are listed as follows:

- Ongoing **data quality challenges** constrain accurate data disaggregation;
- Multiple **“definitions of Indian”** in use by federal agencies impact the utility of disaggregated data; and
- There are some priority **types of disaggregation** emphasized in the literature and an emerging set is being considered.

In addition to these issues, efforts to disaggregate AI/AN data eventually confront the issue and importance of preserving the confidentiality of the individuals included in the aggregate. Also, as the ability to merge traditional datasets with new administrative or private datasets has grown, the issue of individual confidentiality has become more difficult. Another important issue emerges related to group confidentiality when efforts to disaggregate data to the tribal level with tribal identifiers available in a dataset must consider preserving the confidentiality of tribal nations and securing tribal permission to report tribally identified data.

### **Data Quality Challenges**

Before the disaggregation of AI/AN data can become a policy priority, ongoing challenges in **data quality** must first be addressed. There are two major types of issues with data quality cited in the literature: 1) **racial misclassification**; and 2) the **exclusion of AI/AN people and tribal governments**. These issues both contribute to inaccurate counts – with the former affecting the quality of data on individuals primarily and the latter affecting the quality of data on both individuals and organizations. According to the literature, these data quality issues persist due to: 1) differences in self-report of own race; 2) inaccuracies and/or bias in other-report of AI/AN race; 3) a lack of investment in the capacity of tribal, state, and federal governments to collect accurate AI/AN data; and 4) inconsistencies in data collection, reporting policies, and measures.

**Racial Misclassification.** The review of literature found that racial misclassification of AI/AN data is common in health and other datasets, such as hospital discharge data (Bigback, et al., 2015), mortality and cancer registry data (Bauer & Plescia, 2014; Espey, et al., 2014; Hoopes, et al., 2012; Arias et al., 2008; Espey, et al., 2008; Harwell et al., 2002; Rhoades, et al., 2000), child abuse and neglect data (Earle & Cross, 2001), HIV/AIDS reporting (Bertolli et al., 2007), and injury rates (Rhoades, et al., 2000).

The literature clearly documents that when nurses, doctors, funeral directors, child welfare workers, and school staff are required to report race for AI/AN people, they often misclassify race (Bauer & Plescia, 2014; Earle & Cross, 2001). This issue is of particular concern for Native people who are not members of federally recognized tribes or who do not phenotypically present as Native to others. Racial misclassification due to other-report of AI/AN race is complicated by differences in self-report of own race for many AI/AN people. For example, some individuals may opt to identify only with their AI/AN heritage though they may also have heritage from other race(s), while others may choose to claim all their races. Some research has documented that self-reporting of AI/AN identity is significantly less stable over time (by the same person) than self-reporting of several other racial identities, including White and Black (Liebler, et al., 2014). As an example of how complicated this identification can become, Native people in Alaska may choose to identify as an Alaska Native, as a member of a particular tribe or village, with their Alaska Native Claims Settlement Act (ANCSA) Region, or all of the above. Beyond AI/AN racial misclassification, there is also a paucity of vital statistics

collection and reporting at the tribal level inhibiting the calculation of basic life tables for tribal populations (Rodriguez-Lonebear, 2016).

The reviewed literature suggests a range of strategies and solutions to reduce racial misclassification. Bauer & Plescia (2014) provide a summary of several efforts to link Indian Health Service (IHS) patient registration records with mortality and central cancer registry data to reduce racial misclassification. Espey et al., 2008, discuss results of efforts to link IHS data with cancer registry records that demonstrate regional differences in racial misclassification of AI/AN people in cancer registries—with Alaska having the lowest rates of racial misclassification and the Southern Plains the largest. Espey, et al., 2014, describe the efforts to match IHS registration records with records from the US National Death Index to quantify the prevalence of AI/AN death misclassification and cite regional differences in racial misclassification—with the lowest levels in the Southwest and Alaska and the highest in the Southern Plains and East. Bigback et al., 2015, suggest that linking state health records with data from tribal health registries can improve data quality. Plans are in place to integrate Agency for Healthcare Research and Quality (AHRQ) and IHS data (National Patient Information Reporting System – NPIRS – and Healthcare Cost and Utilization Project - HCUP) to provide national estimates of hospital discharge data for AI/AN people. Data linkage strategies are being strengthened by investments in electronic health records across IHS and tribal health clinics. Yet, even when there is sufficient infrastructure to support data linkage, there are a number of policy and practice implementation barriers to enabling the linking of data for AI/AN populations.

For example, the revision and extension of the Indian Health Care Improvement Act (S.1790) within the Patient Protection and Affordable Care Act (P.L. 111-148) designated Tribal Epidemiology Centers (TEC) as public health authorities under the Health Insurance Portability and Accountability Act (P.L. 104-191, 110 Stat. 1936, enacted August 21, 1996). This designation authorized TECs to access public health data held by the US Department of Health and Human Services. However, some TECs report difficulty accessing state data due to state data capacity issues and access fees. Further, “variation in state vital statistics and state disease registry data collection practices” constrains the impact TECs have on public health surveillance with AI/AN communities across a multi-state region (TEC, 2013, p. 125). In another case, state-level data on child abuse and neglect is hosted in the National Child Abuse and Neglect Data System (NCANDS), created through a 1988 amendment of the 1974 Child Abuse Prevention and Treatment Act (CAPTA). Yet, it was not until the passage of the Indian Child Protection and Family Violence Prevention Act of 1990 that child abuse and neglect reporting requirements were established for tribal nations, and passage of the act did not result in implementation resources for tribal data collection and reporting policies or training (Earle & Cross, 2001). Further, tribal data is not entered into the NCANDS database, and there is no system for national tribal data reporting on child abuse and neglect.

In addition to data linkage, some research suggests implementing Sections 4301 and 9007 of the Patient Protection and Affordable Care Act to include self-reported information as part of federal data collection efforts (Bauer & Plescia, 2014). Others suggest that instituting uniform race reporting across states and health care facilities can help with misclassification (Bigback et al., 2015; Moy et al., 2006). Local government partnership between tribes, counties, and cities could also facilitate better reporting of race and tribe, especially on death certificates.

***Exclusion of AI/AN People and Tribal Governments.*** Data quality is also constrained when AI/AN people are not included in datasets and therefore data are not available for analysis and reporting. Federal agencies and other entities cite a number of reasons as to why Native people and tribal governments are excluded in federal and other data, such as the costs to recruit a large enough sample due to the small and hard-to-count nature of the AI/AN population and the geographically dispersed nature of the AI/AN population.

Large national studies that intend to recruit a large sample of AI/ANs must face challenges inherent in conducting community-based and tribal participatory research with multiple tribes, including coordinating tribal research review and data ownership policies across multiple tribal communities. Recruiting a nationally representative sample of AI/AN people would mean working with tribal communities across the country, but research that proceeds community-by-community with close partnership at the community level is hard to conduct on a national scale. Yet, recent federal policy, such as the National Institutes of Health Policy on the Use of a Single Institutional Review Board of Record for Multi-Site Research, discourages engagement with multiple tribal and local research oversight processes. These types of policies illustrate the need to invest time and financial resources in strengthening tribal data infrastructure and to embrace the uniqueness of tribal governments, especially given the federal trust responsibility to steward the needs of the AI/AN population.

The National Congress of American Indians has expressed concern that AI/AN people exist as the “Asterisk Nation” in national studies because AI/AN populations are often described as “too small to be included,” “too difficult to enumerate,” or “too costly to be sampled appropriately.” For example, the National Academies Press released a volume in 2016 entitled, “Framing the Dialogue on Race and Ethnicity to Advance Health Equity: Proceedings of a Workshop” that has one small mention of AI/AN people in its 90 pages.<sup>2</sup> Also, AI/AN people were ultimately not included as a subsample in the National Children’s Study and in the Population Assessment of Tobacco and Health Study (PATH). The head of the Federal Drug Administration described the PATH study as “signal[ing] a major milestone in addressing one of the most significant public health burdens of the 21st century”—and one that most certainly has cultural significance to

---

<sup>2</sup> See <http://www.nap.edu/catalog/23576/framing-the-dialogue-on-race-and-ethnicity-to-advance-health-equity>.

Native people. Tribal nations cannot afford to be excluded in national studies because of their status as small populations.

In another case, NCANDS includes data on AI/AN children only when state or county child protective services workers have the authority in terms of jurisdiction to investigate a reported case, which is estimated to be only 60 percent of all cases (Earle & Cross, 2001). P.L. 280 states where jurisdiction is shared, tribal-state agreements determine that jurisdiction. Data collected by the Bureau of Indian Affairs (BIA) alone on child abuse and neglect, and not by states or counties, are not entered into the national counts of child abuse and neglect.

A study of the gaps in data for AI/ANs in the 2004 National Health Care Disparities Report (NHCDR) found that only 42 percent of the 149 measures tracked related to health care quality could be used to assess disparities in AI/AN populations. Gaps in the AI/AN data vary by the type and source of data because the 2004 NHDR uses multiple sources with various levels of collection, estimation, and/or power issues (Moy et al., 2006). Studies like this also suggest that variation in measurement or indicator definition across federal agencies or states can contribute to exclusion of AI/AN people and poor data quality.

Federal policy often creates and encourages the exclusion of AI/AN people in national and other studies. A range of standards established by the Office of Management and Budget have had some of the largest impacts on these policies. The *American Indian Population & Labor Force Report* (Report) is an example of how policies lead to concerns over the quality of the data provided by tribal nations. The Secretary of the Interior, in consultation with the Secretary of Labor, is statutorily required to publish, not less than biennially, a report that includes gender-specific information on the population eligible for services provided to Indian people by the Secretary of the Department of the Interior (DOI).

The Report is required to include, at a minimum, information at the national level by state, at the Bureau of Indian Affairs Service area, and at the tribal level for the following measures: total service population; service population under age 16 and over 64; population available for work, including those not considered to be actively seeking work; employed population, including those employed with annual earnings below the poverty line; and numbers employed in private sector positions and in public sector positions.

The Report was enacted in Section 17 of Public Law 102-477 in October of 1992, as amended (codified at 25 U.S.C. 3416) and was mandated by the Indian Employment, Training and Related Services Demonstration Act of 1992 (“Act”). The Act allows Indian tribes to integrate federally-funded employment, training and related services programs provided by the Departments of the Interior, Labor, Education, and Health and Human Services. The last Report issued by DOI that included tribally-reported data was provided to Congress in 2007 for the year 2005.



Following a collection of survey data in 2010, it was determined and reported by the Department of the Interior that the planned 2012 Report could not be issued due to inconsistencies and inaccuracies in the survey data<sup>3</sup>. The Department of the Interior's Bureau of Indian Affairs issued a Notice of Informational Sessions and Tribal Consultation Sessions on October 11, 2012, (77 Fed. Reg. 61780) seeking comments on proposals designed to prepare the American Indian Population and Labor Force Report to meet DOI's 2013 deadline.

Data from this Report are used to develop economic policy approaches to address the unique demographic and labor force contexts in tribal contexts that other Department of Labor (DOL) and US Census Bureau measures do not capture. Specifically, the Report's measure of "joblessness" – or "the population available for work, including those not considered to be actively seeking work" – is not currently captured by other federal data collection efforts and is the most cited aspect of the Report. These data are used to inform the Congress' policymaking, serve as the subject of a Senate Committee on Indian Affairs hearings and are regularly used in hearings by the House and Senate. They are also used locally for planning and program purposes to identify appropriate economic development approaches and gauge particular community needs and resources.

Any significant changes to data collection and any non-reporting of data impacts the ability of tribal governments to adequately provide for their citizens, and negatively impacts the ability of the federal government to carry out its trust responsibility for essential social and economic services. While DOI has traditionally relied on tribes to provide data for this report, concerns were raised by the federal government about the quality of data provided by tribes; yet, there were no subsequent discussions about investing in strengthening tribal capacity to collect these data. Referencing the Office of Management and Budget's data quality standards and concerns over the quality of data reported by tribes, DOI produced its 2013 Report using data collected from individuals on the Census' American Community Survey (ACS). These data were aggregated, where possible, to tribal levels specified by the U.S. Census Bureau and often were different from official tribal government groupings.

In addition, tribal nations and data experts have raised extensive concerns about the quality of ACS data in enumerating AI/AN populations. For instance, undercounting of AI/AN people is a major issue in major federal efforts such as the American Community Survey. Undercounting AI/ANs disproportionately affects those living on or near

---

<sup>3</sup> See the 'Dear Tribal Leader Letter' sent from DOI on July 2, 2012, at <http://www.bia.gov/cs/groups/public/documents/text/idc-019173.pdf> and the Powerpoint Presentation made at the NCAI Annual Convention on October 24, 2012, in Sacramento, CA, at <http://www.bia.gov/WhoWeAre/AS-IA/Consultation/IDC-024546.html>

reservations and AI/AN youth, who make up a large proportion of AI/AN people nationally and in certain states. Analyses by Deweaver (2013a, 2013b, 2013c, 2010) suggest that these undercounts may be due in part to the smaller reach in the sampling approach used by the American Community Survey as compared to the broader sampling used in the decennial Census for 2000 and prior years. Other analyses by UCLA researchers Ong & Ong (2012) suggest there may also be weighting issues in the sampling approach used to convert the sample into estimates that result in undercounting of AI/ANs.

These undercounts have serious impacts since ACS data are used as part of the distribution of over \$400 billion in federal and state funds each year (Ong & Ong, 2012), some of which the federal government has a trust responsibility to provide to tribal nations. In 1996, President Clinton signed the Native American Housing Assistance and Self Determination Act, which provided a method for tribes to submit their own population counts to challenge Census undercounts. More accurate data that mitigates undercounting could amount to higher federal funding for tribes for housing that better meets the needs of their people (The Associated Press, 2003). For example, the Cheyenne River Sioux Tribe created their Tribal Ventures Poverty Reduction Plan and the tribe's effort to collect its own data emerged in part because Census ACS data are typically collected over the phone and many tribal members do not have phone service (Wascalus, 2016).

As stated in statute, this Report is the responsibility of the DOI. It is also an essential mechanism for monitoring the quality of services that DOI is responsible to provide to AI/AN people. DOI's 2012 request for comments on the Report included questions about the possibility of using U.S. Census data on unemployment rather than tribal data on joblessness in order to improve data quality and consistency, especially given the Office of Management and Budget's data quality standards. Tribes should not be held responsible for a lack of federal agency coordination around the issue of data quality and the measurement of small populations. Specifically, greater coordination is needed between DOI, DOL, U.S. Census Bureau, and the Office of Management and Budget (OMB) to address the widespread problems that plague data collection for Indian Country. In 2012, NCAI summarized these concerns and put forward a range of recommendations in its official comments filed in response to the DOI's request for comments (see [http://www.ncai.org/policy-research-center/initiatives/NCAI Comments to the AIPLF Report.pdf](http://www.ncai.org/policy-research-center/initiatives/NCAI%20Comments%20to%20the%20AIPLF%20Report.pdf)).

Changes in the way the U.S. Census Bureau collects data complicate any efforts to use tribal data to improve the quality of Census data. The decennial census has been a major source of information on the labor force characteristics of the on-reservation American Indian population. Through and including the 2000 census, the Census provided data on employment and unemployment, along with educational attainment, income and other socio-economic characteristics of the population, by race, down to the reservation level. This socio-economic characteristics data was gathered through the

use of a "long form" census questionnaire distributed to a sample of households. In reservation areas, the sample size was one in every two households, which was an attempt to make the data as representative as possible of the total reservation population.

In 2010, the U.S. Census Bureau discontinued the use of the "long form" questionnaire in the decennial census. Instead, all households received a "short form" questionnaire that asked only for basic information on age, sex, race, ethnicity (Hispanic origin) and relationship to other household members. No labor force information was collected.

The U.S. Census Bureau currently collects data on the socio-economic characteristics of the population through the ACS. The ACS, like the decennial census before it, uses the standard definitions of labor force status, including the requirement that a person must have actively sought work in the previous 4 weeks in order to be counted as unemployed. The ACS is designed to collect the same detailed information that was collected on the "long form" questionnaire. However, the ACS is different in a number of key areas that constrain AI/AN data quality:

- The ACS is a smaller survey, collecting data from fewer households;
- Unlike the "long form," used once every ten years, the ACS is an ongoing survey. It mails questionnaires to a sample of households throughout the US every month. The responses from various geographic areas are aggregated over periods of one and five years, depending on population size, weighted and extrapolated to the estimated total population in that particular area;
- Data is published annually on the labor force status of the AI/AN population, but figures for all reservation areas are available only from the 5-year estimates series. This series aggregates responses over a 5-year period, which is an approach designed to compensate for the potential for error that results from the small sample size. However, this approach obscures year-to-year changes in the levels of employment and unemployment. Further, the 5-year estimates are only valid for small populations of 20,000 or less, which includes the vast majority of tribal communities; and
- There is no major outreach and promotion campaign to make people aware of the ACS and its importance, unlike the major outreach efforts that accompany the decennial Census.

Another policy that impacts the quality of AI/AN data is the *US Department of Education 2007 Guidance on OMB Racial Classifications* (<https://www.gpo.gov/fdsys/pkg/FR-2007-10-19/pdf/E7-20613.pdf>). While the US Department of Education (USDOE) will continue to collect data on AI/AN students whether or not they report a racial/ethnic status that is in combination with other racial/ethnic groups (e.g., Hispanic/Latino, White), the

USDOE will only report AI/AN specific data for students who indicate they are not Hispanic/Latino ethnically and select only AI/AN as their race. AI/AN students who indicate that they are also Hispanic/Latino ethnically will only be reported in the Hispanic/Latino category. Regardless of whether they indicate Hispanic/Latino ethnicity, AI/AN students selecting an additional racial category will only be reported as multiracial.

The effect is major and detrimental at local, state, and national levels as AI/AN communities have historically relied on USDOE data as a quality source of information for planning and development efforts (see the 2012 NCES STATS-DC Presentation prepared by NCAI and NIEA at [http://www.ncai.org/policy-research-center/initiatives/STATS-DC\\_2012\\_070612.pptx](http://www.ncai.org/policy-research-center/initiatives/STATS-DC_2012_070612.pptx)). There is a similar problem with the use of redistricting data after each decennial census. If the U.S. Census Bureau make Hispanic ethnicity equivalent to a race in the 2020 Census, this could have a dramatic effect on the counts of the AI/AN population, especially in a number of large metropolitan areas.

The USDOE has data that it can disaggregate for AI/AN alone, AI/AN in combination with other ethnicities and races, and AI/AN alone and in combination similar to the U.S. Census Bureau data, but it has opted not to do so. Policies such as these defy the Executive Order of May 9, 2013, *Making Open and Machine Readable the New Default for Government Information* (available at: <https://obamawhitehouse.archives.gov/the-press-office/2013/05/09/executive-order-making-open-and-machine-readable-new-default-government->) in which President Obama directed OMB to establish an Open Data Policy (available at <https://www.whitehouse.gov/sites/whitehouse.gov/files/omb/memoranda/2013/m-13-13.pdf>). The Open Data Policy Memorandum “establishes a framework to help institutionalize the principles of effective information management at each stage of the information's life cycle to promote interoperability and openness...Specifically, this Memorandum requires agencies to collect or create information in a way that supports downstream information processing and dissemination activities.” The USDOE policy does not support downstream information processing or dissemination activities in AI/AN contexts.

While it is essential address the inclusion of AI/AN individuals to promote data quality, it is also important to consider how the exclusion of tribal governments from federal and other data collection efforts impacts data quality. For example, the Census of Governments (mandated by 13 U.S.C 161) is conducted every five years and includes data from over 90,000 governments; however it has never collected data from tribal governments.

NCAI has submitted comments calling for U.S. Census Bureau consultation with tribes to include tribal nations as governments in this critical data report. These comments emphasized that the public sector in Indian Country is an important aspect of tribal

economies. Tribal governments are responsible for a broad range of governmental activities on tribal lands, including education, law enforcement, judicial systems, health care, environmental protection, natural resource management, and the development and maintenance of basic infrastructure such as housing, roads, bridges, sewers, public buildings, telecommunications, broadband and electrical services, and solid waste treatment and disposal. Like state and local governments, tribal governments use their revenues to provide essential services for their citizens. Yet, unlike state governments, tribal governments are generally not in a position to levy property or income taxes because of the unique nature of land tenure in Indian Country, fragile economies, and jurisdictional restraints. Income from tribal businesses is the primary non-federal revenue source for most tribes. Sales and excise taxes are becoming an increasingly important source of revenue for tribal governments. Data to describe tribal government economic activity – collected and reported with the permission of tribes – would assist tribal leaders and other decision-makers to better plan, develop budgets, and understand the role of the public sector in Indian Country. The U.S. Census Bureau response to NCAI comments dated July 15, 2016, reads:

“Thank you for your recent comments in response to our Federal Register notice regarding the Census of Governments. As I am sure, you are aware, Tribal governments have not been included in the Census of Governments since its inception in 1952. As a result, the inclusion of tribal governments would necessitate significant start-up costs in addition to increased operational costs. Unfortunately, we currently do not have adequate resources to consider such an undertaking at this time. We would certainly be open to including Tribal governments in future Censuses if adequate funding were to be made available. We definitely agree that there is currently a lack of comprehensive statistics on Tribal governments, and the Census of Governments could potentially provide a vehicle to fill that void. If, at some point in the future, resources are made available for this purpose we would be more than happy to work with you, and your organization to collect statistics on Tribal governments.”

However, other federal agencies have been responsive to the input from tribes for better AI/AN data quality. USDA’s Census of Agriculture was expanded beginning in 2007 to include data on individual American Indian farmers on reservations in addition to reporting reservation total data. Also, the Administration for Children and Families has attempted to improve efforts to include AI/AN people in their programs such as their effort to fund a national study of tribal Head Start programs in 21 AI/AN communities, which includes 900 children and families served by tribal Head Start, as well as to improve AI/AN early childhood by supporting a process to generate three designs for carrying out an assessment of early childhood developmental and service

needs on a national scale<sup>4</sup>. Thus, there are some good examples of federal agencies working to include AI/AN data in meaningful ways that could serve as a starting point or model for others where there is a clear benefit to including AI/AN data in federal and other data collection efforts.

There are emerging efforts to improve business and economic data at tribal, county, and state levels to aid in planning, which has been a huge need over time and can help increase the types of disaggregated data available to tribal nations and other entities. Efforts to include tribal governments must also contend with confidentiality issues and tribal permissions for reporting at a tribal level, especially given “sunshine” guidelines in place that set an expectation for public access and data sharing for data collected using public dollars. Tribal sovereignty over data collected on tribal lands and from tribal citizens and reported at a tribal level must be honored.

Exclusion of AI/AN people from data occurs due to non-collection, non-reporting, and non-linking of AI/AN data at the individual and tribal levels. Exclusion of AI/AN people in these ways due to federal policy is an abrogation of the federal trust relationship with tribal nations. It contributes to poor data quality and hampers communities in their need to access key information and quality data to guide their planning.

### **Definitions of Indian**

How an AI/AN individual is defined by the federal government can cause devastating challenges for how they may or may not be eligible for certain services and resources. Yet multiple definitions exist in statute and policy of who is “Indian” from the perspective of the federal government. Multiple **definitions of Indian** in use by federal agencies impact the utility of disaggregated data because the variation in definitions makes it difficult to develop appropriate comparisons or data linkages. Further, these practices by federal agencies are often used by states and local governments, as well as by private organizations collecting and hosting data.

Defining AI/AN people in policy and law is a complex task, especially given the distinction between the status of AI/AN people as a racial group and as a group with unique political status. While race was once defined by others on the basis largely of phenotype, now it is for many purposes a matter of self-identification. For example, the AI/AN population count increased as measured by the U.S. Census following the change in the 2000 Census which allowed individuals to self-report more than one race.

Political status, however, is determined by more than how an individual chooses to identify or self-report their own race. Some AI/AN scholars have put forth preferred

---

<sup>4</sup> See

[http://www.acf.hhs.gov/sites/default/files/opre/aian\\_ec\\_needs\\_assessment\\_design\\_revised\\_public\\_report\\_clean\\_041816.pdf](http://www.acf.hhs.gov/sites/default/files/opre/aian_ec_needs_assessment_design_revised_public_report_clean_041816.pdf)

definitions for use in research, such as “those individuals who both proclaim indigenous identities and who maintain affiliation with enduring tribal communities in the United States”<sup>5</sup> Further, defining AI/AN people is often done in relation to land and geography because population estimates are used to fund tribal governments, service programs, and other community institutions. And while the U.S. Census has emerged as the best source of data on the AI/AN population, the first U.S. Census was actually preceded by the American Indian Nations Census, designed to enumerate tribal nations.

The revisions to OMB Statistical Directive No. 15 in 1997 were a watershed in the publication of U.S. Census Bureau data on the AI/AN population. They provided an opportunity for an individual to identify as AI/AN in combination with another race. This increased the size of the total AI/AN population by roughly 1.64 million in 2000 over what it had been in the 1990 decennial census. It led to two radically different Census figures for the size of the AI/AN population. Although the revisions did not substantially change the counts of the African-American population or others, the changes made a very significant change in the size of the AI/AN and Native Hawaiian and Other Pacific Islander (NHOPI) populations.

In analyzing the Census data for the AI/AN population, there are important differences between the characteristics of the AI/AN only (“alone” in Census terminology) and the AI/AN multi-racial (“in combination” in Census terminology) populations. Over 90 percent of the multi-racial population lived in areas other than reservations, former reservation areas in Oklahoma, and Alaska Native villages in 2010. There are also substantial differences in the characteristics between the AI/AN “alone” and the AI/AN multi-racial “in combination” group, particularly with respect to educational attainment and poverty status. Use of the AI/AN “alone” and “in combination” group data together obscures these differences.

The history of the “Indian count” and other population counts in the U.S. helps understand the current issues with the multiple definitions of Indian and federal data. While the terms “Indian” and “Black” were used at a different time in federal policy, these are not the terms commonly used to refer to AI/AN and African American people today. Understanding the history of federal definitions, even those that are no longer commonly used in federal counts, is important background information to understand the importance of disaggregating data.

The U.S. Constitution requires the U.S. Census because population counts enable key government functions including establishing a tax base to raise revenue, allocating Congressional seats, counting electoral votes, and allocating government resources. For example, Rhode Island and New York State have a different number of members in the U.S. House of Representatives due to the differences in their population counts. The official population estimate used to allocate each state’s number of U.S.

---

<sup>5</sup> See Gone, J. P., & Trimble, J. E. (2012). American Indian and Alaska Native mental health: Diverse perspectives on enduring disparities. *Annual Review of Clinical Psychology*, 8:131-160.

Representatives is determined by the U.S. Census. Similarly, each state's tax base differs by the size of its population. In addition to apportionment and taxation, population data is also needed to plan and evaluate government spending. U.S. Census data is further used to monitor and enforce compliance with civil-rights statutes and anti-discrimination laws. Consequently, U.S. Census data affects participation in government, determines the scope of government responsibility, and provides data for spending plans and accountability.

The relationship between the U.S. Census and government responsibility and/or accountability is complicated by the fact that all people have not always been counted equally. For example, the original wording the clause of the U.S. Constitution requiring a decennial census was as follows:

“Representatives and direct Taxes shall be apportioned among the several States which may be included within this Union, according to their respective Numbers, which shall be determined by adding to the whole Number of free Persons, including those bound to Service for a Term of Years, and excluding Indians not taxed, three fifths of all other Persons. The actual Enumeration shall be made within three years after the first meeting of the Congress of the United States, and within every subsequent term of ten years, in such manner as they shall by law direct.” (US Constitution, Article 1, Section 2, Clause 3)

Historically, “all other Persons” who were neither free nor indentured were counted as 3/5 of a person. At the time the Constitution was written, only Black people were neither free nor indentured; therefore only Black people were counted as 3/5 of a person. Indians (AI/ANs) were not counted and may not have been counted because they were not considered persons under U.S. law. Today, and as early as 1763<sup>6</sup>, tribes are recognized as pre-U.S.-Constitutional sovereigns. Consequently, at best, “Indians not taxed” referred to those Indians living as subjects of their own tribal authorities<sup>7</sup>, but certainly outside of U.S. authority. They would not be recognized as U.S. citizens for taxation and representation in Congress. Therefore, there was no Constitutional reason to enumerate Indians in a national census. By not considering Indians as persons and in counting Black slaves as 3/5 of a person, the census was constitutionally limited, effectively lowering population counts and reducing the scope of federal government responsibility, and limiting political representation as a matter of law.

---

<sup>6</sup> See, The British Proclamation of 1763; Act of July 22, 1790, ch 33, sec 1, 1 Stat 137 (current version at 25 U.S.C. sec 1777 (2000)), also known as the Trade and Intercourse Act; American Indian political status affirmed and detailed in *Johnson v. M'Intosh* 21 U.S. (8 Wheat.) 543 (1832); and political status as implemented in Indian treaties, Congressional legislation, and additional federal authority.

<sup>7</sup> Fletcher, Matthew, L.M., “The Original Understanding of the Political Status of Indian Tribes,” *St. John's Law Review*; Winter 2008; 82, 1; linking the US decision to recognize Indian tribes as political entities and make law based on political status to Indian lands dispossession when the US could have cleared title through political channels rather than through transactions with individual Indians.



At the time the U.S. Constitution was drafted and long after, political status as a “free Person” or as an “Indian not taxed” followed racial lines. Persons could be identified visually in three Constitutional political categories as White, Black, or Indian according to specific physical traits, such as skin color and hair texture, in order to gauge or assign their political status. This was the first official instance of the other-report (identification by someone other than the individual) that continues to contribute to racial misclassification today. The meanings attached to the physical traits changed over time, affecting the stringency of political status recognition and enforcement.<sup>8</sup>

The genealogically estimated quantity of Indian or Black blood, a metonym for race and political status, was also employed to legitimize or revoke political status. Thus, implicit racial identification usually determined each individual’s explicit political status; but not always. Early census counts enumerated people to meet the needs stated in the U.S. Constitution, so the national census also employed the Constitutional categories conflating racial identification with political status. However, absent a legislative definition of “Indians not taxed”, blood quantum protocols were administratively incorporated into early census instructions and definitions, effectively disconnecting racial identification and the unique political status of Indian people.

In the 1846 appropriation bill funding the Indian Department, Congress directed Indian agents to take a census of Indians and to gather any information required by the Secretary of War.<sup>9</sup> Between 1884<sup>10</sup> and 1940, annual counts of “Indians not taxed” were undertaken to various degrees by reservation agents, and tribal rolls<sup>11</sup> were provided annually to the Commissioner of Indian Affairs. As western expansion reached the Pacific and U.S. Indian policy shifted from removal to forced allotment, better data and narrower racial criteria served to fulfill U.S. land ownership goals. To achieve these goals efficiently, the U.S. needed an accounting of the number of Indian people. The Indian rolls were the first to employ fractional blood quantum in the enumeration of Indian people.<sup>12</sup> The decennial census was inadequate for the purpose of counting the number

---

<sup>8</sup> See for example, Holtje, Kirstin Jane, “Race and Indian Policy in the Jeffersonian Era” tracing the devolution of Indian status from Jefferson’s written beliefs (1782) that Indians are equal to Europeans (differing only in “circumstance”) to “scientific” and popular White belief in Indian racial inferiority by 1840. See also, Berkofer, Robert, F., “The White Man’s Indian: Images of the American Indian from Columbus to the Present” discussing how changes in images of Indians served as “ideological weapons” in subjugation; and Williams, Robert A., “The American Indian in Western Legal Thought: The Discourse of Conquest”, New York: Oxford University Press (1990).

<sup>9</sup> An act making appropriations for the current and contingent expenses of the Indian Department, 1846

<sup>10</sup> (23 Stat. 98), July 4, 1884.

<sup>11</sup> Garrouette, Eva Marie, “The Racial Formation of American Indians,” *American Indian Quarterly*, (Spring 2001), p.25. “Historians agree that the process by which many tribal rolls were initially compiled was almost unbelievably complicated.” Many Indian people resisted individually and collectively further complicating counts by tribe.

<sup>12</sup> See for example, M. Annette Jaimes, “Federal Indian Identification Policy,” tracing the federal government’s standard of blood quantum to the 1887 Dawes Act wherein Indians were required to prove ½ or greater degree of Indian blood to qualify for an allotment of their tribal estate.

of Indian people subject to federal policies because the census was not timely and it specifically did not count Indians with the “not taxed” political status until 1890.

The 1860 U.S. Census was the first to officially estimate the number of American Indians and was the first to begin decoupling race and political status. The 1860 census did not include a “color” classification for Indians. Indians counted in the 1860 census were not U.S. citizens, nor would they have been considered “persons” under law until 1879. By the time of the 1870 census, there was still no Constitutional standard for “Indians not taxed” except, for census purposes, the category applied to “Indians maintaining their tribal relations and living upon Government reservations.” The Census thus produced counts of Indians “out of tribal relations.”

An 1872 report to Congress on the 1870 Census acknowledged that the census should enumerate Indians as a “constituent part of the population of the country” because the data are used for both apportionment and other political purposes.<sup>13</sup> The detailed data provided in the 1870 census included estimates of the total populations on reservations and those maintaining a “nomadic” lifeway, and provides “enumerated” as well as “estimated” numbers for each category.

The 1880 decennial census was the first to be taken when Indians were considered persons under U.S. law, though, in the same year, the Bureau of Indian Affairs also completed a count of “Indians not taxed” or agency Indians.<sup>14</sup> The decennial census introduced the “Special Indian Schedule” produced specifically for the Indian Division in order to distinguish between full-blood tribal members and people of mixed race or tribe but did not enumerate differently based on blood quantum alone.<sup>15</sup> There is

---

<sup>13</sup> “Now the fact that the Constitution excludes from the basis of representation “Indians not taxed” affords no possible reason why, in a census which is on its face taken with equal reference to statistical as to political interests, such persons should be excluded from the population of the country. They should, of course, appear separately, so that the provisions of the Constitution in regard to the apportionment of Representatives may be carried out; but they should appear, nevertheless, as a constituent part of the population of the country viewed in the light of all social, economical, and moral principles.” *Ninth Census—Volume I, The Statistics of the Population of the United States*, p. xvi.

<sup>14</sup> U.S. Congress, *The Miscellaneous Documents of the House of Representatives for the 1st Session of the 52nd Congress, 1891–92*, serial set volume 3016, pp. 17–24.

<sup>15</sup> The instructions for the 1880 census include a definition for “Indians not taxed” and expanded how Indians were to be counted: “By the phrase ‘Indians not taxed’ is meant Indians living on reservations under the care of Government agents, or roaming individually, or in bands, over unsettled tracts of country. Indians not in tribal relations, whether full-bloods or half-breeds, who are found mingled with the white population, residing in white families, engaged as servants or laborers, or living in huts or wigwams on the outskirts of towns or settlements are to be regarded as a part of the ordinary population of the country for the constitutional purpose of the apportionment of Representatives among the States, and are to be embraced in the enumeration.” The 1890 Census altered the definition, “An Indian is considered to be “taxed” if he or she is detached from his or her tribe and living among white people as an individual, and as such subject to taxation, whether he or she actually pays taxes or not; also if he or she is living with his or her tribe but has received an allotment of land, and thereby has acquired citizenship; in either of these two cases the answer to this inquiry is “Yes.” An Indian on a reservation,

significant evidence to suggest that Indian people refused to participate in the 1880 census.<sup>16</sup> Non-participation and distrust at this time in particular makes sense since between the 1870 and 1880 census, treaty making was abolished (1871), the Indian Police Force was created (1878), and “Civilization Regulations” outlawed Native religions, healing practices, and leaving of reservations (1880).

The 1890 Census was the first to tabulate data by machine and also the first census to have a congressional permission to enumerate Indians.<sup>17</sup> Consequently, the 1890 census is the first census to estimate the total number of Indians within the US. Conveniently, 1890 census did not have to deal with nomadic “roaming” Indians and could confine tabulation to Indians on reservations plus those who were “out of tribal relations” or “civilized.”<sup>18</sup> The 1890 census reports also declare that earlier Indian population data were inaccurate. The reports start re-estimating from 1867 Indian census rolls, and revise the Indian populations for 1870 and 1880 by relying on Indian census for those years. The 1890 census figures, however, do not rely on Indian rolls to calculate to the total number of Indians in the U.S. but in using Indian census figures in the re-estimation, agents effectively incorporated the Indian census’ blood quantum requirements into the decennial census.

An argument for more accurately enumerating Indians was advanced by anthropologist Franz Boas in 1899. Boas wrote that the annual Indian reports to the Commission of Indian Affairs were inadequate to the relevant policy questions of the day:

“A census of the Indian tribes should be the means of determining the success or failure of the policy pursued during the past years, and should suggest the policy to be followed in the future. If the census is to be arranged with a view of carrying out this fundamental idea, three problems seem to be of fundamental importance: (1) the effect of the allotment of land in severalty, (2) the effect of boarding schools and of day schools, and (3) the effect of blood mixture between Indians, and whites and negroes.”<sup>19</sup>

---

without an allotment, or roaming over unsettled territory, is considered “not taxed,” and for such Indians the answer to this inquiry is “No.”

<sup>16</sup> Jobe, Margaret M., “Native Americans and the U.S. Census: A brief historical survey,” *Journal of Government Information* 30 (2004) 66-80.

<sup>17</sup> Census Act of March 1, 1889, “The Superintendent of the Census may employ special agents or other means to make an enumeration of Indians living within the jurisdiction of the United States, with such information as to their condition as may be obtainable, classifying them as Indians taxed and Indians not taxed.”

<sup>18</sup> Reports on the 1890 census announce that Indians no longer roam but are either on reservations or locations they own. Those small bands that do continue to roam, according to the census, were either attached to a federal Indian agency or only off reservation “from time to time.” Any Indians census takers found roaming were “off reservation with permission.” <http://www.census.gov/prod/www/abs/decennial/1890.html>

<sup>19</sup> Boas, Franz, *Publications of the American Economic Association*, New Series, No. 2, *The Federal Census*. Critical Essays by Members of the American Economic Association (Mar., 1899), pp.49-53

Boas also argued that the Bureau of American Ethnology (BAE) was the proper agency for carrying out the type of census inquiry required to evaluate the efficacy of U.S. policy; noting that the BAE investigators were better trained than “occasional observations of agents whose prime interest lies in statistical inquiries.”

Nevertheless, the 1900 decennial census did enumerate Indians and its instructions officially adopted the annual Indian census protocol of racially identifying Indian people by their degree of blood.<sup>20</sup> By 1900, the decennial census was only marginally concerned with the Constitutional limit on enumerating “Indians not taxed” and its protocol centered on the current number of racially identified Indian people. During this time, the annual Indian counts by local agents were on-going and reported to the Commissioner on Indian Affairs, allowing for some measure of the efficacy of federal Indian policy.

The 1930 U.S. Census marks the beginning of the U.S. Census takeover of Indian enumeration. The change was enabled, in part, by the 1924 Snyder Act through which the political status of individual Indians became more uniform. The Snyder Act declared all Indians to be U.S. citizens but left intact all rights to tribal or other property. Since the Snyder Act, Indians are U.S. citizens and citizens of their respective tribal nation. After the Snyder Act there should have been no question whether and which Indians counted for apportionment, however the annual Indian census was still required to meet federal goals and responsibilities. Post Snyder Act, 1930 was the first year that the annual Indian Census and the US decennial census converged. There were two different censuses taken in the same year, by each bureau and with different instructions.

By 1930, the concept of “enrollment” was employed as a result of the Indian Census rolls, though there were few official membership enrollment lists for tribes.<sup>21</sup> Existing rolls often required a complex application process through which federal agents determined who qualified for the roll and who did not. The “roll number” concept extends from the annual Indian Census when, starting in 1929, Indian agents were required to indicate what number the person was on the previous roll. If an Indian person did not have a number, the agent could assign one. Presumably, the purpose of roll numbers was to help Indian agents determine who should receive services, allotment, and treaty or other legal compensation. However, the roll number also helped identify who had “left” the agent’s jurisdiction. Thus, the ability of the U.S. government to identify, and limit, the scope of its political obligations to Indian people and to respond with goods, services, and compensation was tied directly to the annual Indian rolls.

---

<sup>20</sup> See generally, James, M. Annette tracing the federal government standard of blood quantum to the 1887 Dawes Act in which Indians were required to prove on half or greater degree of Indian blood land allotments.

<sup>21</sup> <http://www.archives.gov/research/census/native-americans/1885-1940.html>

Through annual Indian Census rolls the particularly political purposes for Indian enumeration were approached separately from the decennial census required by the U.S. Constitution. Contemporary recognition of the historical links to Indians' unique political status is evident today in the number of government funded programs and services designed to meet federal treaty or trust responsibilities which rely on statutorily varying definitions of "Indian." It is through contemporary and historical links to tribes as pre-constitutional sovereigns –through indigenous continuity-- that Indian people retain the distinct and unique political status articulated in the U.S. Constitution as "Indians not taxed."

The annual process of taking the Indian census was discontinued in 1940, although a few later rolls exist.<sup>22</sup> The change coincides with the federal shift in policy toward terminating federal recognition of some tribes and assimilative attempts to encourage reservation populations to relocate to urban centers. Further, the decennial census and ACS have not, and do not currently, include the information required for the U.S. government to plan for, meet, and evaluate its commitments to Indian people. They were designed for the enumeration of individuals and are not appropriate for tribal-level enumeration.

This was affirmed in June 2016 when tribal nations passed a resolution at NCAI's Mid Year Conference (see [http://www.ncai.org/resolutions/SPO-16-043\\_resolution.pdf](http://www.ncai.org/resolutions/SPO-16-043_resolution.pdf)) to oppose the addition of a tribal enrollment question on the 2020 Census for a range of reasons including: 1) the responses to such a question would be based solely on self-identification with no proof of tribal enrollment required; 2) the determination of who is an enrolled tribal member, a tribal citizen of that tribe, is an attribute of the sovereignty possessed solely by that tribal nation and is not a matter of self-identification; 3) there has not been a comprehensive federal effort to improve the capacity of tribes to use existing data or collect tribal demographic data; 4) the Census Bureau's issuance of counts of tribal enrollment based on self-identification are certain to differ from the official counts found only on tribal rolls; 5) the Census Bureau has provided no information to tribes on how such Census Bureau counts of enrolled tribal members will be used by the various federal agencies, such as possible use in the federal funding formulas for the Indian Housing Block Grant program, the Tribal Transportation Programs, and the special Native American programs authorized under the Workforce Innovation and Opportunity Act; 6) the considerable variations in enrollment policies from tribe-to-tribe will inhibit the ability of non-tribal governments, organizations and the general public to accurately interpret any data on tribal enrollment issued by the Census Bureau; 7) the inclusion of any question on tribal enrollment poses serious and complex issues when applied to the identification of Alaska Natives; and 8) the Census Bureau's National Advisory Committee on Racial, Ethnic and Other Populations opposed the testing of a tribal enrollment question by resolution at its spring 2016 meeting and approved a range of recommendations specific to how the tribal enrollment testing

---

<sup>22</sup> The Indian Census taken by the Census Bureau in 1950 will not be available to the public until 2022.

should proceed in relation to adding reservation sites, tribal consultations, and an Alaska Native strategy.

And yet, there is a need for investments in tribal data capacity that include strengthening tribal data infrastructure, increasing training and technical assistance to tribes, improving tribal data coordination and sharing where appropriate, and supporting increased tribal data collection and use where appropriate. For example, there is a need to map the various service areas that tribal governments serve and to enumerate the service area populations for effective planning and federal resourcing. It is important to note that the service area population may include non-Natives served by tribal governments. In addition, measures of joblessness could guide policy decision making specific to tribal economies. Further, there is a need for better measures of impact to assess whether federal investments are producing improved outcomes as part of the federal trust responsibility to tribes.

Considering the 'definition of Indian' is essential in any effort to improve the use of AI/AN data because it requires an awareness of both individual and collective characteristics, as well as federal constraints on AI/AN identity. Often, when the definition of Indian is introduced in data discussions, the result is that the work to develop AI/AN data seems more onerous. However, it could be argued that the unique political status of AI/AN people requires a deeper awareness about how to analyze and report population data in ways that are most useful for policy purposes.

Demographic estimates of racial and ethnic populations have specific uses in policy contexts and often rely on a combination of geographic, cultural, social, governmental, and environmental dynamics. The rapidly growing diversity in the U.S. (Frey, 2014) signals the need for greater understanding of racial and ethnic identity, particularly minority subpopulations for whom existing data are often incomplete. Among the hard-to-count, AI/AN enumeration is especially problematic given the colonial legacy of research and the devaluing of Indigenous people in state data collections (Tuhiwai Smith, 1999).

Moreover, AI/AN identity is complex and straddles the boundaries of race, ethnicity, and nationality. Existing research largely ignores the heterogeneity within the AI/AN population, which yields tremendous potential for data mismatch within the U.S. official statistics system (Rodriguez-Lonebear, 2016). Accounting for different ways to define a population may improve the value of disaggregated data by better aligning official ethno-racial classification schema with how minority populations identify. And while this aspect could be instructive as other communities plan for disaggregation, it is particular to the AI/AN population due to its unique political status.

The formal, legal and descriptive definitions of AI/AN people vary across agencies and multiple levels of government. For example, the Department of Health and Human Services, Department of Housing and Urban Development, and the Department of

Interior adhere to providing services for federally recognized tribes only. The most cited definition originates from the U.S. Office of Management and Budget's (OMB) 1997 Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, which states, "...a person having origins in any of the original people of North and South American (including Central America), and who maintains tribal affiliation or community attachment." The OMB definition was adopted in the 2000 US Census and by the Department of Education (ED). The definition for the term Indian, being used within the Department of Housing and Urban Development documentation, means any person who is a member of an Indian tribe (federally recognized tribe). Though BIA, Indian Health Service (IHS), and the Department of Housing and Urban Development have slightly differing terminology, all acknowledge not one single criterion is a standard for AI/AN identity. An individual that identifies as American Indian, Alaska Native, Native American, Indian, or Native may or may not adequately meet criteria, set forth by their own tribal nation, to verify tribal status.

Since the U.S. Census and the Department of Education use OMB's definition for AI/AN, an advantage of their data practices is the option to collect primary tribal affiliation information. If other surveys and data systems recognized this necessary field in data collection it may lead to consistently describing a tribal nation strengthens and limitations concerning health, economy, education and beyond. However, the value of self-identified tribal membership (as collected in the US Census) is contested given the sovereign authority of tribes to solely confer tribal membership (see for example, El Nasser, 2016).

The definitions used by the Department of Health and Human Services, Housing and Urban Development, and BIA are primarily federally recognized tribes alone. No single criterion is available regarding protocol for racial self-identification as an AI/AN. Racial self-identification is not the same as tribal affiliation or enrollment, and both are often different from how tribes and federal agencies define service area population, which takes into account geography and demography.

The 1974 decision of the Supreme Court of the United States in Morton v. Mancari (or the Morton Policy) is often cited as affirming the unique treatment of AI/AN people as a class with political status as different from racial and ethnic groups—in other words the 'special treatment' of AI/AN people is not considered racial discrimination because tribes are political groups. An individual self-identifying as AI/AN follows criteria set forth by OMB, which includes original people of South and Central American, contradictory to the Morton Policy. To some extent, the OMB definition aligns with the previous legal model but OMB does not use the term Indian to mean the same as AI/AN. The Patient Registration System used by the IHS also follows different criteria when considering individuals eligible for health care services. The IHS eligibility criteria expands to include AI/AN members or descendants of tribes, non-Indian women pregnant by pregnant an eligible Indian, non-Indian members of an Indian household,

and any others eligible per the agreement of IHS and a tribal health program funded by IHS, highlighting another inconsistency for eligibility of services to an AI/AN.

Data collected by federal agencies may not determine whether resources and services are optimal and accessible to an AI/AN, especially given the insufficient data landscape that prevails for the AI/AN population. The conceptualization of AI/AN people relies on federally recognized tribal status and terms used in government legal documents include American Indian, Alaska Native, and Indian although it appears the term Indian is only strongly expressed within IHS definitions. Individual AI/ANs are burdened at best and disenfranchised at worst by the multitude of definitions. Ultimately, conferring status as a tribal member is the sovereign role and responsibility of tribal nations.

### **Types of Disaggregation**

Despite ongoing challenges with data quality and definitions of Indian, there are some priority **types of disaggregation** emphasized in the literature, as well as an emerging set being discussed. The priority types of disaggregation are often driven by the purpose of the disaggregated data. Federal agencies are increasingly working to disaggregate data in order to reduce disparities and improve equity by exploring strengths and needs of subpopulations. States and localities often invest in data disaggregation to inform system improvement and planning. Further, disaggregation can serve to identify AI/AN people when they are obscured in national level data and thus are invisible to service providers. As such, the collection, reporting, and use of disaggregated data can inform policy, funding, and program development in major ways.

Collecting this additional information does not always come without a cost, however. Separating data by all of the potential categories may require increased data infrastructure, additional staff and analyst time, new partnerships, permissions to access data, and/or the collection of additional data. Also, survey respondents might refuse or be reluctant to respond to more specific identifying information. More categories for identification might increase the length of a survey and thus the cost of the data collection.

**Geography** is the most commonly cited type of data disaggregation and can include disaggregation by interstate region, state, reservation or other AI/AN and tribal statistical areas, counties, cities or metropolitan areas, and service delivery areas. In the context of U.S. Census data, differences are important between many American Indian reservations areas, the former reservation tribal areas in Oklahoma (the OTSAs), the Alaska Native villages and the Alaska Native Regions, the small reservations in California and western Washington, and the areas the U.S. Census Bureau also classifies as “AI/AN statistical areas” that can also include homeland areas for landless federally recognized tribes, state reservations, and homeland areas for state-recognized tribes.



Health research has consistently demonstrated the importance of disaggregating national AI/AN data by region to identify communities where health outcomes are greater than national averages, as well as those that are far below. Research tends to use the 12 IHS areas to explore differences or the 12 regions established by the Bureau of Indian Affairs. There is no one area or region that emerges as having generally stronger health outcomes than others across the board, but both IHS data and other research have shown that there are major differences in many outcomes by region. Regional disaggregation on health outcomes relies on the quality, comparability, and accessibility of IHS and state health and vital statistics data.

Increasingly county-level data has been used to explore AI/AN health outcomes, in part as a result of the role of IHS Contract Health Service Delivery Areas (CHSDA), which used to determine eligibility for services not directly available through IHS (Castor et al., 2006; Cho et al., 2014; Cobb et al., 2014; Jim et al., 2014). IHS funds referral care not provided as direct services for eligible patients who officially reside in a CHSDA only, thus creating a differing level of access to care that may impact outcomes.

Beyond disaggregation by geography, the policy experience of several national Native advocacy groups, including NCAI, emphasizes the importance of **disaggregating by age**. AI/AN population is younger than the U.S. population. Whereas 24 percent of the U.S. population is under the age of 18, 32 percent of the AI/AN population is under the age of 18.<sup>23</sup> Similarly, the AI/AN population experiences a disparity in mortality rates with a lower average age of death than some other populations and different risks for young adults in some cases and for older adults in others, so data analysis by age in studies with adults is important as well.

Research has also found some important differences in health experiences and outcomes for AI/AN men and women, so **disaggregation by gender** is important. For instance, the Men's Health Network and the North Carolina Indian Health Board note the lower life expectancy; higher mortality rates from suicide, HIV/AIDS, homicide, unintentional injuries, diabetes, firearm injury, alcohol-related deaths, cancer, heart disease, and liver disease; and higher psychological distress experienced by AI/AN men compared to AI/AN women (available <http://www.menshealthnetwork.org/library/AIANMaleHealthDisparities.pdf?>). There are also differences noted in the rate at which AI/AN women and men access preventative care and utilize health services. Attention on AI/AN men's health reflects a national trend to pay greater attention to health disparities impacting men. Data also suggests that attention to gender differences in how AI/AN youth experience the school discipline and the juvenile justice system are important for meeting their unique needs (see for example, Saar et al., 2015; USDOE, 2014a; USDOE, 2014b; Wiltz, 2016).

---

<sup>23</sup> US Census, 2010 Census Redistricting File.

As mentioned previously, disaggregation by **single race and multi-race** data became important following changes in the 2000 U.S. Census. Much of the analyses of these disaggregated data shows that the multi-race AI/AN population is growing faster than the single-race AI/AN population from the Census 2000 to the Census 2010 (see for example, Census, 2012; Pew Research Center, 2015). These data have been used to report changes in populations on and off tribal lands, and specifically to show the growth of urban and off-reservation populations of AI/AN (NUIFC, 2012). These analyses have been and are being cited in briefs designed to argue “diminishment” of reservation lands, due in part of claims about the decrease of the on-reservation population of AI/AN people, and this argument has been used in arguments before the Supreme Court of the United States (e.g., Nebraska v. Parker), which could undermine tribal jurisdiction and sovereignty.

Another example of the impact of using multi-race data is in how changes in data for the need component of the Indian Housing Block Grant (IHBG) funding formula altered the flow of resources in Indian Country. Although 1.6 million or 40 percent of all American Indians/Alaska Natives identified as multi-race, 91 percent of them lived off tribal land (reservation, Oklahoma tribal statistical areas, Alaska Native areas, and state tribal areas). Thus only about 147,000 or nine percent of all multi-race AI/AN people lived on eligible IHBG service areas. Of all AI/AN people living on IHBG formula areas, multi-race individuals make up only about 14 percent and single-race make up 86 percent. The appropriation for IHBG is set by Congress and the distribution of the appropriation to tribes is a zero-sum game. Instead of every tribe receiving increased funding due to the larger numbers involved when multi-race data is used, the areas that have a larger proportion of multi-race to single-race people received increased funding, and the areas that have the smallest proportion of multi- to single-race people receive decreased funding. The 14 percent of multi-race AI/AN people living on eligible formula area land made a big difference.

While some of these geographies are connected to cultural boundaries, some researchers differentiate between disaggregation by geographic and **cultural similarities**. For example, Coastal communities may have more in common with one another than Plains communities, even when the Coastal communities and Plains communities bound each other, or have physical proximity (Van Dyke et al., 2016). Cultural groupings often include similarities in lifestyle, history, and language. Comparisons of data among groups with cultural similarities and differences may yield important and unique findings.

There is emerging work emphasizing the importance of disaggregation based on **environmental similarities** given the potential differing impacts on health in communities that have differing environmental exposures (e.g., to contaminants), limited access to traditional or other foods, or natural resources (Van Dyke et al., 2016).

Attention is also placed on disaggregation by **community type**, which can include the type of governance in place for services such as health care. While the IHS receives funding to provide services and health programs to AI/ANs, tribes have the opportunity under P.L. 93-638 to receive the funds that IHS would have received to provide for the direct health services of tribal members in their service area, and health services and outcomes may differ in tribal vs. IHS managed programs.

Another community grouping of tribes are those affected by PL 83-280 (or PL 280), which gave state legislatures in Alaska, California, Minnesota, Nebraska, Oregon, and Wisconsin the option to assert criminal and civil jurisdiction over some criminal and civil matters; while tribal nations retained, in all cases, civil regulatory jurisdiction, and in some instances were exempt or fought to regain their jurisdiction via retrocession.

Other types of communities that may impact data on outcomes may be those that have differing land bases; for example, a tribe with a large land base may be different from tribes that have a smaller or more of a checker-boarded (mix of non-Indian and tribal land ownership) land base, or even those that are landless. And some research notes the importance of differentiating communities by the sustainability of their economic base, which could relate to overall affluence, employment and joblessness levels, and even having a consistent stock of housing (Van Dyke et al., 2016).

Another overlooked level of data collection and analysis is **disaggregation by AI/AN tribe**. Tribes contend with multiple and extensive data collection activities to meet mandatory federal grant reporting and research activities. At any one time, a tribal community may have upwards of one hundred federal grants and ongoing data collection projects to support vital services such as healthcare, education, and transportation. Despite what may appear as an abundance of available data, there is a stark gap in analysis and reporting that actually meets the needs of tribes themselves. This dearth of relevant tribal information further exacerbates data inequities in Indian Country. With no official tribal statistical standard in the US, tribes must contend with myriad data sources and inconsistencies. This data reality inhibits meaningful evidence-informed tribal policy and targeted planning.

Current research explains that tribal demand for information is growing as tribes engage in economic, social, and cultural development on a rapid scale. Across Indian Country, examples of tribes reclaiming control over their data through the mechanism of “data sovereignty” is contributing to a wave of tribally driven data futures (Rodriguez-Lonebear, 2016). Any effort to disaggregate data to the tribal level would need to be done with the approval of each tribe to honor tribal sovereignty over data collected on their lands and with their citizens.

The need for reservation- or tribal-level data is particularly true with respect to economic data, which has an important bearing on health status and outcomes. The U.S. Census Bureau appears to be the only provider of an abundance of federal data that can

be issued by reservation areas, precisely defined by their legal boundaries. Yet, in the economic/business area, the U.S. Census Bureau's data from the five-year Economic Census does not provide data at the reservation level, either for individual reservations or for all reservations nationally. Although the annual County Business Patterns series provides much more local data (much of it suppressed for confidentiality reasons for establishments in rural areas), this reaches the county level only. Very few reservations have boundaries that are co-terminus with county boundaries.

In the economic/labor force area, the Labor Department's Bureau of Labor Statistics (BLS) provides virtually no public data on the AI/AN population at all. There are but two variables that appear in the sometimes annual BLS publication on labor force characteristics by race and ethnicity. And there is no AI/AN specific- or reservation specific-data in the monthly Local Area Unemployment Statistics (LAUS) series. Further, the Current Population Survey (CPS) conducted by the Census Bureau for BLS does not publish any data at all on the AI/AN population or for AI/AN areas, even though AI/AN identity is collected in the CPS questionnaire. The problems with the absence of AI/AN data in the CPS carries over in the data released through the Annual Social and Economic Supplement. The ASEC provides valuable data at the national level, by race and ethnicity, but only for the White, African-American, Asian, and Hispanic populations. Particularly notable is the absence of AI/AN data in the annual U.S. Census Bureau poverty reports, even though poverty is more severe among the AI/AN population than any other. The data in the annual poverty report is taken from the CPS.

While federal agencies are beginning to see the importance of investing in tribal-level data, it was not until January 2016 that the U.S. Census Bureau and the Bureau of Indian Affairs within the Department of the Interior (DOI) signed a memorandum of understanding to promote communication and collaboration between the two agencies and improve the dissemination of accurate data for AI/ANs. In previous discussions about the DOI using Census data to produce the American Indian Population and Labor Force Report, U.S. Census Bureau staff noted that almost every other federal agency except the DOI hires the U.S. Census Bureau to conduct analyses. In 2016, the U.S. Census Bureau and BIA agreed to work together to gain an accurate count of AI/ANs, to share files that show boundaries for reservations and off-reservation trust and restricted lands, and to establish a workgroup to discuss and resolve data issues.

The FY 2017 President's Budget request supported this effort with an increase of \$12 million for BIA to enable the DOI to work with tribes to improve federal data quality and availability, to create a reimbursable agreement with the U.S. Census Bureau to address data gaps in Indian Country, and to create a BIA Office of Indian Affairs Policy, Program Evaluation, and Data to support effective, data-driven, tribal policy making and program implementation. The goals of this office were to improve program performance, deliver more effective services, and help advance and deliver results to Indian Country through important initiatives such Generation Indigenous, which seeks to address barriers to success and opportunity for Native youth.

In addition to highlighting the important role data disaggregation can play in AI/AN community development, several studies and resources emphasize the importance of **appropriate aggregation** of AI/AN data (see for example, Westat, 2007). Given the small size of AI/AN population nationally and the challenge this creates for producing statistical power in research, some emphasize the importance of aggregating AI/AN data over time such as Census does in its 5-year estimates (Commission on Indian Affairs, 2012), which is one low cost way to produce new information.

As stated previously, these issues are of particular relevance to AI/AN people who are usually considered to be from small populations, who may belong to tribes that have special political status in addition to being from racial/ethnic groups, and for which the inherent relationships between people and land in defining AI/AN populations is important. While several other groups and subgroups also stand as small populations, particular characteristics of AI/AN people make these challenges distinct.

International research documents the under-identification of Indigenous people in large datasets as a result of complicated and varied policy definitions of Indigenous people, as well as costs involved with collecting data from small populations (see for example, AIHW, 2011, 2013; Thompson, et al., 2012). Further, definitions of Indian often rely on the link between people and place, such as members of federally recognized tribes living on tribal lands; members of federally recognized tribes living off tribal lands but in a county where they can access an Indian health service or urban health clinic; or members of federally recognized tribes living in P.L. 280 states. The link between people and place is further complicated by the limited data availability on the trust status of land. For example, it is difficult to estimate the flow of capital to trust versus fee land in Indian Country.

### **3. What demographic or other variables that impact health outcomes are important to collect related to aspects of the American Indian/Alaska Native experience (e.g., generation)?**

The review of relevant literature on data disaggregation found at least five aspects related to the AI/AN experience that may impact health outcomes that are important for data collection: age, gender, family, language and culture, and place. Health and other related outcomes for AI/AN people vary in important ways by age and gender as stated previously and it is critical to collect data that can be analyzed and disaggregated by these categories. Family is important to AI/AN experience in terms of its structure (e.g., head of household and marital status, presence of extended family, removal from family into the child welfare and/or juvenile justice systems), in terms of its economic base (e.g., income, capital, exposure to poverty, exposure to opportunity, access to health coverage), and in terms of its ability to prevent children from trauma and adverse experiences. Cultural differences and inputs such as a sense of belongingness and connectedness in community are cited throughout the literature as important for AI/AN health outcomes (see for example Bassett et al., 2012; Yoder et al., 2006). In addition,

speaking one's Native language and cultural identity can both be indicators of cultural factors in one's daily life that may impact health and other outcomes. Place is important and can refer to region, environment, state, county, community type (e.g., community in a PL 280 state), rurality/urbanicity, and/or health system type (e.g., tribal, IHS, private, other public). Much has been written to address the question of what variables impact AI/AN health outcomes, and these themes from the literature might be useful in data disaggregation efforts. Reviewers provided a range of sample resources that highlight various factors impacting the health of AI/AN people, including:

Akee, R., Simeonova, E., Costello, J., Copeland, W., Keeler, G., & Angold, A. (2013). Young adult obesity and household income: Effects of unconditional cash transfers. *American Economics Journal: Applied Economics*, 5(2): 1-28. Available at: <http://luskin.ucla.edu/sites/default/files/YoungAdultObesity.pdf>.

Berman, M. (2014). Suicide among young Alaska Native men: Community risk factors and alcohol control. *American Journal of Public Health* 104 (S3): S329-S335.

Watson, T. (2006). Public health investments and the infant mortality gap: Evidence from federal sanitation interventions on U.S. Indian Reservations." *Journal of Public Economics*, 90: 1537-1560.

Wolfe, B., Jakubowski, J., Haveman, R., & Courey, M. (2012). The income and health effects of tribal casino gaming on American Indians." *Demography*, 49(2): 499-524.

Lastly, there is an extensive body of research about the importance of strengths-based, protective, and wellness indicators in gauging and improving AI/AN health outcomes, especially for Native youth, including, for example:

Goodluck, C. T. (2002). Native American children and youth well-being indicators: A strengths perspective. Seattle, WA: Casey Family Programs and Flagstaff: AZ: Northern Arizona University.

Pavkov, T. W., Travis, L., Fox, K. A., King C. B., & Cross, T. L. (2010). Tribal youth victimization and delinquency: Analysis of Youth Risk Behavior Surveillance Survey data. *Cultural Diversity and Ethnic Minority Psychology*, 16(2):123-134.

Willeto, A. A. (2007). Native American kids: American Indian children's well-being indicators for the nation and two states. *Social Indicators Research*, 83(1), 149-176.

**4. What is the potential and importance of disaggregating data among American Indian or Alaska Native groups, or further within each group, for understanding health outcomes?**

Disaggregating American Indian groups from Alaska Native groups is important for understanding how distinct federal policies, state policy, and place impact health outcomes. There is great potential for producing disaggregated data by AI/AN groups as these differences are commonly understood by Native people and federal staff. However, this disaggregation can complicate understandings of American Indian outcomes in states outside of Alaska where there are large numbers of Alaska Natives that obscure or otherwise drive trends for all Natives in a system. For example, the Washington State Board of Education had to separate out data for the 29 Washington state tribes from that of Alaska Natives (n= approx. 19,000) and of “Other Indians” (n= approx. 2,200) served in state schools in order to explore the wide range of experiences facing Washington tribal students, whose numbers average about 200 per tribe. With the large number of Alaska Natives accessing Indian Health Services, tribal, and urban health resources in states like Washington, it is important to promote disaggregation for Washington state tribes and other American Indians.

A very important reason to disaggregate data is to follow a population, tribe, or actual individuals over time in a longitudinal manner, and this data can inform policy evaluation of the effectiveness of changes in policies or programs over time. This analysis can inform the population being studied but also can inform policymakers on whether the program might be useful to expand to further communities. Aggregate data provides an overview and included individuals who were and were not affected by policy or program change and we can only observe the average result and cannot separately identify the causal effect.

In order to conduct statistical analyses in these types of evaluations, researchers must be able to distinguish between those who participated in new programs or were impacted by new policies and those that did not, as well as to compare the before and after outcomes for these same units of observations. Aggregate data does not provide enough details to do this type of subgroup program evaluation. Thus, being able to create longitudinal measures for communities, tribes, and individuals on variables such as health, education, employment, and other measures is essential for accountability and planning purposes. Collecting data at an aggregate level is not often useful in developing evidence-based policy for groups and subgroups of individuals.

**5. What are the potential benefits to tribal and American Indian/Alaska Native communities as a result of disaggregating American Indian/Alaska Native data?**

The potential benefits to tribal and AI/AN communities as a result of disaggregating AI/AN data are to more effectively reduce disparities, to better equip tribes and AI/AN communities with more relevant data for planning purposes, and to enhance efforts to

hold the federal government accountable to the trust responsibility. Health research that has disaggregated data by region, gender, and/or age for AI/AN people has found that health and other outcomes vary widely, and that learning about these differences can inform planning and target resources more effectively to reduce disparities and build on strengths. Data disaggregation can drive tribal accountability and planning through data driven decision making. For example, tribes might identify their own capacity needs and, for example, decide to place emphasis on supporting student scholarships in nursing or public health or research rather than for all health professions.

Tribal leaders and their communities in turn can benefit from both data informed decision making and enhanced internal capacities. Tribes have a particularly important role to play in the collection, analysis and use of disaggregated data, health data and other types of data, for their own populations and their own tribal lands. Tribes are the only entities that have accurate data on who is a member/citizen of the tribe. Tribal governments, by definition, are important stewards of the fate of their populations.

Some literature also suggests that increasing AI/AN data disaggregation may increase the relevance of research and data to AI/AN communities, and could possibly increase the use of data for community planning (see for example Van Dyke et al., 2016). Disaggregating AI/AN community data can also highlight disparities that are obscured by aggregated reporting, which can shed light on policy and program interventions that are working, on policies or programs that are creating harm, or on other efforts that are needed to ensure the federal government is upholding its trust responsibility.

Research suggests that there are regional differences and experiences of certain health conditions such as diabetes, different types of cancer, and suicide. Data disaggregated by region could inform a targeted allocation of resources and health interventions to address disparities specific to a region, as well as to explore how associations or even causal pathways are different by community and/or region. One key benefit of data disaggregation could be to leverage strengths of some AI/AN communities to assist others, as well as to identify states or other localities that could serve as a model for addressing the needs of AI/AN people in their boundaries. Further, as suggested above disaggregated data allows us to track a population or individual over time, which is essential to monitor and intervene effectively in improving health and other outcomes.

## **6. What organizations could lead and inform work on data disaggregation with American Indian/Alaska Native people?**

Building regional data capacity is one means of facilitating the use of disaggregated AI/AN data in meaningful ways in Indian Country. Few AI/AN tribes and urban communities are equipped with the technical and institutional infrastructure and resources required to handle the collection, analysis, reporting, and maintenance of



data on any scale. At present, there is limited investment in growing such capability among tribes, the federal government, and in private and public sectors.

Each year at the NCAI's Mid Year Conference, a Tribal Leader/Scholar Forum is held. The purpose of this forum is to create an opportunity for tribal leaders and researchers to discuss research and data based on tribal policy priorities. These forms have revealed a growing call for investment in tribal data capability and infrastructure. Tribal leaders acknowledge the importance of data systems, yet the "how" remains less clear.

As data disaggregation to the tribal level requires tribal approval, tribal nations must be engaged as full partners in this work. The National Indian Health Board advocates nationally and supports the work of Area Indian Health Boards in ways that could add great value to data disaggregation efforts. The National Indian Child Welfare Association has a great deal to add in the realm of child, family, and community wellness with regard to their mission and extensive network and could add great insight on this work. Further, the Indian Health Service provides some disaggregated data and is in a position to add significant value to these efforts. Other intertribal and pan-tribal organizations like the National Tribal Land Staff Association can add great value on building tribal and partner data capacity around complex issues related to land, policy, and populations.

Given that region and place emerged as important in the AI/AN data disaggregation literature, it would seem that regional organizations with data capacity would be in a good position to lead and inform this work as it evolves. Tribal epidemiology centers are uniquely poised with status as public health entities, and have public health surveillance missions and research and data capacity to drive this work. Area Indian Health Boards also have regional data capacity and relationships to guide these efforts. Regional intertribal organizations such as the Affiliated Tribes of Northwest Indians, Intertribal Council of Arizona, the United South and Eastern Tribes, or the Alaska Native Tribal Health Consortium have strong regional roots and research and data capacity to inform data disaggregation. University partners who have a demonstrated commitment to supporting tribally-driven research can also inform the work.

Canada's First Nations Information Governance Centre is a decentralized model that offers guiding practices for "ownership, control, access, and possession" of data by Indigenous populations. Through carefully negotiated partnerships between First Nations and the Canadian government, provincial First Nations data hubs provide technical and infrastructure resources to First Nations governments and communities with respect to data collected on their populations. These data hubs are the link between official state data collections, researchers who wish to access said data, and First Nations governments (see <http://fnigc.ca/fndc> and <http://data.fnigc.ca/online>). Ultimately, the FNIGC only sees itself as a "placeholder" until such time that First Nations can assume control over these data hubs and expand. Their planned obsolescence is a strong best practice that seeks to uphold the data sovereignty of Indigenous nations.

Additionally, the U.S. Indigenous Data Sovereignty Network (USIDSN) is an organization that offers potential for future data disaggregation work. The USIDSN brings together data users, tribal leaders, information and communication technology providers, researchers, policymakers and planners, businesses, service providers, and community advocates to provide research information and policy advocacy to safeguard the rights and promote the interests of Indigenous nations and people in the U.S. in relation to data. The USIDSN is member driven and led by a twelve-member Advisory Council. It is based out of the University of Arizona's Native Nations Institute (<http://usindigenousdata.arizona.edu/>). The hope is that some "best practices" may emerge across the network with regard to tribal and AI/AN data collection and standards which could be shared and disseminated to expand data collection, data management, and data use capacity for all network partners.

## A Case Study

**Data Disaggregation to Understand the Educational Experiences of AI/AN Males.** In order to illustrate the importance of data disaggregation when reviewing AI/AN data for program or policy purposes, researchers and program officials could use the following examples to explore the educational status and experiences of AI/AN boys and young men, and their conclusions or decisions could be impacted in very different ways depending on the resources they review. In addition, this case study reveals the various data sources available and the information they can provide for decision-making, and highlights where data is needed.

Sources with good disaggregated data on education related measures include the following:

- Public high school averaged freshman graduation rate (AFGR), by sex, race/ethnicity, and state or jurisdiction: 2012-13; NCES Digest of Education Statistics (see [Table 219.40](#)).
- Rates of Juveniles in Residential Placement, Census of Juveniles in Residential Placement, Office for Juvenile Justice and Delinquency Prevention (see [http://www.ojjdp.gov/ojstatbb/ezacjrp/asp/Age\\_Sex\\_Race.asp](http://www.ojjdp.gov/ojstatbb/ezacjrp/asp/Age_Sex_Race.asp))
- Total fall enrollment in degree-granting postsecondary institutions, by level of enrollment, sex, attendance status, and race/ethnicity of student, NCES Digest of Education Statistics (see [Table 306.10](#)).
- Degrees conferred by postsecondary institutions, by race/ethnicity and sex of student, NCES Digest of Education Statistics (see [Table 321.20](#), [Table 322.20](#), [Table 323.20](#), [Table 324.20](#)).
- Degrees conferred to males by postsecondary institutions, by race/ethnicity and field of study, NCES Digest of Education Statistics (see [Table 321.40](#), [Table 322.40](#), [Table 323.20](#), [Table 324.30](#))

There is a need for data disaggregated by gender (information is available by state and race/ethnicity) in the following areas:

- School enrollment, NCES Digest of Education Statistics (see [Table 202.25](#); [Table 203.70](#) and [Table 203.60](#))
- School expulsion, Civil Rights Data Collection, Office for Civil Rights, US Department of Education (see <http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf>).
- Percentage of high school dropouts among persons 16 through 24 years old (status dropout rate), NCES Digest of Education Statistics (see [Table 219.85](#)).
- Percentage of 18- to 24-year-olds enrolled in degree-granting postsecondary institutions, NCES Digest of Education Statistics (see [http://nces.ed.gov/programs/digest/d15/tables/dt15\\_302.65.asp](http://nces.ed.gov/programs/digest/d15/tables/dt15_302.65.asp))
- Fall enrollment in degree-granting postsecondary institutions, NCES Digest of Education Statistics (see [http://nces.ed.gov/programs/digest/d15/tables/dt15\\_306.60.asp](http://nces.ed.gov/programs/digest/d15/tables/dt15_306.60.asp)).

There is a need for data disaggregated by state (information is available by race/ethnicity and gender) in the following areas:

- Children served under Individuals with Disabilities Education Act (IDEA) - Part B, NCES Digest of Education Statistics (see [http://nces.ed.gov/programs/digest/d15/tables/dt15\\_204.50.asp](http://nces.ed.gov/programs/digest/d15/tables/dt15_204.50.asp))

There is a need for data disaggregated by state and gender (information only available nationally by race/ethnicity) in the following areas:

- School arrests (see <http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf>).
- Referrals to law enforcement from school arrests (see <http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf>).
- Number and percentage of persons 16 to 24 years old who were neither enrolled in school nor working, NCES Digest of Education Statistics (see [Table 501.30](#)).

There is a need for data disaggregated by state and race/ethnicity (information only available nationally by gender) in the following areas:

- Students with disabilities receiving out-of-school suspensions (see <http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf>).

There is a need for data disaggregated by state, race/ethnicity, and gender (information is available for two of the three categories but not all three) in the following areas:

- Percentage of students suspended and expelled from public elementary and secondary schools, NCES Digest of Education Statistics ([Table 233.40](#)).
- Percent of GED Candidates, GED Testing Service (see <http://www.gedtestingservice.com/uploads/files/5b49fc887db0c075da20a68b17d313cd.pdf>).

- Labor force participation, employment, and unemployment of persons 16 to 24 years old who are not enrolled in school, NCES Digest of Education Statistics (see [Table 501.20](#)).
- Percentage of high school students age 16 and over who were employed, NCES Digest of Education Statistics (see [Table 503.10](#)).

There is a need for data disaggregated by state, race/ethnicity, and gender (information only available nationally) in the following areas:

- Students with disabilities being arrested in school (see <http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf>).
- Students with disabilities being referred to law enforcement (see <http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf>).

## Recommendations

Based on this review of literature, a series of recommendations was developed to promote the appropriate, meaningful disaggregation of AI/AN data to improve health and other outcomes:

- **Amend existing policies and reporting practices that inhibit disaggregation of AI/AN data.** For example, change policies in the US Department of Education and in the National Center for Education Statistics on data collection. NCAI has recommended applying the approach used by the U.S. Census Bureau to report data on AI/AN alone, AI/AN alone and AI/AN in combination with other races and ethnicities. A case study of disaggregating data to understand the educational experiences of AI/AN boys and young men is included below.
- **Assess the potential for and impact of federal agency coordination to develop standards for AI/AN data collection and reporting.** There is a clear need for increased federal investment and coordination to improve the appropriate collection and use of AI/AN data to inform policy, planning, and accountability. Assessment of the potential and impact of data disaggregation on tribal nations is critical to ensuring that the federal government carries out its trust responsibility. However, analysis of disaggregated data among and within tribes cannot occur without consistent, accurate and standardized reporting among programs. Standardization of data collection can also serve the important purpose of revealing inconsistencies and duplication of data collection efforts that can be streamlined to reduce the burden of effort on grant and program reporting by tribes.

A few emerging efforts may be important to consider. First, there is a growing use of and emphasis on administrative data across federal agencies. Some tribal nations are building their capacity to use administrative data and link existing databases to add analytical database capability; and example is the WE-CARE system at the White Earth Band of Chippewa in Minnesota that integrates administrative data on families they

serve. Second, staff of some agencies, such as the Administration for Children and Families within the US Department of Health and Human Services, have begun to assess the data collection requirements of tribal grantees in order to reduce overlap and are providing technical assistance in data collection and management.

- **Equip regional intertribal entities to support the development of tribal data capacity and increase data disaggregation where appropriate.** Regional intertribal entities such as Tribal Epidemiology Centers and Area Indian Health Boards have existing data capacity to support data collection, analysis, and disaggregation. As health outcomes often differ by region, it is important for these entities to support the development of tribal data capacity and increase data disaggregation reporting where appropriate.
- **Invest in tribal data capacity.** Tribal nations have the authority to support the collection and reporting of data at the tribal level. They also know best what their data needs are for planning and accountability. It is essential to invest in the capacity of tribal nations to collect, manage, disaggregate, report and use their data to improve the lives of their members. However, tribes need resources in terms of funding, staff and technical assistance to enhance their data capacity and ability to use data to inform policy.

## Acknowledgements

The NCAI Policy Research Center is grateful for the work of NCAI staff during the project period: Malia Villegas Ed.D., former Director of the NCAI Policy Research Center; Amber Ebarb MPP, Program Manager, NCAI Policy Research Center; Sarah Pytalski MPP, Policy Research & Evaluation Manager, NCAI Policy Research Center; and Yvette Roubideaux MD MPH, Director, NCAI Policy Research Center.

We would like to thank the following individuals for providing substantive review of earlier drafts of this review:

- Randy Akee (PhD), Native Hawaiian, University of California Los Angeles
- Sherry Salway Black (MBA), Oglala Lakota Nation
- Terry Cross (MSW), National Indian Child Welfare Association
- Norm DeWeaver, Independent Consultant
- Michelle Sarche (PhD), University of Colorado Denver
- Greg Tafoya (MPH), Santa Clara Pueblo enrolled member, and Sac & Fox Nation
- Richard Todd (PhD), Federal Reserve Bank of Minneapolis
- Research Team, National Indian Child Welfare Association

This report is based on work supported by the Robert Wood Johnson Foundation under Grant ID No. 73478. Any opinions, findings, conclusions or recommendations expressed in this material are those of the author(s) and do not necessarily reflect the views of the Robert Wood Johnson Foundation.

# APPENDIX

## Disaggregating American Indian & Alaska Native Data:

### Annotated Bibliography

**Agency for Healthcare Research and Quality (2014). Race and Ethnicity Data Improvement Toolkit. Healthcare Cost and Utilization Project (HCUP). September 2014. Agency for Healthcare Research and Quality, Rockville, MD: Available at: [https://www.hcup-us.ahrq.gov/datainnovations/raceethnicitytoolkit/home\\_race.jsp](https://www.hcup-us.ahrq.gov/datainnovations/raceethnicitytoolkit/home_race.jsp)**

The Race and Ethnicity Data Improvement Toolkit “provides practical tools and guidance to organizations interested in improving their collection of hospital patient race, ethnicity, and primary language data (R/E/L).” A research program was launched in the fall of 2010 and awarded 3-year data improvement grant projects to grantees in California, New Mexico, and the Northwest region (Washington, Idaho, and Oregon). In California, efforts have been made to screen all hospital patients with self-report questions about race, ethnicity, and primary language. Not only was it critical to train and educate staff and administrators of the value of this effort, but also to communicate the data’s value and uses to patients. They found that 93 percent of polled patients strongly agreed that it is important for hospitals and clinics to conduct studies to ensure equitable and high-quality health care for members of *all* racial/ethnic backgrounds. As a result of implementing this new data collection program, “nearly all hospitals reported collecting race and/or ethnicity (97 percent)...the majority of hospitals used standardized forms for collection, and 75 percent audited patient information for completeness.” In New Mexico, not only were race and ethnicity data reports mandated, but the project also collected tribal identifier/affiliation data and has established methods and procedures that have served as a model for other states. “The change was supported...by implementing verification and tracking mechanisms such as post-discharge surveys and electronic linkage of hospital records with birth certificates and Indian Health Service records.” New Mexico recognized that there is a higher percent of AI/AN in their overall state population and that this group faces unique health disparities. They provide the example of the Washington State registry doing a great disservice to AI/ANs by underestimating their population size (by one-third) and therefore the rate of their cancer incidence (underestimated by 46 percent). The data collection system implemented is self-report and allows patients to choose multiple races and tribal affiliations. The state’s form has 22 tribal affiliations in addition to “other,” “unknown,” and “declined” response categories. In the Northwest region, the Improving Data & Enhancing Access–Northwest (IDEA–NW) Project of the Northwest Portland Area Indian Health Board conducted record linkages with an array of health-related data systems in a three-state region to identify and correct racial misclassification using the most complete roster of Northwest American Indians/Alaska Natives (AI/AN) available. The newly linked, more accurate data allowed researchers to assess AI/AN cancer rates, blood lead levels, the leading causes of death, among other health concerns.

**Akee, R., & Taylor, J. (2014). Social & economic change on American Indian reservations: A Databook of the US Censuses and the American Community Survey 1990 – 2010.. Available at: <http://taylorpolicy.com/us-databook/>.** This publication presents data on 13 indicators of demography, income, employment, education, and housing for reservations in the lower 48 states to explore variations among AI/AN people living on reservations with gaming operations, without gaming operations, and off reservations. It is designed to update earlier research on changes from 1990 to 2000 on reservations. Key findings suggest that more than 92 percent of all American Indians on reservations lived on reservations with gaming operations, gains in real per capita income, gains in median household income, and large reductions in family and child poverty noted for those living on American Indian reservations between 1990 and 2000 were much smaller through 2010, Indian female labor force participation increased steadily, the number of crowded homes and homes lacking complete plumbing have dropped significantly, and education levels have increased.

**Arias, E., Schauman, W. S., Eschbach K., Sorlie, P. D., & Backlund, E. (2008). The validity of race and Hispanic origin reporting on death certificates in the United States. The National Center for Health Statistics. *Vital and Health Statistics*, 2008; 2(148): 1-24. Available at: [http://www.cdc.gov/nchs/data/series/sr\\_02/sr02\\_148.pdf](http://www.cdc.gov/nchs/data/series/sr_02/sr02_148.pdf)**

Utilizing a sample from the National Longitudinal Mortality Study (NLMS), the authors compare racial and Hispanic origin classification captured on death certificates to self-identification in the Current Population Survey (CPS). They note a central problem of incongruence between race and Hispanic origin reporting for both numerators (data from death certificates) and denominators (data from census population estimates) in population mortality calculations, especially for populations with high rates of exogamy such as American Indians and Alaska Natives (AI/ANs). Previous studies have shown a decreased rate of matching between AI/AN race recorded on death certificates and census self-report. This mismatch is attributed to the significant growth of the AI/AN population in the census since the 1960s, which is not due to natural increase. A significant finding of this study is that AI/AN racial misclassification on death certificates is far greater than any other racial or ethnic population examined. Correcting for death certificate misclassification significantly impacts both age-specific and age-adjusted death rates for the AI/AN population. Specifically, the age-adjusted death rate for the AI/AN population climbs from 85 percent to 111 percent of that of the white population. This reveals a substantial mortality disadvantage for AI/ANs compared to whites. Another important finding is that co-ethnic concentration, defined as whether a person died in a county where a sizable number of co-ethnic deaths took place or not, resulted in a higher rate of racial matching for AI/ANs. Importantly, the authors found that the degree of misclassification on death certificates for AI/ANs is substantial and has shown no improvement over time.

**Arya, N., & Rolnick, A. C. (2008). A tangled web of justice: American Indian and Alaska Native youth in federal, state, and tribal justice systems [Policy Brief: Race and Ethnicity Series, Volume 1]. Washington, DC: Campaign for Youth Justice. Available at: [http://cfyj.org/images/policybriefs/race/CFYJPB\\_TangledJustice.pdf](http://cfyj.org/images/policybriefs/race/CFYJPB_TangledJustice.pdf).**



The authors highlight how the federal Juvenile Justice and Delinquency Prevention Act of 1974 designated federal funds to strengthen state and local juvenile justice systems after states submit plans specifying the use of these dollars. Over time, federal funders required states to address disproportionate minority contact and confinement in their state plans. This required state and federal systems to disaggregate data by race/ethnicity. Yet, authors note the following: that these data are often only reported for Black, White, and occasionally Hispanic youth while Asian and AI/AN youth are reported as other; that no states disaggregate the data by tribe; and that OJJDP does not require states or localities to collect data on a group that does not make up at least one percent of the jurisdiction's total population. Data trends on AI/AN juvenile justice is provided for Alaska, Arizona, Minnesota, Montana, North Dakota, Oklahoma, South Dakota, Washington, Wisconsin. The brief includes recommendations on comprehensive data collection, including: that states should collect and publish data about AI/AN youth even if they are less than one percent of the population; that Congress should fund a baseline study of AI/AN juvenile delinquency; that the BIA and DOJ should collaborate to ensure data on AI/AN juveniles in tribal and federal custody are accurate, updated, and publicly available.

**Australian Institute of Health and Welfare (AIHW) (2013). Taking the next steps: identification of Aboriginal and Torres Strait Islander status in general practice. Cat. no. IHW 100. Canberra: AIHW. Available at: <http://www.aihw.gov.au/publication-detail/?id=60129543899%20>.**

In this article, the Australian Institute of Health and Welfare (AIHW) evaluates the implementation of the National best practice guidelines for collecting Indigenous status in health data sets (the Guidelines) across multiple sectors and over the period of 2 years. Several stakeholder groups met during this period and discussed progress and lingering impediments to the successful deployment of the Guidelines. As a top-down approach, it was determined that more mid-level, sector leaders would need to be recruited as advocates in rolling out the new strategies—building a multi-layered, yet centrally-coordinated effort. Among the barriers identified by the stakeholders were: the need to establish a central point of contact at the federal level—such as a taskforce; the need to improve clinical information systems; and the need to inform Aboriginal and Torres-Strait Islanders of relevant programs and interventions for which they may be eligible.

**Banks, D., Perry, S., & Lee, A. (2011). Tribal Crime Data Collection Activities, 2011. Office of Justice Programs, Bureau of Justice Statistics (NCJ 234518). Washington, DC: US Department of Justice.**

In 2009, the FBI's *Crime in the United States* report disaggregated data to the tribal level for the first time and only included data from 83 tribes were included. Formerly, the BIA reported aggregate tribal data to the Uniform Crime Report (UCR)—as few as 25 tribes were submitting data directly to the FBI. In response to the mandates of the Tribal Law and Order Act (TLOA) of 2010, federal investments have been directed towards enhancing tribes' direct engagement with the UCR and the National Crime Information Center (NCIC)—via training, competitive funding opportunities, interagency collaboration, and tribal consultation. As of 2010, the number of tribes reporting data has grown to 144. One priority area is the need for automated



IT systems to capture and transmit tribal issued domestic violence and stalking records to the NCIC Protection Order File.

Beyond the UCR, primary crime data collection vehicles for tribes include the Survey of Tribal Court Systems, and the Survey of Jails in Indian Country, and the Census of State and Local Law Enforcement Agencies. The latter collects data on suspects and defendants processed in the federal criminal justice system (including prosecutions) as well as reports of crimes on Indian lands.

**Bauer, U. E. & Plescia, M. (2014). Addressing Disparities in the Health of American Indian and Alaska Native People: The Importance of Public Health Data. *American Journal of Public Health* 2014; 104 (S3): S255-S257.**

This editorial provides an overview of several articles that link IHS patient registration records to reduce racial misclassification of AI/ANs in order to better understand health disparities and improve public health data on AI/AN populations. While the authors note issues with linking mortality and central cancer registry data with IHS data, they mention that work in this area will improve the accuracy of morbidity and mortality rates in the AI/AN population. Such data are prone to racial misclassification (as nurses, doctors, funeral directors, etc. are reporting race for others), and AI/ANs who are not members of federally recognized tribes or who do not phenotypically present as Native to others are often excluded.

The authors identify potential avenues for improving data beyond these preliminary linkages. They first cite Section 4301 and Section 9007 in the Patient Protection and Affordable Care Act, which requires all federal data collection efforts to include self-reported information on race and ethnicity. Second, great progress has been made among IHS and tribal health systems in implementing Electronic Health Records (EHRs) across clinical sites. The Centers for Medicaid and Medicare Services and Office of the National Coordinator for Health IT have mandated the submission of data to immunization registries, and these incentives to exchange health information between the EHRs and public health data systems (which include Tribal Epidemiology Centers) hold great potential for measuring, benchmarking, and improving clinical services and health outcomes. Last, the authors look to the National Health Interview Survey and Behavioral Risk Factor Surveillance System as potential models for how other datasets might collect and protect geographic information from individual participants to better identify social determinants of health.

**Bertolli, J., Lee, L. M., & Sullivan, P. S. (May-June 2007). Racial misidentification of American Indians/Alaska Natives in the HIV/AIDS reporting systems of five states and one urban health jurisdiction, U.S., 1984-2002. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1847482/>.**

In this study, the authors probabilistically link HIV Reporting Systems (HARS) data with Indian Health Service patient records to identify AI/ANs with misidentified race. Overall, 1,523 AI/AN individuals were identified in both the HARS and IHS datasets. The findings show racial misidentification for 30 percent of AI/AN individuals in the HARS dataset. Misidentification was

highest in California at 55 percent. AI/AN individuals were most likely to be misidentified as white (70 percent). Variables associated with racial misidentification of AI/ANs in HARS are urban residency, degree of AI/AN ancestry, and mode of exposure. As is the case with other health surveillance systems, including cancer, injury and STDs, these findings demonstrate a significant undercount of AI/ANs with HIV due to racial misidentification. Such undercounts compromise the accuracy of data for AI/ANs in nationwide health surveillance systems, which impact funding appropriations and effective prevention and care. The authors recommend collaboration between regional health departments and tribal governments to address racial misidentification. Practical efforts could include training health providers to document their patient's self-reported race using a standard system, and matching surveillance databases with tribal membership records.

**Bigback, K. M., Hoopes, M., Dankovchik, J., Knaster, E., Warren-Mears, V., Joshi, S., & Weiser, T. (2015). Using record linkage to improve race data quality for American Indians and Alaska Natives in two Pacific Northwest state hospital discharge databases. *Health Services Research* 50 (S1, Part II): 1390-1402.**

This article discusses AI/AN racial misclassification in two hospital discharge datasets in the Pacific Northwest. A state record was considered misclassified if it matched the Northwest Tribal Registry, which accounts for all those AI/AN individuals who have accessed health services in IHS and tribal facilities as well as in Urban Indian Health Organizations, and was coded as non-AI/AN or if the race data were missing. The data analyzed do not include Veterans Administration hospitals, special or rehabilitative care hospitals, long-term care facilities, and psychiatric hospitals.

The researchers advance a compelling argument that the analysis of Native health outcomes in the Pacific Northwest cannot be performed with state hospital administrative records. By revealing that 55 percent of AI/AN inpatient discharge data in Oregon State (66.5 percent of those were miscoded as white and 22.1 percent were missing race information) and 45 percent of those in Washington State were racially misclassified over the year 2010-2011, the case is made for linking these data with those from the Northwest Tribal Registry. Both states abide by the Office of Management and Budget standards for race and ethnic reporting—and while Oregon had only one race field, Washington allowed up to five race fields for multiracial patients. It should also be noted that a relatively large percentage of the state records were missing all race data, which the authors felt may have introduced bias to their estimates. They accordingly point to laws in California and New Mexico that mandate the collection of racial/ethnic information in hospital discharge data—as well as the development of protocols, training, patient education materials, and verification methods (e.g., post-discharge surveys, record linkages).

Data quality issues hinder the ability to accurately measure and report AI/AN health disparities at the state and local levels. The Improving Data and Enhancing Access—Northwest (IDEANW) project, part of the Northwest Tribal Epidemiology Center and Northwest Portland Area Indian

Health Board, has conducted record linkage studies with state health datasets in Idaho, Oregon, and Washington.

**California Administrative Office of the Courts, Center for Children Families and the Courts. (2010). Native American Communities Justice Project: Beginning the Dialogue – Domestic Violence, Sexual Assault, Stalking & Teen-Dating Violence. Research Report. May 2010. San Francisco, CA: Judicial Council of California. Available at:**  
<http://www.courts.ca.gov/documents/NACJPResearchReport051310.pdf>.

In 2009, the California Administrative Office of the Courts (AOC) consulted with Native American communities across the state—in 17 community meetings—to understand how to better serve victims of violence. The paucity of reliable, accurate, or *any* tribally-specific data meant that there was no way to document the magnitude or nature of issues such as child neglect or abuse, juvenile crimes, domestic violence crimes, etc. To respond to this data crisis, the Native American Communities Justice Project issued a series of recommendations, including: (1) develop cooperative protocols between tribes and county law enforcement to standardize data collection efforts and disaggregate to a tribal level; (2) mine existing data to see what might be tribally-specific; (3) identify potential data exchanges and crosswalks with existing administrative data from other government agencies; and (4) enhance accuracy of data by reducing barriers to filing reports on crimes such as domestic violence, abuse, etc.

The report summarizes the reasons why tribal data are lacking as follows: “relatively small population sizes lead data collectors to aggregate Native data into an ‘other’ category for statistical purposes; resistance on the part of AI/AN communities to take part in research projects and data collection efforts because of past problematic research that focused on irrelevant or offensive areas of inquiry; a lack of understanding about the political nature of tribes and the usefulness of tribally specific data to tribes and funders; difficulty in identifying some of those with AI/AN heritage because of mixed heritage and a long history of erasing Native cultures in North America; reluctance on the part of some keepers of data to share the information they have with Native tribes for whom they do not feel responsible; and antiquated or underfunded systems for collecting, cleaning, and analyzing relevant, tribally specific data.”

The AOC partnered with the Tribal Law and Policy Institute at the University of California, Los Angeles to compile an AI/AN data availability matrix and an annotated bibliography cataloguing national and California-specific databases and research reports. The matrix reveals where efforts are being made to collect AI/AN reservation-specific data versus where there is only aggregated race data.

**Capriccioso, R. (March 26, 2014). “Accuracy is Victory: NAIHC and Census Bureau to Improve Tribal Data,” *Indian Country Today Media Network*. Available at:**  
<https://indiancountrymedianetwork.com/news/politics/accuracy-is-victory-naihc-and-census-bureau-to-improve-tribal-data/>

This article covers the MOU signed between the U.S. Census Bureau and the National American Indian Housing Council (NAIHC). The U.S. Census Bureau sees that the MOU can help them develop credibility in Indian Country and increase response rates that were previously low due to lack of trust for the federal government. NAIHC sees the MOU as an effort to increase tribal response rates to get a more accurate picture of what is going on in tribal communities and to be able to tell their stories to legislators, federal partners, and the public.

**Capriccioso, R. (February 7, 2014). "Frustration Surrounds New Tribal Labor Force Report," *Indian Country Today Media Network*. Available at: <https://indiancountrymedianetwork.com/news/business/frustration-surrounds-new-tribal-labor-force-report/> .**

This article covers the 2013 Indian Population and Labor Force Report and the limitations and criticisms of the data that covers the labor and employment statistics in tribal areas. Critics call the use of the data outdated and not helpful to tribes or to Congress in depicting the economic landscape of Indian Country.

**Castor, M. L., Smyser, M. S., Taulii, M. M., Park, A. N., Lawson, S. A., & Forquera, R. A. (2006). A nationwide population-based study identifying health disparities between American Indians/Alaska Natives and the general populations living in select urban counties. *American Journal of Public Health* 2006; 96(8): pp. 1478-1484. doi: 10.2105/AJPH.2004.053942**

This article examines the health status of urban American Indians and Alaska Natives (AI/ANs) served by urban Indian health organizations (UIHOs) throughout the country. The authors linked data from the 2000 U.S. census, death certificate (1990–1999), birth certificate (1991–2000), and infant death/natality (1995–2000) data from the National Center for Health Statistics. The population of study is important as urban AI/ANs are a growing segment of the AI/AN population, and relatively little is known about their health status in comparison to AI/ANs who live on reservations or within service areas of the Indian Health Service. The authors note that lack of data on the health status of urban AI/ANs remains a critical obstacle to mitigating health disparities. Racial misclassification errors compound this problem given that many urban AI/ANs are intermarried and face issues of social and cultural isolation. The study points to a need for the creation of standardized definitions of AI/AN, as well as uniform data collection methods across local, state, and federal public health agencies. Due to a lack of data on patients served by urban Indian health organizations, AI/ANs living in UIHO service areas were used as a proxy in this study. The findings show disparities in socioeconomic status, maternal and child health, and mortality indicators between AI/ANs in UIHO service areas and the general population. Urban AI/ANs were approximately twice as likely as the general population to be poor, to be unemployed, and to not have a college degree. Disparities were also noted among children born to mothers who received late or no prenatal care or consumed alcohol. Moreover, higher rates of mortality were observed for sudden infant death syndrome, liver disease, and alcohol consumption.

**Centers for Disease Control. (2015). “Improving Surveillance Systems and Collecting American Indian and Alaska Native Data.” Available at:**

**[http://www.cdc.gov/reproductivehealth/mchebi/ai-an/improving\\_collecting\\_ai-an\\_data.html](http://www.cdc.gov/reproductivehealth/mchebi/ai-an/improving_collecting_ai-an_data.html).**

To gain a better understanding of AI/AN women’s response patterns to the Pregnancy Risk Assessment Monitoring System (PRAMS) survey, the CDC examined characteristics of AI/AN PRAMS participants across 10 states and laid out recommendations for how states might collaborate with tribes to boost response rates. The CDC was able to provide funding to a few states with larger AI/AN populations—New Mexico, Washington, and Oregon—however, other states such as South Dakota, Wyoming, and Michigan has started their own PRAMS surveillance programs with Tribal Oversight Committees. According to the CDC, the South Dakota Tribal PRAMS succeeded in obtaining a response rate upwards of 70 percent among mothers who gave birth to American Indian infants.

**Cho, P., Geiss, L. S., Burrows, N. R., Roberts, D. L., Bullock, A. K., & Toedt, M. E. (2014). Diabetes-Related Mortality Among American Indians and Alaska Natives, 1990–2009.**

**American Journal of Public Health 2014; (104) S3: S496-S503. Available at:**

**[http://www.nec.navajo-nsn.gov/Portals/0/NN Research/AJPH/Research and Practice/DiabetesRelatedMortality1990-2009.pdf](http://www.nec.navajo-nsn.gov/Portals/0/NN%20Research/AJPH/Research%20and%20Practice/DiabetesRelatedMortality1990-2009.pdf).**

This article links death certificate data with Indian Health Service patient registration data for years 1990-2009 to determine whether diabetes may be disproportionately represented as a cause of death among non-Hispanic AI/ANs (versus Whites) aged 20 years and older. The AI/AN Mortality Database (AMD) also “includes bridged single-race population estimates developed by the U.S. Census Bureau and the National Center for Health Statistics...adjusted for population shifts occurring in 2005 because of Hurricanes Katrina and Rita.” The primary data quality concern alluded to in these intercensal population estimates is the overestimation of AI/AN individuals of Hispanic origin. As such, the analyses are restricted to non-Hispanic AI/ANs, which may not present a truly representative portrait of the health and mortality of enrolled tribal members of mixed ancestry – particularly in some regions of Indian Country, such as the Southwest, Pacific Coast, and Southern Plains. Moreover, the death certificate data carry their own inherent flaws—as AI/AN individuals may be misidentified by coroners and funerary directors. Unfortunately, with non-Hispanic Whites as the only reference category, comparisons across other minority groups is not possible. The AMD does allow for stratified data analyses by race, sex, age group, and IHS region residence, yet it is unclear whether the data could be more compellingly linked to compare, for example, diabetes-related mortality outcomes between AI/AN men and women, ages 20-44, residing in the Northern Plains.

**Cobb, N., Espey, D., & King, J. (2014). Health behaviors and risk factors among American Indians and Alaska Natives, 2000–2010. *American Journal of Public Health* 104 (S3):481-489.**

This article provides contextual risk factor information on causes of death among American Indians and Alaska Natives (AI/ANs). Composite data at the national or regional level depends

on population-based surveys, such as the Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is conducted annually by state health departments in coordination with the Centers for Disease Control and Prevention (CDC).

The authors analyzed 11 years of Behavioral Risk Factor Surveillance System (BRFSS) data for AI/AN respondents in the U.S. The authors combined BRFSS data from 2000 to 2010 to determine the prevalence of selected risk factors for AI/AN and White respondents residing in IHS Contract Health Service. AI/AN people had high prevalence estimates of tobacco use, obesity, and physical inactivity, and low prevalence estimates of fruit and vegetable consumption, cancer screening, and seatbelt use.

The authors identified a range of data issues. All BRFSS information collected, including race/ethnicity, is self-reported and not otherwise validated. AI/AN people constitute less than two percent of the US population, so the number of AI/AN persons included in the survey sample is small, and single year and single state estimates may vary considerably. To approximate the time frame and geographic divisions of the analysis of death records, the authors combined BRFSS data from 2000 to 2010 and grouped states into six IHS regions. Previous publications had not restricted the study population to the Indian Health Service (IHS) Contract Health Service Delivery Area (CHSDA) as the authors did in this study. CHSDA residence is used by the IHS to determine eligibility for services not directly available within the IHS. Analyses restricted to CHSDA counties make risk factor estimates more comparable with other publications in the supplement, which also drew their data from this set of counties.

There were a range of survey limitations. Phone surveys are problematic in AI/AN communities, where a single landline phone might serve several families, and many may have no phone at all. This might bias the sampled population toward urban or economically advantaged groups. BRFSS also focuses on risk factors measured on the individual level and does not capture social and environmental factors that might be contributing to these patterns in risk factors. Because the Hispanic AI/AN population was excluded (7.7 percent of the sample), the exclusion might disproportionately affect some states. Due to limited number of observations for AI/AN persons in BRFSS for individual years, it was not practical to include time trends. Future analyses of BRFSS for this population would benefit from a focus on time trends where data permit.

**Deweaver, N. (2013a). American Community Survey data on the American Indian/Alaska Native population: A look behind the numbers. Washington, DC: National Congress of American Indian. Available at: [http://www.ncai.org/policy-research-center/initiatives/ACS\\_data\\_on\\_the\\_AI/AN\\_Population\\_paper\\_by\\_Norm\\_DeWeaver.pdf](http://www.ncai.org/policy-research-center/initiatives/ACS_data_on_the_AI/AN_Population_paper_by_Norm_DeWeaver.pdf).**

This paper reviews the difference between the American Community Survey and the long-form data that the U.S. Census Bureau collected and reported before 2010. The paper describes the ACS sample size and the move to 1-, 3-, and 5-year estimates reported in the ACS versus the 10-year point in time estimates reported in the long-form Census. The impact of the move to the ACS masks the year-to-year changes in populations for smaller geographic areas, such as reservation areas and smaller tribal geographies.

The paper also points out that the numbers for the AI/AN alone and alone youth populations are substantially below numbers for these populations in the decennial count in 2010. At the same time, the ACS 1-year estimates for the AI/AN multi-racial population from 2008 through 2011 are considerably above the level of this population as counted in the 2010 Census. The U.S. Census Bureau has yet to publicly explain why the ACS figures at the national level and for many local areas fall so short of the counts in the 2010 Census. The position of Bureau staff appears to be that people who report as AI/AN alone on a decennial census questionnaire change their racial identification to AI/AN multi-racial when responding to an ACS questionnaire. The conclusions of the paper are: ACS data should be used with caution; the U.S. Census Bureau has an obligation to work with AI/AN data users in researching the apparent undercounts and other issues with ACS data; although prodded by the National Congress of American Indians, the Census Bureau appears to have done little on its own to conduct research on the inadequacies of data on the AI/AN population; Census Bureau efforts to improve coverage of the AI/AN population in the ACS should be continued and expanded; Federal agency officials that have used decennial census data in the past to allocate program funds and that are now likely to turn to ACS data should be aware of the issues with the ACS and take steps to prevent the inequitable allocation of funding that can result from the use of potentially inaccurate ACS data; and efforts should be undertaken to strengthen the capacity of tribes and Indian-controlled nonprofits in urban areas to collect, tabulate and analyze data on the populations they serve.

**Deweaver, N. (2013b). Comments on Census Bureau evaluation report on ACS coverage measured by comparison with the 2010 Decennial Census. Washington, DC: National Congress of American Indians. Available at: [http://www.ncai.org/policy-research-center/initiatives/Census Evaluation of ACS coverage - DeW comments.docx](http://www.ncai.org/policy-research-center/initiatives/Census%20Evaluation%20of%20ACS%20coverage%20-%20DeW%20comments.docx).**

These comments were submitted to the U.S. Census Bureau's ACS Research and Evaluation report #ACS13-RER-1 dated January 16, 2013. The report estimates the coverage of the pre-controlled 1-year ACS estimates for 2010 by comparing these with the results of the 2010 decennial census for various population groups and geographies. These comments focus on the portions of the report dealing with estimates of coverage for the American Indian/Alaska Native (AI/AN) population, especially the AI/AN "alone" population. The report provides potential reasons, but not a full explanation, as to how or why the ACS estimates for the size of the AI/AN alone population nationally and in a substantial number of reservation areas and counties with predominantly off-reservation populations are well below the size of this population as counted in the 2010 decennial census.

Roughly 19 percent of the AI/AN alone population counted in the 2010 decennial is missing in the ACS 2010 1-year estimate for 2010, according to the ACS13-RER-1 report. Including the control adjustments, the published figures indicate that just 13 percent of the AI/AN alone population as counted in the decennial is missing in the ACS count. The overcount of the AI/AN "in combination" population tends to roughly equal the AI/AN alone undercount, resulting in a



coverage ratio for the AI/AN alone or in combination population of .971, close to the coverage ratio for the White alone or in combination population.

The matching of the number of AI/AN alone persons undercounted with the number of AI/AN "in combination" (multi-racial) persons overcounted appears to lead Bureau staff to conclude that the alone undercount is explained by persons who switch from identifying as AI/AN alone in the decennial census to AI/AN multi-racial in the ACS. On page 3,5 the report contends that "The differences seen between AI/AN alone or in combination, AI/AN alone, and AI/AN in combination were most likely due to differences in how race was reported, a topic which merits further research." The Bureau had yet to publish any research based on an actual matching of a representative number of decennial and ACS questionnaires for the same persons at the national and selected local levels to substantiate this contention.

**Deweaver, N. (2013c). Trends in size of AI/AN Alone youth population by type of land area – 1990 to 2010. Washington, DC: National Congress of American Indians. Available at: [http://www.ncai.org/policy-research-center/initiatives/Declining\\_AI-AN\\_Alone\\_Youth\\_Population.docx](http://www.ncai.org/policy-research-center/initiatives/Declining_AI-AN_Alone_Youth_Population.docx).**

This paper compares the rate of growth of the American Indian/Alaska Native (AI/AN) youth population (ages of 0 to 17) between 1990, 2000, and 2010 and finds that the youth population appears to have declined both nationally and in reservation areas. The author calls for a more in-depth analysis of the trends in the size of the AI/AN alone youth population and suggests such analysis draw on data from the IHS as well as decennial census data.

From 1990 to 2000, the AI/AN alone youth population grew by 21 percent nationally, which is a lower rate of growth than for the total AI/AN alone population, and the on-reservation growth rate was just 14 percent. From 2000 to 2010, the AI/AN alone youth population grew by only six percent nationally. From 2000 to 2010 the on-reservation AI/AN alone youth population decreased by 11 percent. In Alaska Native villages, the AI/AN alone youth population grew by just seven percent from 1990 to 2000, but declined by nine percent from 2000 to 2010.

**Deweaver, N. (2010). The American Community Survey: Serious implications for Indian Country. Washington, DC: National Congress of American Indians. Available at: [http://www.ncai.org/policy-research-center/initiatives/ACS\\_Serious\\_Implications.PDF](http://www.ncai.org/policy-research-center/initiatives/ACS_Serious_Implications.PDF).**

This paper describes the move by the U.S. Census Bureau from the "long form" questionnaire to the American Community Survey. The paper poses questions about what this change means for tribal leaders, policy-makers, and other users of data on the American Indian and Alaska Native (AI/AN) population.

Compared to the data that was previously available from the "long form," the paper explores if ACS data will: be available for all areas, down to the smallest reservations, tribal political subdivisions and Alaska Native villages; be accurate, reflecting the actual on-the-ground



conditions of AI/AN people; and be more timely, since it will be released annually, rather than once every ten years.

This analysis looks at all three questions, examining ACS data from 2006, 2007 and 2008. Data on the AI/AN population from the 2000 Census, the Census Bureau's Population Estimates program and the 3-year estimates from the ACS are compared at the national level and for selected local areas with significant AI/AN populations, including 17 reservations and other types of AI/AN areas, 11 counties and one city.

The analysis raises several serious issues including: an undercount of the AI/AN Alone population, especially youth, in the ACS at both the national level and for many local areas; the ACS data for some reservations contains unexplained changes in key socio-economic characteristics of the AI/AN Alone population; sampling error for population characteristics raises questions about the reliability of the published ACS estimates; and although ACS estimates will be released annually, comparisons of data for nearly all reservations should be made only at five-year intervals.

The paper calls for more discussion among tribal leaders, tribal planners, AI/AN data users in off-reservation areas, and federal agencies on these issues.

A range of issues with disaggregation were highlighted. First, the sample size for ACS is much smaller. In 2000, "long form" data was collected from about 18 million households. Nationally, one in every six households received a "long form." In most reservation areas, one in every two households did. In contrast, ACS samples just 3 million addresses each year, producing information on about 2 million households. ACS data for the nation as a whole, all states and all areas with a total population (of all races) of 65,000 or greater is made available annually the year after it is collected. This data set is called the ACS 1-year estimates. However, the smaller sample size of the ACS means that the U.S. Census Bureau has to add up the responses over several years before it can publish data it considers accurate for smaller geographic areas.

Second, data for areas with a total population (of all races) of 20,000 or more is aggregated over a three year period and released annually for the most recent three year period. This data set is called the ACS 3-year estimates. A very small number of reservations is included in the 3-year estimates since the total population of all races in most such areas is less than 20,000.

Third, data for all areas, including those with total populations of less than 20,000, is aggregated from responses to the ACS questionnaire over a 5-year period. The first of these 5-year estimates was due to be available late in 2010 and covers the 2005 to 2009 time frame. Each year a new set of 5-year estimates will be available, covering the most recent 5-year period. The smaller sample size means that the potential for sampling error is greater; that is, there may be a bigger difference between the true values and the published counts. This issue is especially significant when the counts are for small populations, like the Native population, and for small geographic areas, like most reservations and many smaller off- reservation counties.

**Earle, K. A., & Cross, A. (2001). Child abuse and neglect among American Indian/Alaska Native children: An analysis of existing data. Seattle, WA: Casey Family Programs.**

The authors discuss a range of challenges accessing child abuse and neglect data on AI/AN youth. One major issue is the Resource Patient Management System that hosts IHS data from the Mental Health and Social Services Program Branch provides abuse category codes for staff to use if child abuse and neglect may be reasons for a visit to an IHS mental health program; yet these data are not publically accessible or available separate from other data that obscures the child abuse and neglect information in other categories. The report highlights the establishment of the National Child Abuse and Neglect Data System (NCANDS) created through a 1988 amendment of the 1974 Child Abuse Prevention and Treatment Act (CAPTA), which has included state reported data from all states since 1998 in the annual *Child Maltreatment* report and others. The Summary Data Component of the NCANDS offers state-level data, while the Detailed Case Data Component provides data at a case-level from 15 state agencies. A child may be counted more than once in the data if there has been more than one report for that child – so it is essential to differentiate between child and case data, especially for AI/AN youth who were more likely to appear more than once when compared to Whites in this four-state analysis. The Adoption Assistance and Child Welfare Act of 1980 and the Adoption and Safe Families Act of 1997 were important in enforcing state reporting of child abuse and neglect data by tying certain state practices to federal funding. The Indian Child Protection and Family Violence Prevention Act of 1990 established reporting requirements for tribal nations, as CAPTA did not specifically apply to tribal nations.

The National Indian Justice Center issued a report in 1990 providing some state-level data on abuse and neglect of AI/AN children. The Bureau of Indian Affairs and the IHS are cited as sources for regional and tribal data on substantiated cases of child abuse and/or neglect though it is also reported that information on the incidence of and response to child abuse and neglect is not available from his. Further, concerns are raised that data collected by BIA alone, and not by states or counties, are not entered into the national counts of child abuse and/or neglect. The report notes that the Youth Risk Behavior Surveillance System does not include questions about physical or sexual abuse. Data from the National Crime Victimization Survey allows for disaggregation for AI/AN victims by age and perpetrators of crimes against AI/AN victims by race, but does not seem to allow for disaggregation by state for AI/AN victims.

There continue to be issues in consistent understanding and reporting of what constitutes abuse and neglect in Indian Country. Disaggregation by type of abuse results in neglect emerging as the most frequent type of reported abuse, which has led some researchers and community leaders to raise questions about the training of child welfare workers and the potential of bias to more easily affect reports of neglect over those that require other physical evidence. NCANDS includes data on AI/AN children only when state or county child protective services workers choose to investigate a reported case, which is estimated to be only 60 percent of all cases.

The report concludes with concerns about inconsistencies across datasets, as well as questions about the need to invest in tribal data infrastructure and reporting, the impact of Hispanic ethnicity on results for AI/AN populations, opportunities for data linkage across federal sources, and the effect of misclassification of abuse type by case workers.

**El Nasser, H. (November, 3, 2015). "U.S. Census challenge: counting every Native American and Alaska Native," *Al Jazeera America*. Available at:**  
<http://america.aljazeera.com/articles/2015/11/3/us-census-challenge-counting-every-american-indian-and-alaska-native.html>.

This article discusses the plans to enumerate AI/AN people as part of the 2020 Census. It includes insights from tribal leaders about the undercounts and the need for tribal nations to be involved in leading enumeration efforts. It highlights issues with federal categories and processes for Indigenous affiliation.

**Ericksen, E. P. (1997). Problems in sampling the Native American and Alaska Native populations. *Population Research and Policy Review* 16 (1-2): 43-59. Available at:**  
<http://www.ncbi.nlm.nih.gov/books/NBK233090/>.

This article explores the challenges of sampling the AI/AN population. The author notes that characteristics used by statisticians to draw samples of African Americans may not work for Native people. Challenges in sampling AI/ANs include wide geographic spread, vast cultural diversity among tribal subgroups, and complexity in identifying the AI/AN population. The author catalogues a range of challenges involved in defining the AI/AN population in research studies, including those of self-report. The article notes the tension between research design that maximize precision for overall estimates and those that maximize precision of subclass (or local) estimates. The author posits that in order to make AI/AN data more meaningful, it must capture the diversity of the subgroups within the AI/AN population. Some key subgroups identified here include: AI/AN; those living on and off reservation lands; cultural and tribal groupings; and regional groupings. This is difficult to operationalize, however, given the oversampling required for smaller subgroups like the Alaska Native population and individual tribes. Geographic dispersion compounds this burden because most AI/ANs live in areas where they comprise a small proportion of the total population. The research expense required to screen for eligible AI/AN respondents in areas where their numbers are small can become prohibitive. These constraints are even further amplified when considering the oversampling required to achieve accurate estimates at the tribal level.

The author concludes by recommending several sampling strategies to better cover the AI/AN population. The first is sampling by optimal allocation, whereby the population is divided into strata and the rate at which each strata is sampled varies according to the costs of obtaining the average interview in each stratum. Another strategy is area sampling, that is selectively choosing sampling areas (i.e. counties, states, regions) where there is a minimum AI/AN threshold of 10 percent. To supplement area sampling, the author recommends utilizing tribal rolls and adding all persons listed on tribal rolls who live outside the area samples. The author

does, however, address issues of cost, access, and errors, which can compromise the use of tribal rolls. A third option is multiplicity sampling, which could include taking a sample of AI/AN individuals living in a concentrated area and obtaining contact details for relatives who would be added to the sample. Ultimately, no one sampling method is going to provide complete coverage. The AI/AN population of interest—whether it be a tribal population, regional population, or aggregate national population—will ultimately dictate the best survey sampling method.

**Espey, D. K., Jim, M. A., Richards, T. B., Begay, C., Haverkamp, D. & Roberts, D. (2014). Methods for improving the quality and completeness of mortality data for American Indians and Alaska Natives. *American Journal of Public Health* 104 (S3): S286-294. doi:10.2105/AJPH.2013.301716.**

Researchers explore the vast racial misclassification that results in underreporting of American Indian and Alaska Natives (AI/ANs) in national mortality data. Among other studies, the authors cite 2008 findings from the National Longitudinal Mortality Study (NLMS) demonstrating a mismatch of 30 percent between the self-identified race of AI/AN individuals in the US Census and their race as recorded by funeral homes at the time of death (see <http://www.ncbi.nlm.nih.gov/pubmed/19024798>). By matching 176,137 US National Death Index (NDI) records with IHS registration records, the researchers identified the prevalence of AI/AN death misclassification between these two datasets. Given the changing demographics of Indian Country, the treatment of multi-race individuals as a single race is of interest. Individuals who identify as AI/AN plus another race are assigned a single race according to an algorithm used by both the U.S. Census Bureau and the National Center for Health Statistics.

While several studies have linked IHS data with AI/AN records in central cancer and mortality registries, this particular study disaggregates and analyzes these linkages at a regional level—revealing distinct differences across regions regarding racial misidentification. The researchers linked the U.S. National Death Index with IHS registration records with a two-step process and independent review. They found that between the years of 1990-2009, the percent of racial misclassification was 17.7 percent overall. The rates were the lowest in the Southwest and Alaska, at 6.3 and 6.5 percent respectively, and highest in the Southern Plains and East, at 35.6 and 35.2 percent respectively.

While the analysis is not nationally representative and is limited to individuals who live within IHS Contract Health Service Delivery Areas or Tribal Service Delivery Areas, it suggests that current methods are not sufficient in accurately identifying who is an AI/AN at the time of death. The authors' multi-step method for linking national data and administrative data offers insight into improving the accuracy of mortality rates for AI/ANs and other critical data areas. Once more, the limitations of the IHS data being representative only for federally recognized tribal members and under-representative of urban Indian populations were raised.

**Espey, D. K., Wiggins, C. L., Jim, M. A., Miller, B. A., Johnson, C. J., & Becker, T. M. (2008). Methods for improving cancer surveillance data in American Indian and Alaska Native population. *American Cancer Society* 113(5): 1120-1130. doi: 10.1002/cncr.23724. Available at: <http://onlinelibrary.wiley.com/doi/10.1002/cncr.23724/pdf>.**

The authors contend that existing cancer surveillance data do not accurately enumerate the full American Indian and Alaska Native (AI/AN) population due to racial misclassification in cancer registries. Without accurate data, the cancer burden in AI/AN communities cannot be comprehensively assessed nor can effective cancer prevention and control measures be developed. As an exercise towards mitigating racial misclassification of AI/ANs in cancer surveillance data, the researchers link IHS data with records from U.S. cancer registries to identify racially misclassified AI/AN individuals.

Data were sourced from 47 participating cancer registries that agreed to link their data with IHS records. Data were restricted to AI/AN residents living in IHS Contract Health Service Delivery Areas in 33 states. The results show significant differences by IHS region in misclassification of AI/AN race in cancer registries, ranging from 3.4 percent in Alaska to 44.5 percent in the Southern Plains. The research is limited to only AI/ANs who are members of federally recognized tribes, live in the IHS service delivery area, and access health services at IHS facilities. The authors acknowledge the limited generalizability of their findings. The analysis suggests the need for further research into data linkage methods and the importance of AI/AN data partnerships with state, federal, and private entities. While the data did not lend themselves to tribal analysis, the authors make note of the need to expand tribal rosters, such as the Northwest tribal roster, in order to facilitate data disaggregation at the tribal level and enhance data linkages.

**Harwell, T. S., Hansen, D., Moore, K. R., Jeanotte, D., Gohdes, D., & Helgersen, S. D. (January-February 2002). Accuracy of race coding on American Indian death certificates, Montana 1996-1998. *Public Health Reports* 117: 44. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1497410/pdf/12297681.pdf>.**

This article examines the consistency with which American Indians (AIs) are racially classified on Montana death certificates. The authors linked 769 patient registration files from the Indian Health Service (IHS) with Montana Department of Health and Human Services death certificates across a two-year period (1996-1998). Records were linked by matching Social Security numbers. This study was possible due to the high rate of Social Security number matching between these two databases—97 percent of names in the IHS records and the state death records had accompanying Social Security numbers. The findings show 91 percent of decedents were correctly classified as AI on the death certificate. Nearly all of those who were not identified as AIs on the death certificate were instead classified as white, and only one person was classified as race unknown. Individuals who died from suicide were less likely to be classified as AI. Conversely, those who died from alcohol-related causes were more likely to be consistently coded as AI. Findings suggest that AI mortality rates are underestimated in Montana, especially for AIs who do not live in a county on or adjacent to an Indian reservation. Montana is a unique case, however, in that a high proportion of AIs live on or near Indian

reservations. This is not so for other regions of the country, which suggests that underestimation of mortality rates for AIs in other states may be even higher than in Montana. The authors explain the need for additional studies to assess the accuracy and consistency of AI/AN classification on death certificates. Selecting sound databases with an appropriate level of data linkage is key. This research also points to a paucity of disaggregated mortality statistics by tribe. Lastly, the article demonstrates the importance of outreach from state vital statistics agencies, including medical examiners and coroners, and next of kin in correctly classifying American Indians on death certificates.

**Hoopes, M., Peterson, P., Vinson, E., & Lopez, K. (2012). Regional differences and tribal use of American Indian/Alaska Native cancer data in the Pacific Northwest. *Journal of Cancer Education* 27 (S1): 73-79.**

This study corrected AI/AN race coding in cancer registries in Washington, Oregon, and Idaho using patient registration records. The study calculated cancer incidence and mortality measures by state comparing non-Hispanic White to AI/AN. Data was used from the IHS and Seattle Indian Health board to get a fuller spectrum of the AI/AN population in the Pacific Northwest. The authors report that 41 percent of matched cancer cases were misclassified as non-AI/AN in the primary race field. The results indicated that when compared to non-Hispanic Whites, AI/AN faced disproportionate rates of some screen-detectable cancer. Regional differences in the study did arise for cancer surveillance demonstrating that there was variation in cancer incidence, mortality and stage distribution across tribes. This information was provided to tribes that could be used in community health assessments and local program planning.

**Indian Health Service. (2014). Trends in Indian health. Washington, DC: US Department of Health and Human Services. Available at:**  
[https://www.ihs.gov/dps/includes/themes/newihstheme/display\\_objects/documents/Trends2014Book508.pdf](https://www.ihs.gov/dps/includes/themes/newihstheme/display_objects/documents/Trends2014Book508.pdf).

This report provides narrative, tables, and charts that describe the health status of AI/ANs served by IHS programs. The Report presents demographic data on the AI/AN population and patient care delivery services. The report includes current and trend information as well as comparisons to the U.S. All Races population at large. Content includes: Indian Health Service Organizational Structure, Population Statistics, Natality and Infant/Maternal Mortality Statistics, General Mortality Statistics, Patient Care Statistics, and Community Health Statistics.

The report discusses a range of limitations to the data. The service population estimates are based on U.S. Census Bureau county data; therefore data are for self-identified AI/AN people who may or may not use IHS services. The report estimates IHS service populations between census years using a smoothing technique. The technique tends to result in upward revisions to the service population projections prior to a census, which actually enumerates AI/AN people. IHS service populations beyond the latest census year are projected through linear regression techniques. The regression uses the most current ten years of AI/AN birth and death data provided by the National Center for Health Statistics (NCHS) at the Centers for Disease Control

and Prevention (CDC). State birth and death certificates do not reflect whether an individual used IHS services, so IHS service population figures are used in calculating AI/AN vital event rates for the IHS service areas.

**“Tribes and educators push for newer data for key funding program,” Published on Indianz.com website on May 10, 2016 and available at:**  
<http://www.indianz.com/News/2016/05/10/tribes-and-educators-push-for-newer-data.asp>.

This article covers the 2014 Johnson O’Malley Act which calls for more recent and accurate data to secure funding for Native student education. Funding levels relied outdated data on Native student populations, despite more reliable data from the U.S. Census and the National Center for Education Statistics.

**Jim, M. A., Arias, M., Seneca, D. S., Hoopes, M.J., Jim, C. C., Johnson, N. J. & Wiggins, C. L. (2014). Racial misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area. *American Journal of Public Health* 104 (Supplement 3): S295-S302. Available at:**  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4035863/>.

This study evaluates how well IHS Contract Health Service Delivery Areas perform in the identification of AI/ANs in cancer incidence and all-mortality datasets by reviewing data contained in the IHS-National Vital Statistics System (NVSS), IHS-National Program of Cancer Registries (NPCR)/Surveillance, Epidemiology and End Results (SEER) program, and National Longitudinal Mortality Study (NLMS). Sensitivity and classification ratios that were calculated and classified by sex, IHS region, and urban–rural County status indicated that Contract Health Service Delivery Areas that were rural and had larger proportions of AI/ANs were far more likely to accurately identify their patients. As such, the authors recommend that data from the Contract Health Service Delivery Areas are more reliable and should be consulted as a superior source of health information on AI/AN populations.

**Johnson, J. C., Soliman, A. S., Tadgerson, D., Copeland, G. E., Seefeld, D. A., Pingatore, N. L., Haverkate, R., Banerjee, M., & Roubidoux, M. A. (2009). Tribal linkage and race data quality for American Indians in state cancer registry. *American Journal of Preventative Medicine* 36 (6): 549-554.**

The undercounting of AI/ANs in disease registries poses a major problem for the prioritization of public health interventions and resource allocations. This Michigan-based study demonstrates how the linkage of state cancer registries with tribal enrollment data improves AI/AN racial classification validity above and beyond linkages with IHS records. Specifically, the IHS linkages between 1995-2004 found 643 racially misidentified AI/AN cancer cases and the 2007 tribal enrollment linkage served to identify an additional 190 cases. The authors argue that these software-enabled (Registry Plus™ Link Plus 2.0) linkages are a simple and noninvasive way to obtain quality, tribe-specific cancer data. Washington State is also cited for its successful efforts to link its cancer registry, IHS patient files, and 19 tribal rolls in 1990—thereby greatly increasing the accuracy of AI/AN cancer incidence rates.



**Johnson, P. J., Call, K. T., & Blewett, L. A. (2010). The importance of geographic data aggregation in assessing disparities in American Indian prenatal care. *American Journal of Public Health* 2010; 100(1): 122-128.**

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791242/>

Researchers examined whether the rates for prenatal care utilization for American Indians/Alaska Natives (AI/AN) and for non-Hispanic Whites were significantly different at the national, regional, and state levels. They found that prenatal care utilization varied by IHS region and state for AI/AN and non-Hispanic White women, and that there were even greater differences in 12 states with the largest number of AI/AN births (see <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791242/table/tbl2/>). There were also differences noted for rural and urban IHS service areas. Examining disaggregated rates at the state level for AI/AN prenatal care utilization also identified states that have reduced disparities and those where disparities are increasing but are not highlighted by national aggregate trend reporting.

The article cites the 2005 decision by the National Center for Health Statistics to revise its data-release policy to comply with CDC goals and state requirements to make data available at the state-level while adequately protecting participant confidentiality. This analysis suggests that the common practice for national vital records public-use data files is to not contain geographic identifiers, which prohibits local-area analyses. Concerns also noted include that the maternal race data for AI/AN mothers in California was lower than elsewhere (54 percent) due in part to hospital staff reported race rather than mother's self-reporting.

Data were drawn from the National Perinatal Mortality Data files within the National Vital Statistics System at the National Center for Health Statistics. These files are compiled annually at the national level and include birth-certificate data for all live births by all 50 states, 1995-1997 and 2000-2002.

**Kickingbird, K., & Rhoades, E. R. (2000). The relation of Indian Nations to the U.S. government. In E. R. Rhoades (Ed.), *American Indian health: Innovations in health care, promotion and policy* (pp. 61-72). Baltimore, MD: Johns Hopkins University Press.**

This article reviews the special political status of Indian tribes, their sovereign status, and the current federal-Indian relationship which shapes health care services for Indian people. Defining tribes' political status has resulted in a complex situation that is often ambiguous and contradictory. The trust responsibility and the political independence of tribal governments often conflict and this conflict remains unresolved.

The paradox of the trust relationship and tribes' political independence leads to ambiguity in basic definitions of Indian, tribe, nation, and eligibility. Definitions tend to rely on legislative language devised for specific purposes instead of general purposes. To analyze any Indian issue, three factors must be considered: 1) concept of tribal government, 2) concept of "Indian country," which has specific implications for Indian health, 3) and tribal membership.

The definition of Indian is very complex and varies based on several factors, especially which



branch of government is defining Indian and for what purpose. Two major purposes for defining who is Indian are: 1) questions of legal, judicial, and administrative jurisdiction; and 2) identifying who is eligible for federal services. No single statute defines Indian for all federal purposes. Felix Cohen laid out a rule however upon which most definitions of Indian depend and which serves as the basis for eligibility requirements for federal health services. An Indian may be defined as a “person meeting two qualifications: (a) that some of his ancestors lived in American before its discovery by Europeans, and (b) that the individual is recognized as an Indian by his or her tribe or community.” Another principle is that a definition of Indian may use a test that excludes individuals from the scope of legislation dealing with Indians, which is an exclusionary concept directed toward those not eligible for services intended for Indians.

The Indian Reorganization Act of 1934 illustrates the complexity. The term Indian “shall include all person of Indian descent who are members of any recognized Indian tribe now under Federal jurisdiction, and all person who are descendants of such members who were, on June 1, 1934, residing within the present boundaries of any Indian reservation, and shall further include all other persons of one-half or more Indian blood. For the purposes of said sections, Eskimos and other aboriginal peoples of Alaska shall be considered Indians. The term tribe wherever used in said sections shall be construed to refer to any Indian tribe, organized band, pueblo, or the Indians residing on one reservation.”

Another category of importance is federally recognized tribes versus non-federally recognized tribes. Federal recognition is important for tribes to qualify for BIA and IHS services, assistance, and funding as well as other federal funds on the same basis as states. The Indian Self-Determination and Education Assistance Act (1975) defines Indian tribe as: “any Indian tribe, band, nation, or other organized group or community, including any Alaska Native village or regional or village corporation as defined in or established pursuant to the Alaska Native Claim Settlement Act which is recognized as eligible for the special programs and services provided by the United States to Indian because of their status as Indians.”

The IHCA includes this definition: “Indians or Indian, unless otherwise designated, means any person who is a member of an Indian tribe.” Tribes determine their own members and the federal government can establish eligibility criteria but generally relies on tribal membership as its primary criterion. It is possible to be an Indian by ethnicity or descent but not meet tribal membership criteria.

**Lane, N. A., Evans, K., Attakai, A., Witte, C., Riding In-Warne, M., & Coe, K. (2012). Responding to American Indian Communities: Southwest American Indian Collaborative Network (SAICN) Cancer Educational Activities. *Journal of Health Disparities Research and Practice*, 4(3): 3.**

To develop educational materials and training for American Indian communities, complex issues must be addressed to develop appropriate strategies for each unique tribe. This paper describes the educational activities conducted over a four year period by the Southwest American Indian Collaborative Network. Activities fell into two areas: cancer information dissemination through trainings and workshops and development of culturally-tailored

educational materials. Cancer data on AI/AN populations are limited and inconsistent. Small numbers of AI/AN make it difficult to calculate rates of incidence, however, IHS trends show disproportionate mortality for certain cancers. The limited number of established cancer programs in reservation areas hinders efforts for cancer awareness and education. The paper reviewed progress on meeting the goal of the Training and Education Core to improve access to culturally-responsive cancer interventions for American Indian communities in Arizona, Utah and Nevada.

**Lavelle, B., Larsen, M. D., & Gundersen, C. (2009) Research synthesis: Strategies for surveys of American Indians. *The Public Opinion Quarterly* 73: 385-403.**

This literature summary identifies available strategies for improving sampling and response rates for surveys of American Indians. The authors first outline the multiple approaches to defining who is American Indian and discuss how researchers must establish their own operational definition because there are many ways the AI population can be determined. The literature review on the challenges of research on AI population includes sections on availability and accuracy of address listings, telephone access, household mobility, language and cultural barriers, and distrust of outside researchers. The authors also suggest strategies for researchers to implement to ensure both high data quality and to ensure that the AI communities can also benefit from the research including use of strategies such as community-based participatory research. The strategies used by the U.S. Census Bureau enumeration efforts are one example used to demonstrate the recommendations for AI population research including securing support from tribal leaders, educating the population about the importance of the data collection, public appearance of researchers at community events, cultural awareness trainings for researchers and enumerators, and hiring local people to be involved in the implementation and data collection.

**Liebler, C., A., Bhaskar, R., & Rastogi, S. (2014). America's churning races: Race and ethnic response changes between Census 2000 and the 2010 Census [CARRA Working Paper Series, Working Paper #2014-09]. Washington, DC: US Census Bureau, Center for Administrative Records Research and Applications. Available at:**  
<https://www.census.gov/content/dam/Census/library/working-papers/2014/adrm/carra-wp-2014-09.pdf>.

This paper examines the extent to which race and/or Hispanic origin responses in the U.S. Census change over time, whether such change varies by individual characteristics, and the extent to which these changes affect researchers. The paper uses individual responses that have been linked across internal U.S. Census Bureau data from the 2000 and 2010 censuses. The linked data were non-representative; about 9.8 million people, six percent, of the linked data have a different race and/or Hispanic origin in 2010 than in 2000. American Indians/Alaska Natives, Native Hawaiians and Other Pacific Islanders, Hispanics, and multiple-race response groups experienced racial fluidity when reporting race. However, responses for single-race non-Hispanic whites, blacks, and Asians were more consistent from 2000 to 2010. Changes from

2000 to 2010 include: people who change from multiple races to a single race and vice versa, from a single race to another single race, and adding or dropping Hispanic origin.

The authors acknowledge that who is considered American Indian has been governed by tribal and legal definitions which exclude some individuals with Indian heritage. The paper cites research that reveals, in the past half century, more people have marked American Indian on the census, which indicates a decreased influence of what the paper calls “hyperdescent” rules. About 44 percent of American Indians reported at least one other race in the 2010 Census. Research on multiracial individuals finds that connections to culture and homelands are key factors influencing the reporting of mixed race heritage.

The authors point out how changes in racial and ethnic reporting by individuals could affect researchers, who assume a racial or ethnic group includes the same group of people at different points in time, except due to births, deaths, and migration. As an example, in researching the economic characteristics of the American Indian population across time, changes in race responses could account for economic changes if the individuals who identified as Indian in 2000 but non-Indian in 2010 had different economic characteristics than individuals who identified as Indian in both censuses were. The issue can also affect point in time correlations of experiences, such as living in a specific place e.g. reservation or segregated neighborhood, cause some people to be more or less likely to identify with a group. Data from the 2000 and 2010 censuses were linked across years by the U.S. Census Bureau’s Center for Administrative Records Research and Applications (CARRA). The data do not include people missing a Social Security Number and those whose personal information was too incomplete to assign a “Protected Identification Key” (PIK). Also not included were people who died between 2000 and 2010, new immigrants who arrived after 2000, children born after 2000, people who were not enumerated in 2000 and/or 2010. Among people with unique PIKs in 2000, 81 percent were included in 2010 as well.

Propensity to change races varies by characteristic: for instance, adults are overrepresented among people who change between white and/or American Indian responses, and children are overrepresented among those changing responses between single-race black and white-black.

**Liebler, C., A., Rastogi, S., Fernandez, L. E., Noon, J. M., & Ennis, S. R. (2014). Dynamics of race: Joining, leaving, and staying in the American Indian/Alaska Native race category between 2000 and 2010 [CARRA Working Paper Series, Working Paper #2014-10]. Washington, DC: US Census Bureau, Center for Administrative Records Research and Applications. Available at: <https://www.census.gov/content/dam/Census/library/working-papers/2014/adrm/carra-wp-2014-10.pdf>**

This paper addresses the role changes in racial reporting plays in observed increases between the 2000 and 2010 censuses. The authors use linked data from the 2000 and 2010 census (N = 3.1 million) and the 2006-2010 American Community Survey (N = 188,131). The paper examines the extent to which people change responses to include or exclude American Indian; whether people who change their response are different from those who do not; and whether those

who leave the AI/AN category are different than those who stay. The authors find considerable response change, particularly among multiple-race and/or Hispanic American Indians and the turnover is concealed in cross-sectional comparisons because the number of people joining the American Indian category roughly equals the number of those who leave. The paper finds differences between the people who added or dropped American Indian compared to those who remained in category from 2000 to 2010; the authors also find differences between people who moved between single-race and multiple-race American Indian. Those who reported American Indian in both censuses (even if they added or dropped another race response) were more likely to report a tribe, live in a tribal area, and live in the West.

**Liebler, C. A. & Zacher, M. (2011). The case of the missing ethnicity: Indians without tribes in the 21<sup>st</sup> century [CES 11-17]. Washington, DC: US Census Bureau, Center for Economic Studies. Available at: <https://www2.census.gov/ces/wp/2011/CES-WP-11-17.pdf>.**

The authors examine why almost one million people whose census response included American Indian/Alaska Native did not respond to the tribal affiliation part of the 2000 census race question. One-third of multi-racial American Indians and one-sixth of single-race American Indians did not report a tribe. Four hypotheses for why tribal affiliation was not reported include: 1) survey item non-response, an issue with all surveys, 2) American Indian identities in which tribal affiliation is not salient, 3) genealogy-based identity, and 4) mestizo identity without a tribal affiliation. The authors use multivariate logistic regression models and high-density restricted-use Census 2000 data. The paper reports support for hypothesis 1 and 2.

**Moy, E., Ryan Smith, C., Johansson, P., & Andrews, R. (2006). Gaps in the data for American Indians and Alaska Natives in the National Healthcare Disparities Report. *American Indian and Alaska Native Mental Health Research: The Journal of the National Center*: 52-69.**

This study quantifies gaps in data for AI/ANs in the 2004 National Health Care Disparities Report and overviews effort and opportunities to improve the data quality to close the gaps. This study briefly outlines the methods and the domains of quality and access used by the NHDR to ensure high quality data and consistency across data sets to compare across different population groups. The report reviews measures in the NHDR to assess the lack of data about health disparities and health care quality in the AI/AN populations. Each measure was classified as having collection issues, estimations issues, power issues, or no problems. Of the 149 measures related to quality health care tracked, the study found that only 42 percent could be used to assess disparities in AI/AN populations. Gaps in the AI/AN data also varied by the type and source of data because the 2004 NHDR uses multiple sources with various levels of collection, estimation, and/or power issues.

The study also offers suggestions to improve data quality to allow for better targeting of health interventions and to reduce disparities in health outcomes and quality of care. There is reference to a project between AHRQ and IHS to integrate their datasets (NPIRS and HCUP) to provide national AI/AN estimates of hospital discharge data that is absent in other data sets to quantify a national count for AI/AN. Person based surveys and quality improvement data needs

to be expanded, and the authors suggest that increasing the number of AI/AN represented in national data sets could help address the issues. Furthermore improving the uniformity of race reporting across states and hospitals can help with misclassification.

**National Urban Indian Family Coalition (NUIFC). (2012). Urban Indian America: The status of American Indian and Alaska Native children and families today [A Report for the Annie E. Casey Foundation]. Seattle, WA: Author. Available at: [https://caseygrants.org/wp-content/uploads/2012/04/NUIFC\\_Report2.pdf](https://caseygrants.org/wp-content/uploads/2012/04/NUIFC_Report2.pdf).**

This report provides a snapshot of urban Indian communities and needs and calls on policymakers and community leaders to develop an awareness and understanding of this population which is growing. Authors highlight the lack of research on urban Native families despite the needs and series of reports produced (e.g., a 1998 special edition of the *American Indian Culture and Research Journal* on the status and wellbeing of urban Indian families). Authors also note that these reports tend to only provide national and state-level aggregate data, which obscures key differences across metropolitan areas and between urban Indians and those on tribal lands. The report indicates that key metropolitan areas include: Albuquerque, NM; Anchorage, AK; Oakland, CA; Buffalo, NY; Chicago, IL; Denver, CO; Los Angeles, CA; Minneapolis, MN; Oklahoma City, OK; Phoenix, AZ; Portland, OR; San Antonio, TX; Seattle, WA; Tucson, AZ; and Tulsa, OK. The report highlights key health trends for urban Natives, including: higher rates of accidental deaths, diabetes, liver disease and cirrhosis, alcohol-related deaths, infant mortality; and lower rates of prenatal care.

**Ong, J., & Ong, P. (2012). Los Angeles American Indian and Alaska Native Project Technical Memo 5: AIAN Underrepresentation in the ACS. Los Angeles, CA: American Indian Studies Center, University of California Los Angeles. Available at: [http://www.aisc.ucla.edu/research/pb1\\_memo3.aspx](http://www.aisc.ucla.edu/research/pb1_memo3.aspx).**

This memo examines the underestimation of AI/AN in the American Community Survey (ACS) compared to the AI/AN population in the 2010 decennial census. Ong and Ong state the problem is due to a major underestimation of the single-race AI/AN population. The decennial census numbers are considered the baseline in the memo. The ACS is based on a sample of about three percent of all US households each year; the sample is then weighted to generate estimates of the population. The accuracy of ACS estimates depends on the representativeness of the ACS sample as well as the precision of the weights, in addition to sampling error. This memo examines the 2009-2011 ACS. Racial categories can include: 1) AI/AN alone or in combination with other races, 2) single-race AI/AN, 3) AI/AN in combination with other races. The ACS estimates for the total population (all races) is close to the 2010 number, within a fraction of a percentage point of the 2010 census number, with the difference perhaps due to nonlinear growth between 2009 and 2011. The AI/AN alone and in combination ACS estimate is about three percent lower than the 2010 count; the ACS AI/AN alone population is 86 percent the size of the decennial count; the ACS AI/AN multi-race estimate is 110 percent the size of the decennial number. These results are illustrated below from data in Table I of this paper:

<b>2010 Enumeration Counts and ACS Estimates</b>	<b>AI/AN Alone or In Combination</b>	<b>AI/AN Alone</b>	<b>AI/AN in combination</b>
2010 Decennial Enumeration	5,220,579	2,932,248	2,288,331
2011 ACS 3-year estimate	5,055,427	2,529,104	2,526,323
ACS-to-Decennial Ratio	96.8%	86.3%	110.4%

The authors argue that the differences between the ACS and decennial counts cannot be explained by sampling error. The differences are much larger than the margin of error at the national level and at smaller levels of geography, such as LA County and California. The two potential sources of underestimate are **under sampling AI/AN people** and **incorrect weights**. Ong and Ong analyze ACS Public Use Micro-Sample data to investigate sources of underestimation because weighted ACS PUMS produces very similar population estimates to the web-published ACS tables. PUMS, a subsample of ACS data, covers approximately one percent of the population.

The three-year PUMS sample contains AI/AN alone and in combination roughly proportionate to the AI/AN share of the decennial counts (1.2 percent in the decennial to 1.8 percent in the unweighted PUMS). However, according to the PUMS unweighted sample, oversampling is noticeable for the AI/AN in combination population at the national level (0.8 percent in unweighted PUMS data compared to 0.7 percent in the decennial), and for California and Los Angeles. In Los Angeles, the AI/AN alone population made up 0.7 percent of people counted in the 2010 decennial census but only 0.6 percent of the ACS PUMS sample, which shows under-sampling.

<b>A/IANs as a percent of 2010 Count and Unweighted ACS Sample</b>	<b>AI/AN Alone</b>	<b>AI/AN in combination</b>	<b>AI/AN Alone or In Combination</b>
<b><i>United States</i></b>			
2010 Decennial Enumeration	0.95%	0.74%	1.69%
2009-2011 ACS PUMS unweighted	1.00%	0.83%	1.83%
<b><i>California</i></b>			
2010 Decennial Enumeration	0.97%	0.97%	1.94%
2009-2011 ACS PUMS unweighted	0.91%	1.09%	2.00%
<b><i>Los Angeles</i></b>			
2010 Decennial Enumeration	0.74%	0.69%	1.43%
2009-2011 ACS PUMS unweighted	0.59%	0.88%	1.47%

In addition to under sampling AI/AN people, the paper explores differences in weights used to translate ACS sample data to population estimates. For the total population (all races) the mean weight is slightly more than 100, which is needed to translate the one percent ACS sample to a population estimate. The mean weight for AI/AN alone is 82, which is needed for an over sampled group such as the AI/AN alone population nationally. Ong and Ong argue that the weights used for Los Angeles and California are too low; the weights interact with under sampling which leads to a severe underestimation of the AI/AN alone population in the ACS.

**Perry, S. (2012). Tribal Crime Data Collection Activities, 2012. Office of Justice Programs, Bureau of Justice Statistics (NCJ 234518). Washington, DC: U.S. Department of Justice.**

While the 2011 report provided top-line information on the means of supporting and enhancing tribal crime data collection, the present analysis dives into the data and shares its methodology. Its primary data sources include the 2010 U.S. Census, the Census of State and Local Law Enforcement Agencies, the UCR, the Edwards Byrne Memorial Justice Assistance Grant (JAG) Program, and the Federal Justice Statistics Program. These data are not comprehensive, however; the information gaps identified concern the annual caseloads in tribal courts; the implementation of TLOA enhancements; and the selection criteria for judges, prosecutors, and public defenders. To fill these gaps, the Bureau of Justice Statistics (BJS) has “awarded a multi-year grant to conduct a National Survey of Tribal Court Systems... In addition, BJS initiated the development and design of an Indian Country justice statistics webpage with the goal of pulling together all available statistical data on the tribal justice system in one place.”

**Pew Research Center. (2015). Multiracial in America: Proud, diverse and growing in numbers. Washington, DC: Pew Research Center. June 11, 2015. Available at: <http://www.pewsocialtrends.org/2015/06/11/multiracial-in-america/>.**

This report reviews the results of a survey of multiracial adults. The survey includes 1,555 multiracial adults. The biracial groups in the analysis include: white and American Indian, black and American Indian, white and black, and white and Asian. One tri-racial group is also included: non-Hispanic white, black and American Indian. The survey was conducted online and was intended to be nationally representative. More than 21,000 adults were initially contacted. Other subgroups are not broken out individually due to small sample size. The results show that while multiracial adults have some experiences in common, their experiences and attitudes vary depending on their races. For example, multiracial adults with a black background are closely aligned with the black community, whereas multiracial Asian/white adults feel more connected to whites than Asians. The largest group of biracial adults is white/American Indian. Just 22 percent of the white/American Indian group says they have a lot in common with American Indians and 61 percent report having a lot in common with whites. About 30 percent of adults with a multiracial background report changing their response to race, with some moving from single race to multiple races and vice versa.

The Pew Research Center took into account the racial background of parents and grandparents in addition to self-reported race; using this technique, Pew estimates that seven percent of the adult American population is multiracial. The white/American Indian population makes up half of the country's multiracial population, the largest multiracial group, but also the group least likely to self-identify as multiracial. Of the multiracial population, 12 percent are black/American Indian; 11 percent are black/white; six percent are white/black/American Indian; and four percent are white/Asian.

The Pew technique leads to a different number of multiracial white/American Indian than the 2013 ACS; in the ACS, adults who said they were non-Hispanic white and American Indian accounted for 25 percent of the mixed-race population compared to half in the Pew Research survey. Pew explains that in their survey, white/American Indian biracial adults are least likely to identify as multiracial and only 22 percent report a lot in common with American Indians while 61 percent report a lot in common with whites. The Pew survey includes individuals who have weak ties to an American Indian background and who would likely report their race as white on government forms but who may report having an American Indian racial identity in an anonymous online survey.

Topics covered in the survey include: understanding the gap in identifying as multiracial; the overall multiracial experience; politics, policy views, and social values; marriage and friendships. In the Pew survey, only 39 percent of multiracial adults identify as mixed race or multiracial. Of the 61 percent who do not identify as multiracial, half say they do not identify as multiracial because they look like one race and half say they were raised as one race. About a third of mixed race people who do not identify as multiracial say they did not know the family member or ancestor who was the different race. Only a quarter of white/American Indian adults identify as multiracial. One out of five multiracial individuals reported pressure to identify as a single race. In this survey, biracial adults who are white or black and American Indian report stronger connections with the white or black community than the connections with the American Indian community. About 25 percent or less in each group (white/American Indian or black/American Indian) report having a lot in common with American Indians. Biracial white/American Indians' political leanings resemble that of single-race whites, with 53 percent identifying as Republican and 42 percent Democrats/lean Democrat. This group is the only mixed-race group that leans Republican. The sample was too small to analyze single-race Native Americans.

Among those surveyed, the way people describe their own racial background may not match the way they sense that others perceive them. About 90 percent of white/American Indian biracial adults in the Pew survey stated that a stranger would say they were single-race white, two percent say they would be perceived as multiracial, and seven percent said they would be viewed as American Indian only. On the other hand, more than 60 percent of white and black adults believe they are seen as black; only 19 percent say they would be seen as multiracial. More than 20 percent of multiracial adults report dressing or behaving in a certain way to influence how other people perceive their race. One-fifth of white/black biracial adults report having behaved in a way to influence how others perceive their race; about 11 percent of white/American Indian adults report such behavior. Only 20 percent of white/American Indian



adults report that their racial identity is “essential” to their personal identity, compared to 40 percent of black/American Indian adults, 57 percent of black/white/American Indian adults, and 31 percent of white/black adults. Only nine percent of multiracial adults report that a relative or member of their family has treated them badly due to being mixed race, however such experiences vary by multiracial group. White/black biracial adults are more likely (21 percent) than biracial white/American Indian adults (four percent) to report bad treatment by family.

**Rhoades, D. A., D’Angelo, A. J., & Rhoades, E. R. (2000). Data sources and subsets of the Indian population. In E. R. Rhoades (Ed.), *American Indian health: Innovations in health care, promotion and policy* (pp. 93-100). Baltimore, MD: Johns Hopkins University Press.**

The IHS recognized the need for statistical information and developed a system for gathering and analyzing such data for providing health care and planning for health programs and allocating resources. Collecting highly accurate data however is difficult as is defining the population of Indians that use IHS services. The difficulties in acquiring AI/AN data are related to the elusive precision in defining Indian. Subsets of the Indian population have evolved based on legislative programs and requirements. Enumerating different tribes, bands, and villages is also difficult. The IHS has sought to identify the proportion of the Indian population for which it is responsible.

The dominant source used to estimate the number of Indians is the decennial census, yet the census is not definitive. In 1990, a substantially greater number of individuals identified as AI/AN than in any previous census, while just 1,959,234 identified as predominantly Indian. Indian population data collected at different times are not comparable. Census data do not provide accurate estimates of the population receiving IHS services, so a subset of the overall population is used: those self-identified persons living in states having a federal Indian reservation and in Oklahoma and Alaska. IHS considers this as the population that most nearly represents those for whom it is responsible; IHS uses this population for planning and implementation of programs.

Before 1972, vital event data were compiled for reservation states on a statewide bases, and after 1973 on a county basis which permitted IHS to further refine this subset of the Indian population to those living in counties in or adjacent to reservations. These counties became known as the IHS Service Area, and the population therein became known as the IHS service population. In the 1990 Census, 1,103,082 persons identified predominantly as AI/AN in the IHS Service Area, a 33 percent increase over 1980, although much of the increase may have been the result of more individuals identifying as AI/AN in 1990 than in 1980.

IHS estimates annual population numbers through linear regression techniques using the most current 10 years of births and deaths applied to the latest census enumeration, and accounts for the numbers for occasional newly federal recognized tribes. A comparison of the IHS service population projection for 1990 with the results of the 1990 Census shows the two were remarkably close, with a difference of 5 percent, although some areas had higher IHS estimates than Census and others had lower. IHS also identifies those individuals who receive IHS care.

The difference between the user population and the service population is small, which means most Indians located in a service area use IHS care.

IHS and tribes believe Congress should provide resources for all eligible Indians living in the Service Areas, but OMB has supported resources only for those persons using IHS and tribal health programs. The user population designation grew out of claims that IHS had not been providing care to as many Indians as it had claimed, leading to an actual count.

No truly representative studies or reports of the U.S. Indian population exist. Neither is there regular information on the other 39.4 percent of the U.S. Indian population. Direct collection of data on Indian groups is “labor intensive and prohibitively expensive.” Local area studies have been conducted but the generalizability of those studies to the broader Indian population is not known. The small size of many Indian groups limits the ability of and confidence of investigators to draw inferences. Large studies mask the differences between communities. IHS compiles annual regional and national statistics for service and user populations and averages vital event data for three-year periods. More than half of Indian people in the U.S. live in urban areas and many urban areas do not have access to IHS services, although some do through the IHS urban Indian health program.

IHS relies on the National Center for Health Statistics (NCHS) for the enumeration of births and deaths of Indians. The IHS does not have its own system. NCHS obtains birth and death certificate data for all U.S. residents from the respective state departments of health. Records do not have tribal identities. IHS applies these data to its service population to calculate vital event rates. Investigators have found errors in Indian vital event rates from different racial designations on birth compared to death certificates, especially those relating to infants designated as Indian on the birth certificate but assigned a different race on death certificates. In a national survey of all U.S. infants who died during 1983-85, 37 percent of infants classified as Indian on the birth certificate were classified differently on the death certificate. Differential errors have been found as well: accuracy of race on death certificates may be influenced by cause of death. Persons dying from cancer were less likely to be classified as Indian on death certificates in WA than were persons dying from alcohol-related conditions. Also injury rates were underestimated in the Oregon Injury Registry due to misclassification. IHS conducted a study using the National Death Index from NCHS. The study matched IHS patient records of those patients who could have died during 1986-1988, published in *Adjusting for Miscoding of Indian Race on State Death Certificates*. In 11 percent of the matched IHS-NDI records, the race reported was not AI/AN, however some areas had a larger percentage of misclassification than others, with California’s rate being the highest (30 percent), then Oklahoma City (28 percent), Bemidji (16 percent), then Nashville (12 percent). Navajo had the lowest at 1.2 percent. IHS applies adjustments to the death rates to provide comprehensive analysis of health status. Cause of death also has substantial error.

**Rodriguez-Lonebear, D. (2016). Building a Data Revolution in Indian Country. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty*. Canberra: Australia National University Press.**

In this chapter, Rodriguez-Lonebear highlights the need for tribal nations in the U.S. to exercise sovereignty in relation to data collection, management, and use. She cites issues related to multiple sources and types of data on AI/AN populations and notes that less than two percent of the data come from tribal sources. Rodriguez-Lonebear goes on to emphasize the link between tribal data sovereignty and tribal citizenship, indicating several issues with the range of definitions of Indian in use by federal agencies. The chapter concludes with insights from tribal leaders collected at the National Congress of American Indians Mid Year Conference in 2015 about the need for better quality tribal data.

**Rose, Richard A. (2012). American Indian race and ethnicity data: An historical analysis and comparison of NCES and NYS data for NYS school districts. Sage Graduate School.**

This research study offers a secondary analysis of existing data on American Indian students in New York State school districts to investigate disparities. The study compares data from the National Center for Education Statistics (NCES) and the New York State (NYS) School Report Card. The study also provides a historical review of the archival record of American Indian education policy in New York since 1975, when the Regents' Native American Education Policy Statement was issued. The unit of analysis is the NYS school district. The study used matched pairs of school districts from the NYSED and NCES data sets. The race categories used are the standard federal U.S Census Bureau categories. The author defines an undercount of American Indian students as the difference between the two data sets in the number of American Indian students by district and in which the NYS count is less than the NCES count. The research study finds a significant difference between the Native student counts in the NYS and NCES data sets. While the Census Bureau has made progress in reducing undercounts and improving the quality of data for the AI/AN population, the author notes inconsistency between the Census data (and NCES which is based on Census) and the data reported by the NYS government as collected by school districts. While the American Indian population is increasing according to the Census Bureau, the number of American Indian students has declined according to the NYS education data. Limitations: The author discovered a difference in the lists of school districts in the NCES and NYS data collections, leading to a lack of a one-for-one match for each district. Another limitation relates to the definition of AI/AN and the inconsistent method that the definition is applied as well as the rules applied to data aggregation. Also, the NCES excludes American Indians who also identified as Hispanic, which leads to a structural undercount. The author points out another data quality issue due to a conflict in guidance between the NYS education department and the 1997 Federal Register notice on the Revision to the Standards for the Classification of Federal Data on Race and Ethnicity. The NYSED guidance encourages LEAs to identify race of a student independently, using "their own local practices and procedures..." (NYSED SIRS Dictionary, 2008, p.31) while the federal guidance says that the classification guidance "do[es] not tell an individual who he or she is, or specify how an individual should classify himself or herself..." (OMB, 1997, p.1). The study does not examine the process used by each school to determine the race of each student, the application of which could be inconsistent across schools. Significance of study: the study contributes an analysis of the interplay of "the reporting of American Indians in educational settings, the relationship to

school district accountability measures, and existing federal data with which to compare the basic count” (p. 24).

**Sandefur, G. D., Rindfuss, R. R., & Cohen, B. (Eds.). (1996). *Changing numbers, changing needs: American Indian demography and public health*. Washington, DC: National Academy Press, National Research Council. Available at: <http://www.nap.edu/read/5355/>.**

In this edited collection, Sandefur et al. focus on the complexity of identifying American Indians (AI), as well the policy implications of health and socioeconomic disadvantages that contribute to a hard-to-count and hard-to-reach AI population. Comprising four sections, this volume interweaves the demography and health of American Indians illustrating the need for more research on this population and caution among policy makers when comparing AI data over time and/or across data sets. Among other measures, the authors suggest the utilization of ranges rather than point estimates for projections of AI population growth. Another notable finding is due to its small size, the AI population (and other small populations) are susceptible to data errors. The authors cite a study of the 1950 census where a small error in the punch card system falsely coded middle-aged white men to teenage American Indian widows. The low error rate did not have an effect on the numbers for middle-aged white males, but it dramatically increased the number of teenage American Indian widowers (see <http://www.tandfonline.com/doi/abs/10.1080/01621459.1962.10480663>). While these types of data errors may not be visible in larger populations, they can have a significant impact on the size and composition of smaller populations.

Papers in the four sections of this report utilize aggregate population data, including data from the census, the Panel Study of Income Dynamics, the Indian Health Service’s Survey of American Indians and Alaska Natives, and other national surveys. Very few examples of disaggregated data are mentioned. In his chapter on sampling issues among the AI population, Ericksen (pp.113-129) provides insight into the opportunities and challenges of examining AI data at the subpopulation level. He cites the Strong Heart Study (see <http://aje.oxfordjournals.org/content/132/6/1141>) as an example of tribal level data analysis. The study sampled 1,500 people from the tribal rolls of 11 federally recognized tribes. While the size of each tribal sample enables tribal comparisons, a major limitation of the study is the inability to generalize to the full AI/AN population enumerated in the census. It is suggested that in order to make AI/AN data more meaningful, it must capture the diversity of the subgroups within the AI/AN population. This is difficult to operationalize, however, given that the Alaska Native population is much smaller than the American Indian population and requires extensive oversampling. Geographic dispersion compounds this burden, and such constraints are even further amplified when considering estimates at the tribal level.

Central themes in this collection are the “ambiguity” of the AI population, and the paucity of available data on American Indians in large national data sets relative to other ethnic minority groups. As a result, less is known about American Indians than many other populations in the US. The authors further note the methodological difficulties that arise in studying the AI population, especially considering the high rates of shifting self-identification, exogamy,

subgroup diversity, and changes in tribal membership criteria. These “changing numbers” warrant particular attention in demographic research with American Indians, and in the determination of health service provision due to unreliability of population predictions and other population statistics.

**Sarche, M., & Spicer, P. (2008). Poverty and Health Disparities for American Indian and Alaska Native Children: Current Knowledge and Future Prospects. *Annals of the New York Academy of Sciences*, 1136, 126–136. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2567901/>.**

This report describes current inequalities and their effect on AI/AN children. The report reviews gaps in the current knowledge and potential early interventions to address development challenges in AI/AN children. This overview documents demographic (mostly U.S. Census Bureau data and NCES data), social (DOJ, CDC, and IHS data), health (also CDC and IHS), and health care disparities affecting AI/AN children. Some of the gaps in knowledge include: data on children exposed to domestic violence, extent of traumatic loss, studies on urban American Indian health, and studies of interventions targeting young AI/AN children. The authors note frustration in the focus of many studies documenting disparities and problems but not as many studies on interventions that consider the unique cultural and social context of AI/AN people. Many studies focus on lack of service as opposed to effective interventions. More work should be done on what works and for whom. Cultural strengths include extended family, parenting, and child-rearing beliefs.

The authors note that educational disparities exacerbate other disparities (demographic, social, health) and may be causally related to disparities driven by poor health literacy and health behavior. The AI/AN Head Start Research Center attempts to address education disparities and acknowledges that school settings can play an important role in promoting Native children’s development in culturally supportive ways. Literature points to goals for Native education that include: working collaboratively with communities to determine the goals and activities of educational programming, identifying different norms for behavior and education goals by reconsidering the validity of educational achievement, accommodating different learning styles, and supporting school infrastructure such as trained school staff.

**Schulhofer-Wohl, S., & Todd, R. M. (2015). High death rates on the High Plains: A call for better data on American Indian communities. Paper presented at the NCAI Mid Year Conference. Available at: <https://www.minneapolisfed.org/indiancountry/research-and-articles/cicd-blog/high-death-rates-on-the-high-plains>.**

This article reports on a pattern of persistently high mortality rates in group of counties in the Northern Plains and Midwest that have a high proportion of AI/AN people living on reservations. Importantly, the authors found that non-natural causes of death (e.g., accidents, suicide, murder, and poisoning), although often occurring at a high rate in these counties, are not the primary cause of the high overall death rates. Rates of death by natural causes are persistently quite high in most of the counties in this high-mortality cluster. The authors note

that there may be conditions or best practices in the low-mortality AI/AN communities that could be replicated to reduce mortality rates in other AI/AN communities, which would require a better understanding of why mortality rates are so high in some AI/AN communities and yet quite low in others. They suggest the need to create more geographically precise data on health and mortality specifically for American Indian reservations and other communities with high AI/AN populations.

**Schultz, J. L., & Rainie, S. C. (June 3, 2014). "Good Data Leads to Good Sovereignty," Indian Country Today Media Network. Available at:**

**<https://indiancountrymedianetwork.com/news/opinions/good-data-leads-to-good-sovereignty/>.**

This editorial points out the lack of quality data for AI/ANs and how this problem hinders the development of tribes, but also creates a space for tribes to better practice sovereignty. The authors call for more tribes to be involved in their own data collection as it allows tribes to be strategic, responsive, and culturally authoritative. They also note that tribes already have a lot of data collected from federal programs that is not being used, but this data can have the potential to be converted for strategic use if further analyzed and linked to other data sets. The tribes collecting and analyzing their own data will allow tribes increased sovereignty and the ability to tell their own stories with self-collected and trusted data.

**Tafoya, G., Chavez C. J. (2007). Healthy people, healthy community: A profile of the health of Santa Clara Pueblo. Albuquerque, NM: Santa Clara Pueblo Governor's Task Force on Youth & Families; Pueblo of Santa Clara, Office of the Governor; LithExcel Communication Services.**

This report sets out to frame a profile that details the health status of the Santa Clara Pueblo to inform community planning. It also identifies quality of health care, existing health resources, and gaps in health services. The profile is the first step in completing a community health assessment and represents a partnership between Santa Clara Pueblo, Indian Health Service, the New Mexico Department of Health, the University of New Mexico (UNM), and the UNM Center for Rural and Community Behavioral Health. The report showcases how one tribal nation prioritizes health data and the types of data disaggregation that are important to its purposes, such as age, gender, language speakers, and county.

**The Administration for Children & Families Office of Family Assistance. Requirements for Tribes and States Concerning Service Areas and Populations for Tribal TANF Programs [TANF-ACF-PI-2005-03]. Section 412 of the Social Security Act and Federal regulations at 25 CFR 20.100 and 45 CFR 286.20, 286.30, 286.75, and 286.160. Available at:**  
**<http://www.acf.hhs.gov/programs/ofa/resource/policy/pi-ofa/2005/pi200503htm>.**

This policy document stipulates the service area and eligible population for Temporary Assistance for Needy Families (TANF) programs operated by AI/AN tribes. TANF utilizes definitions used by the Bureau of Indian Affairs for the administration of its support programs. These definitions are the standard by which data are collected in this federal program. The funding levels for Tribal Family Assistance Grants are generally determined by data collected

and submitted by states. Tribes can include all AI/AN families residing on the reservation in their eligible population, regardless of tribal membership. Moreover, tribes can also consider non-AI/AN families residing on the reservation, with state approval. If a tribe wishes to administer its Tribal TANF program, it must submit a Letter of Intent, clarify its administrative capacity and other requirements. Specific questions are raised, such as “ How can ‘unaffiliated American Indian or Alaska Native families’ be included in a Tribe's service population?” and “If two or more Tribes seek to serve the same area and population and cannot agree to a mutually acceptable arrangement, what are the roles of the State and ACF in resolving this matter?”

The following definitions apply to the Tribal TANF program: “*Service area* means a geographic area designated by the Assistant Secretary where financial assistance and social services programs are provided. Such a geographic area designation can include a reservation, near reservation, or other geographic location. *Near reservation* means those areas or communities designated by the Assistant Secretary that are adjacent or contiguous to reservations where financial assistance and social service programs are provided. *Reservation* means any federally recognized Indian tribe's reservation, pueblo, or colony.”

**The Associated Press. (November 28, 2003). “Rejecting 2000 Census Counts, Tribes Are Tabulating Their Own,” *The New York Times*. Available at:**  
<http://www.nytimes.com/2003/11/28/national/28CENS.html>.

This article presents the case of over 100 AI/AN tribes contesting their tribal population numbers in the 2000 Census. It features the Warm Springs Indian Reservation efforts to challenge the 2000 Census data by conducting their own count to receive a more accurate level of funding. When Warm Springs finished their challenge count they found that Census had an error rate of 14 percent. It also identifies a series of challenges for enumerating AI/ANs, especially those living on reservations, including high rates of mobility, large and changing household sizes, varied definitions of AI/ANs, and mistrust. According to a spokesperson for the Department of Housing and Urban Development (HUD) quoted in this article, “78 tribes had completed their recounts and 39 had won challenges to their official numbers.” The right of tribes to contest census counts is authorized under the 1996 Native American Housing Assistance and Self Determination Act. The article does not identify how tribes contested the census counts, nor whether the tribal recounts were accepted by any other federal department aside from HUD.

**Thompson, S. C., Woods, J. A. & Katzenellenbogen, J. M. (2012). The quality of Indigenous identification in administrative health data in Australia: Insights from studies using data linkage. *BioMed Central Medical Informatics and Decision Making* 12: 133. Available at:**  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3536611/>.

The authors survey eight studies conducted in Western Australia and New South Wales that performed data linkages to improve existing knowledge of Indigenous health indicators and differentials. As in the U.S., the under-identification of Indigenous status was plaguing the health care system and resulting in severe over- and under-estimations of disease incidence. In Australia, “there are three components to the definition of an Aboriginal and/or Torres Strait

Islander Australian: descent, self-identification and community acceptance”—and in administrative datasets, only self-identification is used as a metric. Yet across the country, there was a gap between how patients were self-identifying at interview and how they were being reported in hospital records—roughly 10-20 percent of Indigenous patients were being mislabeled. The Australian Institute of Health and Welfare developed correction factors to improve these outcomes, increasing the accuracy to upwards of 97 percent in many regions. The first Australian linkage system was developed in 1995 and consists of links within and between seven state-based core population health datasets, clinical datasets, and other national administrative databases—on mortality, births, cancer, mental health, etc.—spanning up to 40 years.

The authors speak to the complexities of the interview and self-identification process, including the fact that “some people are reluctant to ask questions on Indigenous status, out of concern for causing offense” and “differences in the way the question is asked or perceived differences in how Indigenous people are treated may contribute to some of the variability in an individual’s identification.” And depending on the kind of data, the collection process varies. For mortality data, funeral directors rely on a relative to identify Indigenous status, whereas infectious disease data are obtained through direct patient-provider interviews. When the data were linked to Indigenous status, rate ratios increased for mortalities (indicating under-estimation) and decreased for STI/BBVs (indicating over-estimation). The authors conclude that there is great value in linking datasets, yet recommend that researchers undertake sensitivity analyses under different identification scenarios—and name the ranges in which the true parameters lie in order to make more explicit “the measurement error that is ubiquitous in administrative health data.”

**Tribal Epidemiology Centers (TEC). (2013). Best practices in American Indian & Alaska Native public health: A report from the Tribal Epidemiology Centers. Available at: <http://www.glitc.org/forms/epi/tec-best-practices-book-2013.pdf>.**

This article presents an overview of the various Tribal Epidemiology Centers (TECs) and their core functions and projects, and presents an argument as to why TECs are best equipped to obtain, analyze, and disseminate accurate AI/AN health data. One reason is that TECs have local, community-based strategies to support data collection in a trusted and informed way. The TECs have data sharing agreements, adapt data gathering practices to local needs of the community, and work with trained tribal staff to access the data. TECs also help inform the design of state and federal public health surveillance systems to reduce and prevent racial misclassification among AI/AN patients. On a local level, they “perform targeted data linkage studies to identify regionalized misclassification rates to reduce under-counting of health events and underestimated disease and mortality rates.” To work against the exclusion of AI/ANs from analyses due to their small population size, the TECs recommend oversampling or stretching the sampling timeframe to every 3-5 years, for example. They are also actively involved in developing local, culturally-guided adaptations of national surveys and increasing community participation in the data collection process.



**United Nations, Department of Economic and Social Affairs, Division for Social Policy and Development, Secretariat of the Permanent Forum on Indigenous Issues. (2004). Workshop on data collection and disaggregation for Indigenous People. New York: International Labour Office. Available at:**

**[http://www.un.org/esa/socdev/unpfii/documents/workshop\\_data\\_ilo.doc](http://www.un.org/esa/socdev/unpfii/documents/workshop_data_ilo.doc).**

This paper provides an overview of the availability, types, sources, and uses of data pertaining to Indigenous and tribal people in countries that have ratified ILO Convention No. 107 or No. 169 where the data has been submitted to the ILO as part of the supervisory process. Data concerning indigenous and tribal people is not found only within the context of Conventions Nos. 107 and 169. The Forced Labour Convention, 1930 (No. 29); the Discrimination (employment and Occupation) Convention, 1958 (No. 111); and the Worst Forms of Child Labour Convention, 1999 (No. 182) are all of relevance to Indigenous and tribal people. There is some discussion about the difficulties in comparing data as a result of different definitions of Indigenous and tribal people across nations. Findings from the report indicate that the current status of data on Indigenous and tribal people gathered within the context of the ILO's supervision of Conventions Nos. 107 and 169 shows considerable disaggregation and documentation in about 60 percent of ratifying countries. A summary of data on socio-economic status, education, health, land, development projects, development infrastructure, labour and employment, and human rights violations is provided. Some findings include the following: 1) while some information is provided on the provision of and access to services, there is a need for further data on the quality of the services provided to Indigenous and tribal people; 2) disaggregation is rarely available at a tribal level, but is occasionally provided for all Indigenous people as compared to the national population; 3) Indigenous people are often excluded from national policy due to a lack of disaggregated data; 4) countries that have ratified Convention No. 169 include more consideration for Indigenous cultures in collecting and reporting education and health data than do those that have ratified Convention No. 107; 5) economic and political interests drive data collection in the context of development and create a need for independent data collection and tribal consultation; 6) there is a need to link existing data on geographic infrastructure to that about the infrastructure needs facing Indigenous populations; 7) there are opportunities to strengthen the collection of labour data (e.g., ongoing collection of child labour by ILO) on Indigenous people, as well as a need to improve understanding of the informal economy and work conditions facing these communities; 7) there is evidence that while NGOs provide a great deal of data from Asia, Europe, and Latin America, Indigenous people are not often involved in the collection of their own data. A few existing reports noted include the Report of the National Commission for Scheduled Castes and Schedules Tribes in India and the Greenland Statistical Yearbook.

**Van Dyke, E. R., Blacksher, E., Echo-Hawk, A. L., Bassett, D., Harris, R. M., & D. Buchwald. (2016). Health disparities research among small tribal populations: Describing appropriate criteria for aggregating tribal health data. *American Journal of Epidemiology*. doi: 10.1093/aje/kwv334.**

Authors used the Tribal Participatory Research framework to solicit community input from five small tribes in Washington, Idaho, and Montana on what type and level of aggregation would

be appropriate in work with tribal health data. The research questions driving this project were: 1) How can data on small tribal populations be included in regional or national programs of research and health surveillance without sacrificing accuracy?; and 2) Which factors should be considered when aggregating tribal health data? Results from interview and focus group data indicate that five criteria are important in guiding tribal health data, including: geographic proximity (linked to similarities in culture, lifestyle, and history; e.g., Coast Salish or Pacific Northwest); community type (defined by local population density, landforms, and natural resources – characteristics deemed more important than physical proximity; e.g., rural/urban, coastal/inland); environmental exposures (e.g., to contaminants); access to resources and services (e.g., disparities in health care, affordable and healthy food, education, and physical activity); and economic development (related to overall affluence, employment and joblessness, and economic sustainability).

**Wascalus, J. (February 25, 2016). “Building stronger Native communities through data,” *Federal Reserve Bank of Minneapolis, Community Dividend*. Available at: <https://www.minneapolisfed.org/publications/community-dividend/building-stronger-native-communities-through-data>.**

This article is an interview with Eileen Briggs about the Cheyenne River Tribal Ventures Voices Research Project of the Cheyenne River Sioux Tribe, an effort to collect tribal level data on a broad range of economic, social, and educational indicators. The interview goes over in detail about the efforts of the survey to gather high quality data about the reality of lives for people living on the reservation not captured by other surveys. The accuracy and quality of the data collected and analyzed at the tribal level has shown to be valuable for a better understanding of the community and used for grant needs and other programming.

**Washington State Board of Education. (2016). Data spotlight: New disaggregated data and work plan for the 2016 Biennial Report on the Indicators of Educational System Health. Olympia, WA: Author. Available at: [http://www.sbe.wa.gov/documents/BoardMeetings/2016/May/110\\_DataSpotlight.pdf](http://www.sbe.wa.gov/documents/BoardMeetings/2016/May/110_DataSpotlight.pdf).**

A key goal of the Washington State Board of Education’s 2015-2018 Strategic Plan is to analyze achievement and opportunity gaps through the disaggregation of student demographic data. This memo provides disaggregation of 2015 Smarter Balanced Assessment results for the Native American student group. The analysis shows considerably different assessment results by tribal nation student groups. The memo includes maps showing the districts where Native American students are enrolled. The goal of further disaggregation is to improve outcomes for the Native American student group and to use data to communicate priorities to the state legislature. One of the major issues facing the state is the small size of the Washington state tribal groups when compared with the larger “Other American Indian” (n= approx. 19,000) and “Alaskan Native” students (n= approx. 2,200) in state data. Further, the small size of many Washington state tribal groups of students means that several grade levels had to be combined to meet the federal suppression threshold of 10 students designed to protect student privacy, which prevented disaggregation at the district and school levels. Findings indicate that there are disparate assessment results among the tribal student groups within Washington. For instance,

on the 2015 ELA SBA in grades three through eight combined, 65 percent of students who identified with the Samish tribe met standard on the state assessment while 33 percent of students who identified with the Lummi tribe met standard, thus showing a large gap of 32 percentage points. In Math, the results were similar with a 31 percentage point gap between Samish students at 52 percent proficient and Lummi students at 21 percent proficient.

**Westat. (2006). Data on health and well-being of American Indians, Alaska Natives, and other Native Americans: Data catalog. Washington, DC: US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Human Services Policy. Available at: <https://aspe.hhs.gov/sites/default/files/pdf/74856/report.pdf>.**

This study reviewed federal survey, research survey, state and community survey, and administrative databases to document the nature of information on AI/AN/NA population characteristics and measures of health and well-being. It differentiates between health policy issues such as the measurement of health status and factors contributing to measured health disparities and well-being issues such as economic well-being and family well-being. The value of this study is in the extensive descriptions of what is available in existing data sources and some input about the quality of these data.

**Westat. (2007). Gaps and strategies for improving AI/AN/NA data: Final report. Washington, DC: US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Human Services Policy. Available at: <https://aspe.hhs.gov/sites/default/files/pdf/74926/report.pdf>.**

Building off the Westat (2006) study, this report summarizes a review of 67 data sets and interviews with 13 experts related to the quality of AI/AN/NA health data hosted by DHHS. The review included information on dataset availability in 10 policy areas (e.g., child well-being, education, health, housing, justice system). Key findings revealed that there were no data sets available to examine child well-being, elder well-being, justice system issues, and military/veterans issues. Strategies are presented to address several data issues such as: small population sizes; geographic dispersion and rural concentration of the AI/AN population; misclassification of race; lack of/inconsistent collection of race identifiers in some data sources; inadequate racial representation, limited response rates and question interpretation; and inadequate collection of data on AI/AN subgroups. The report recommends a DHHS-wide coordinated approach to implementing suggested strategies, coordination and sharing of results across federal agencies, increased work with states on race identifiers, and consultation and involvement of tribes as partners to improve data.