

Indigenous Epidemiology:

An Introduction to the Urban Indian Health Institute's Data Dashboard for Identifying Health Priorities among Urban Native Populations

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**Urban Indian
Health Institute**
A Division of the Seattle Indian Health Board

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**Welcome! Let us begin
in a good way...**

Learning Objectives

- Identify elements and applications of the Data Dashboard regarding its content, capabilities, and limitations for program planning, interventions, and community needs and health assessments.
- Increase knowledge regarding data points and analyses performed showing health disparities between urban American Indians and Alaska Natives (AI/AN) and non-Hispanic Whites (NHW).
- Describe how the use of the Data Dashboard will illustrate differences among urban American Indians and Alaska Natives and non-Hispanic Whites for various Urban Indian Health Programs service areas.

Tribal Epidemiology Centers

TRIBAL EPIDEMIOLOGY CENTERS



Tribal Epidemiology Centers





Who are urban Indians?



Who are urban Indians?



1,289,490

American Indians and Alaska Natives alone or in combination with other races



78%

of American Indians and Alaska Natives live off reservation



71%

of American Indians and Alaska Native live in urban areas

Urban Indians are Tribal people living off federally defined tribal lands and currently residing in urban settings

Reasons for Living in Urban Areas

- Original Inhabitants
 - e.g. the Duwamish in Seattle
- Forced Residents
 - AI/ANs forced to move due to various public policies (e.g. the Termination Era)
- Permanent Residents
 - Locals, professionals, students, employment seekers
- Medium and Short Term Visitors
 - Those who temporarily relocate (e.g. medical services)

Who is the Urban Indian Health Institute?



- One of 12 Tribal Epidemiology Centers (TECs)
- Established in 2000 , UIHI serves Urban American Indians and Alaska Natives (AI/AN)
- Supports the Urban Indian Health Network
 - 62 organizations including Urban Indian Health Programs and urban Indian social and health service organizations
- UIHI's mission is to decolonize data for indigenous people by indigenous people
- Unique features
 - National scope
 - Only TEC integrated into an UIHP, Seattle Indian Health Board

Urban Indian Health Institute

- 30 Public Health Professionals
- Over 100 years experience in Public Health
- Epidemiology and Evaluation departments
- 8 trained epidemiologists
- 60 years experience in epidemiology and statistics
- 50 years experience in evaluation
- 80 years experience working with AI/AN population



Urban Indian Health Programs



Urban Indian Health Institute Projects

- HIV/Hepatitis C
- Epidemiology Surveillance
- **Community Health Profiles**
- Diabetes
- Suicide Prevention
- Domestic Violence
- Sexual Violence
- Methamphetamine Use
- Cancer Mortality
- Mortality Linkage
- Good Health and Wellness in Indian Country
- Epidemiology Data Mart
- Demystifying Data
- Red Vision
- Maternal and Child Health
- Elders Health
- Adolescent Health
- Indigenous Foods and Practices

What are Community Health Profiles?

Community Health Profiles

- Since 2009, UIHI has provided an overview of the health status of urban AI/AN people living in UIHP service areas
 - National aggregate report of 101 urban counties
 - 31 individual UIHP service area reports
- Based off national census and surveillance data (i.e. ACS, Vital Statistics, etc.)
- Used for program planning, grant writing, and identifying data gaps

Indicators

**Socio-
demographics**

Mental health

**Social determinants
of health**

**Maternal and child
health**

Mortality

**Sexually
transmitted
infections**

Substance use

- Sociodemographic
 - Population/Race
 - Unemployment
 - Poverty
 - Education
 - Health Insurance
 - Housing
 - Food Stamps
- Mortality
 - All-Cause
 - Homicide
 - Suicide
 - Top 5 Mortalities
 - Top 5 Cancer Mortalities



- Sexually Transmitted Diseases
 - Chlamydia
 - Gonorrhea
 - Syphilis
- Maternal and Child Health
 - Total births
 - Education of mother
 - Martial Status
 - Cesarean Section
 - Maternal Mortality
 - Gestational Diabetes
 - Maternal Smoking
 - Prenatal Care
 - Infant Mortality
 - Premature Births
 - Low Birth Weight
 - Admission to NICU



- Substance Abuse

- Tobacco Use
- Alcohol Use
- Binge Drinking
- Alcohol Use or Dependence
- Marijuana Use
- Marijuana Abuse or Dependence
- Pain Reliever Use
- Pain Reliever Abuse or Dependence
- Illicit Drug Use

- Mental Health

- Adult Mental Health
- Youth Mental Health



Data Sources

**American
Community
Survey**

**National Survey
of Drug Use and
Health**

**2010 National
Census**

**National
Notifiable
Disease
Surveillance
System**

**National Vital
Statistics
System**



Analysis and Methods

- AI/AN defined as AI/AN-only (unless otherwise specified)
- Non-Hispanic Whites (NHW) used as comparison population
- Urban definition – varies by data source
- Two to six-year aggregates used to stabilize estimates and protect privacy
- Confidence intervals used in some analysis
- Significance testing at p-value of <0.05
 - Chi-square
 - Odds ratios
 - Confidence Intervals

Data Limitations

- Small sample size can limit some indicators in individual UIHP service areas
- Data only available for AI/AN-alone, not AI/AN in combination with another race
- Racial misclassification
- Underestimates

Making Data Actionable



Identify strengths-based programs and interventions and research opportunities



Assist in program planning, grant writing, and advocacy



Identify health priorities



Document and assess health disparities and resiliency

Data Visualization

Why visualize data?

- Customization of data
 - users select indicators and services areas of interest
- Identify relationships between data
- Tell a story through data

Beta testing

- UIHI conducted beta testing with partner agencies
 - Denver Indian Health and Family Services, Inc.
 - Native American Lifelines
 - Alaska Native Tribal Health Consortium
 - Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion
 - National Indian Health Board
 - University of Colorado, Denver



Dashboard 101



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A Division of the Seattle Indian Health Board

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OUR BODIES, OUR STORIES

Sexual Violence Among Native Women in Seattle, WA

[Click here to read the report](#)

*The content in this report may be triggering.

The mission of Urban Indian Health Institute is to decolonize data, for Indigenous people, by Indigenous people.

Urban Indian Health Dashboard

Click the map below to view.



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URBAN INDIAN HEALTH

According to the US Census, approximately 71% of American Indians and Alaska Natives (AI/AN) live in urban areas. The urban Indian population is composed of self-identified AI/ANs who are currently living off federally defined tribal lands in metropolitan areas.

Urban Indians experience a disproportionate burden of disease, including chronic disease, infectious disease and unintended injury with extraordinarily high levels of co-morbidity and mortality. For all AI/ANs, there are systemic issues which give rise to health disparities: genocide, uprooting from homelands and tribal community structure, bans on cultural practices and language, racism, poverty, poor education, and limited economic opportunity. In addition, for urban AI/ANs, forced relocation due to 1950's federal relocation and termination policies is another contributing factor. Today, AI/ANs come to the city for educational, employment or housing opportunities, and health care needs, resulting in an indigenous urban population that is enormously diverse and inter-tribal.

To meet the unique health needs of urban Indians, there are numerous programs located across the United States that are culturally grounded and focus on providing holistic care. These include private, non-profit corporations funded in part under Subchapter IV of the Indian Health Care Improvement act who receive limited grants and contracts from the Indian Health Service. In addition, there are numerous social service and faith-based organizations serving the public health needs of urban AI/ANs. We define these as Urban Indian Health (UIH) service areas.





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- Gestational Diabetes by Age Group
- Maternal Smoking
- Maternal Smoking by Age

HEALTH

Approximately
 100,000
 Alaska Natives
 and
 1.5 million
 urban Indian
 Americans
 have been
 identified
 as
 Urban Indian
 Health (UIH)
 service areas.

Disproportionate
 mortality rates
 for chronic disease,
 injury with
 disability and
 morbidity and
 mortality rates
 are systemic
 disparities:
 health care
 access and
 quality, poverty,
 poor
 opportunity,
 and
 geographic
 location

Access to the
 health care
 system for housing
 needs,
 and
 population
 growth in
 inter-tribal.

To meet the unique health needs of urban Indians, there are numerous programs located across the United States that are culturally grounded and focus on providing holistic care. These include private, non-profit corporations funded in part under Subchapter IV of the Indian Health Care Improvement act who receive limited grants and contracts from the Indian Health Service. In addition, there are numerous social service and faith-based organizations serving the public health needs of urban AI/ANs. We define these as Urban Indian Health (UIH) service areas.





METHODS AND ANALYSIS

For each indicator presented, a point estimate that determines a prevalence or incidence was calculated for the AI/AN population and compared with the NHW population. The point estimate may be a rate, such as a death rate, or a frequency, such as the percent of individuals living in poverty. Because NHWs are the racial/ethnic majority, this population was chosen as the comparison group.

The AI/AN population was defined as AI/AN only (not in combination with other races) unless otherwise indicated. The NHW population was defined as White only and excluded the Hispanic population unless otherwise indicated. Results were calculated using aggregate data from a two- to six-year time-period in order to have sufficient data to provide stable estimates and protect individual privacy.

For some data displayed in the dashboard, confidence intervals were calculated and used in comparisons to determine significant differences between aggregate UIH data points and individual UIH data points. Confidence intervals were calculated at a p-value of <0.05, the 95 percent confidence level. Differences between the study and comparison groups were considered significant if confident intervals did not overlap between both groups. In addition, significance testing between study and comparison groups for some indicators was performed using a chi-square testing with a probability level (p-value) of 0.05 to determine a statistically significant difference in results. Lastly, relative risks (rate ratios) were calculated to show the risk of outcomes between aggregate UIH data and individual UIH data.

For data displayed in the dashboard that compares outcomes between individual UIHs, relative risks were calculated; however no statistical tests were completed. Interpretation of results and any inferences should be made with caution.

Data points within this dashboard that indicate 0% can be interpreted that the point estimate was 0%. Data points with missing data can be interpreted that data was not available for the indicator or the n-value for the indicator was too small.

Data analysis for indicators were analyzed using StataSE version 13 or SAS version 9.4.

*The data does not reflect any individual (clinic-level) data for any urban Indian area.





INDICATORS AND LIMITATIONS

INDICATOR SELECTION

A list of indicators was selected after conducting an analysis of the available data sources. Sample size and stratification of each population based on demographics, such as age groups, gender, and education, were considered.

This dashboard uses national surveillance data, which may or may not include patients served directly at UIHs. There may be information not captured by these systems that better represent the unique strengths and challenges in communities served by UIHs. Local sources of data may provide a more region-specific and comprehensive understanding of the community's health.



DATA LIMITATIONS

Although data analysis and assessment of results were conducted for all indicators, data limitations were observed and experienced during the selection of these indicators and their analyses for this report. In some instances, the number of cases/sample size was limited, thus impacting the analysis and preventing or limiting the reporting of results. Frequently, data was only available for AI/ANs alone and was not inclusive of AI/ANs who also identify with another race or ethnicity. Thus, the estimates provided in this report may be an underestimation of the true value of the outcome or behavior for any indicator analyzed in this report.

Another factor affecting and limiting the analysis of data are errors in racial misclassification, particularly for demographic and mortality data. Racial misclassification is defined as incorrect coding of an individual's race or ethnicity in public records. This can greatly underestimate the true rate of disease, risk factor, or outcome. AI/ANs are especially likely to experience problems of incorrect classification on death certificates; therefore, true mortality rates among AI/ANs are assumed to be higher than reported numbers suggest. Because mortality data are extracted from death certificates, the race/ethnicity category is not self-reported and is often completed by a funeral director based on information received from a family member or personal observation. In a national sample, age-adjusted mortality for AI/ANs was underestimated by 9.7%. The bias created by misclassification varies by age, proximity to a reservation, and cause-of-death. Based on documented racial misclassification of AI/ANs in surveillance data, any of the health disparities presented in this community health profile are assumed to be larger than reported.



DATA SOURCES

2010 U.S. Census

The U.S. Census takes place every 10 years and provides official population counts for individuals living in the United States and provides information by age, race, Hispanic origin, and sex. In 2010, the U.S. Census allowed individuals to self-report belonging to more than one race group. When determining a population count, this report considers people to be of AI/AN race if they report AI/AN as their only race or if they report being AI/AN in combination with other races. Some Census statistics are not easily accessible when including individuals who report multiple races. For these indicators in the profile, only individuals who report AI/AN alone are included.

For more information about the U.S. census, visit:
<https://www.census.gov>

American Community Survey

The American Community Survey (ACS) is a nationwide, continuous survey that collects demographic, housing, social, and economic data every year. To provide reliable estimates for small counties, neighborhoods, and population groups, the ACS provides 1-, 3-, and 5-year aggregate estimates. Estimates for this report are from aggregated data from 2010-2014.

Race is self-reported on ACS, with similar race categories as the U.S. Census. However, some ACS data are not easily accessible for multiple race groups. Therefore, ACS data are reported for AI/AN alone in this report. ACS estimates in this profile are not adjusted for age; observed differences in estimates may be due to a true difference in rates or due to differences in age distribution in the population.

For more information about the ACS, visit:
<https://www.census.gov/acs>



National Notifiable Disease Surveillance System

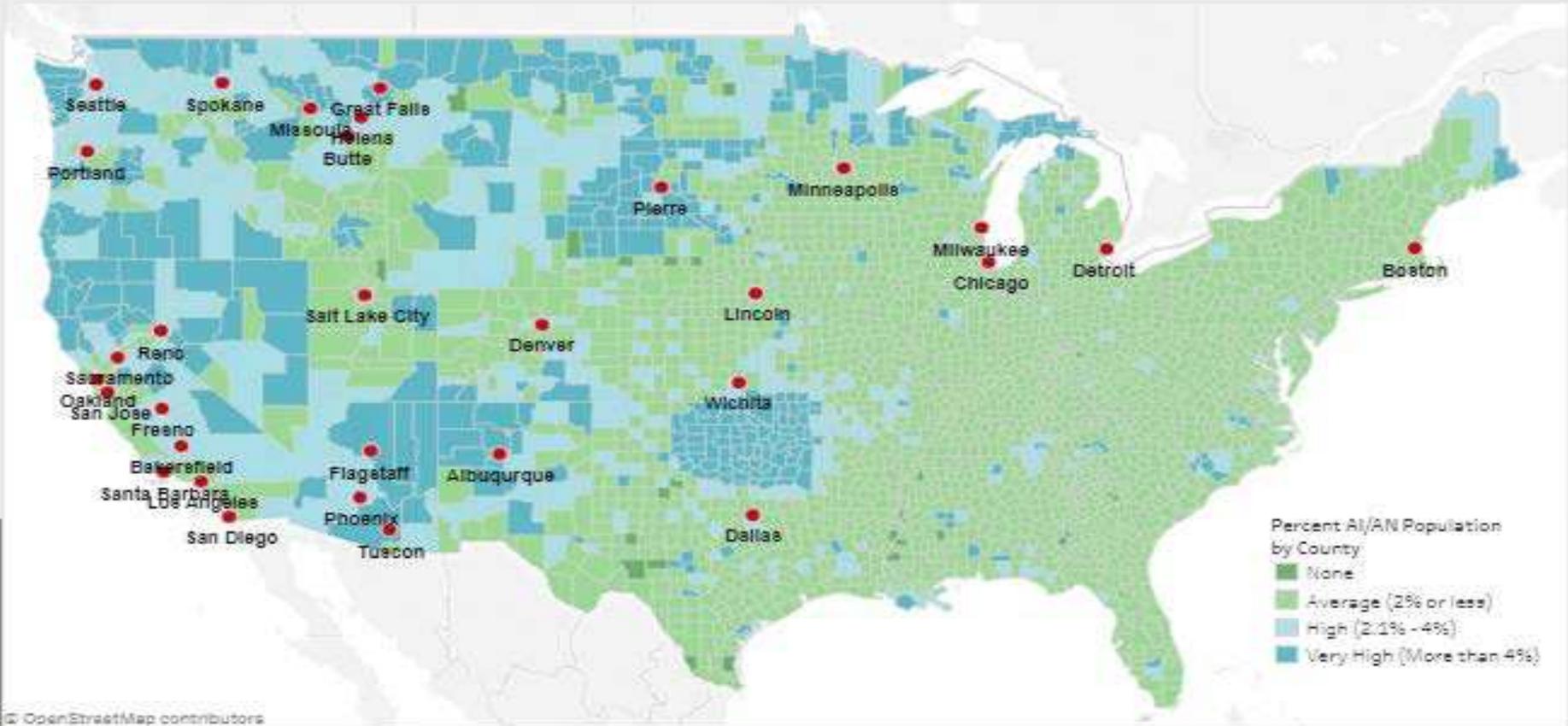
Sexually transmitted diseases (STDs) are a component of the National Notifiable Disease Surveillance System (NNDSS) and incident cases are submitted to the Centers for Disease Control and Prevention (CDC) from state health departments and other local reporting jurisdictions. Case definition for STDs are outlined in Case Definitions for Infectious Conditions under Public Health Surveillance. The majority of cases are reported in non-STD clinic settings, such as private physician offices. It is mandatory that reportable disease cases be reported to state health departments when identified by a health provider, hospital, or laboratory; however, it is voluntary that notifiable disease cases be reported to CDC by the state for national surveillance. Data for this report include analysis on chlamydia, gonorrhea, and syphilis from aggregated data from 2010-2014. Estimates of rates are based on the counties for the UIH service areas.

For more information about NNDSS, visit:
<https://www.cdc.gov/nndss/>



UIH LOCATIONS

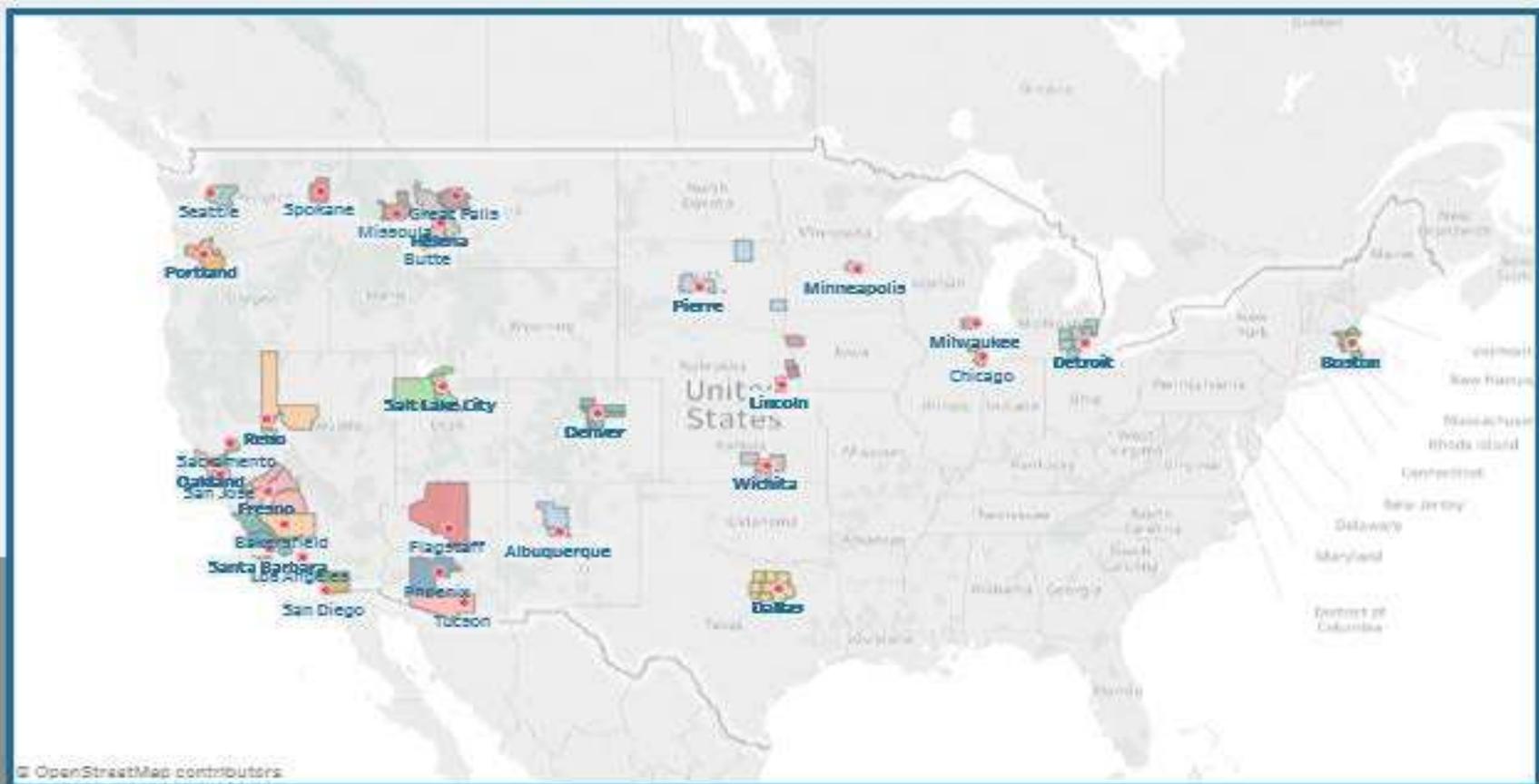
The map below identifies urban Indian health areas. Shading indicated the AI/AN population density in the area.



Data source: 2010 U.S. Census

UIH SERVICE AREAS

The map below identifies counties used in this analysis. These areas include but not limited to, high density AI/AN population and urban indian health areas defined by IHS. You can select a specific geography to see a more detailed map of the counties in the service area.





Geography:
 Compare to:



SOCIODEMOGRAPHICS

Age and Gender



Relative to the NHW population, the AI/AN population in the All UIH Service Areas service area was younger. In the All UIH Service Areas service area, 41.5% of AI/AN males were under the age of 25 years, compared with 28.2% of NHWs. In contrast, 6.4% of AI/AN males were over the age of 65 years, compared with 14.4% of NHWs.

This difference in the representation of AI/AN populations over the age spectrum may reflect inequities in access to health care resources or overall inequities in social determinants of health experienced over the average life course of AI/AN people living in the All UIH Service Areas service area.

All UIH Service Areas Age and Gender, 2010-2014

Comparison/Race: Female Male





SOCIODEMOGRAPHICS

Age and Gender



Geography
 Bakersfield

Compare to
 Albuquerque

Relative to the NHW population, the AI/AN population in the Bakersfield service area was younger. In the Bakersfield service area, 39.8% of AI/AN males were under the age of 25 years, compared with 28.5% of NHWs. In contrast, 7.8% of AI/AN males were over the age of 65 years, compared with 17.4% of NHWs.

This difference in the representation of AI/AN populations over the age spectrum may reflect inequities in access to health care resources or overall inequities in social determinants of health experienced over the average life course of AI/AN people living in the Bakersfield service area.

Data Source: American Community Survey

Bakersfield Age and Gender, 2010-2014

Comparison: Albuquerque
 Female
 Male

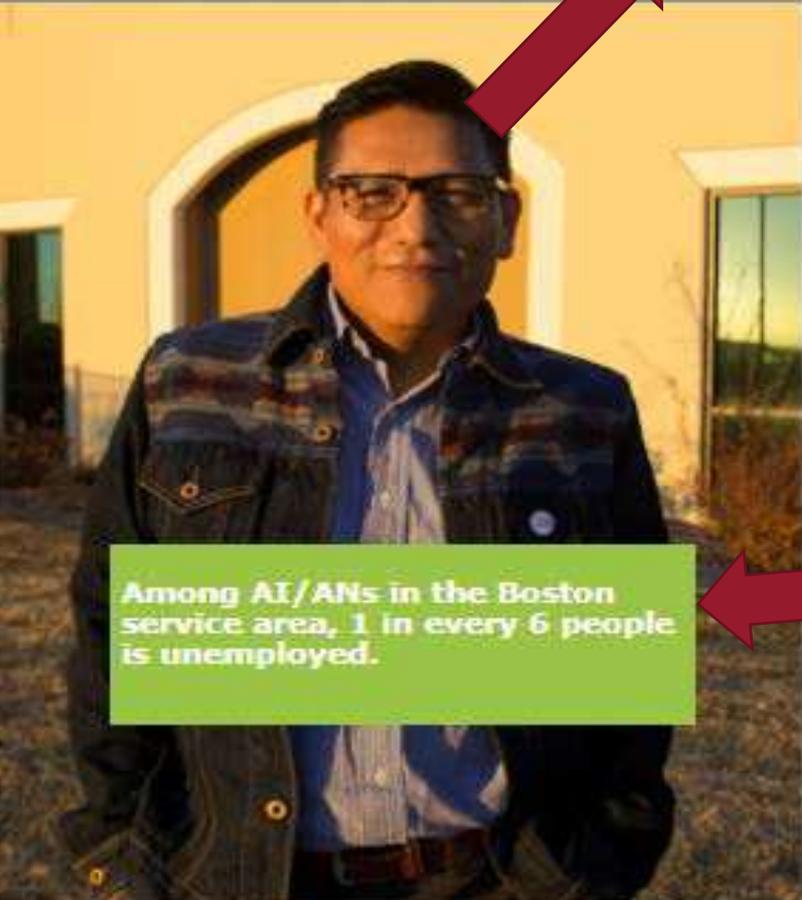




SOCIODEMOGRAPHICS

Unemployment

RANK 12 of 30

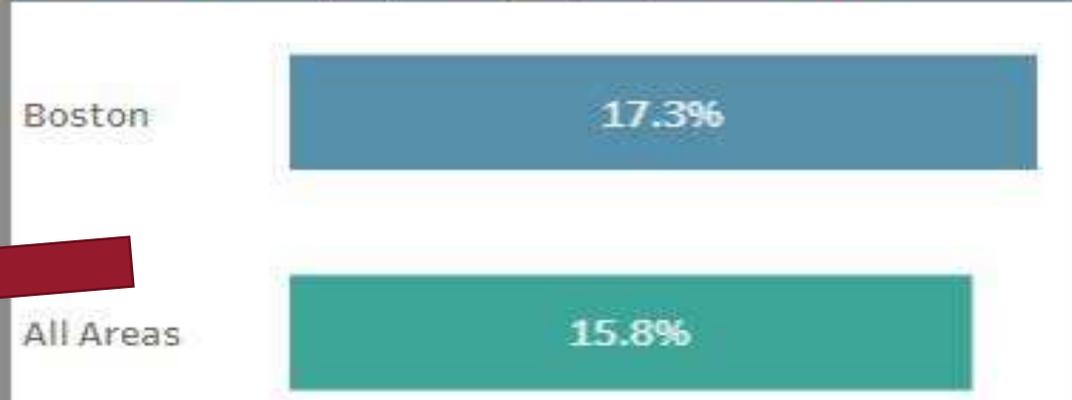


Among AI/ANs in the Boston service area, 1 in every 6 people is unemployed.

Extensive evidence has shown that unemployment has a negative effect on health. Unemployed individuals may experience financial insecurity and reduction in social status, social relations, and self-esteem. In addition, unemployed individuals are also more likely to lack health insurance coverage.

Unemployment numbers shown reflect the civilian labor force 16 years and older. These proportions do not include individuals in the military or individuals who are institutionalized.

Percent of Unemployment, AI/AN, 2010-2014



Comparison groups should be interpreted with caution as some comparisons were not statistically tested.

Data source: American Community Survey

SOCIODEMOGRAPHICS

Educational Attainment

RANK
8
OF 31

The relationship between education and health, or the "health-education gradient," is well documented. Disparities in life expectancy by level of education are found among all demographic groups and are arguably increasing over time.



The proportion of AI/ANs in the Boston service area whose highest level of education obtained was a high school diploma or equivalent was 1.3 times higher than in the Chicago service area.

Educational Attainment, AI/AN, 2010-2014



Comparison groups should be interpreted with caution as some comparisons were not statistically tested.



Geography: Dallas Compare to: All UIH Service Areas

MORTALITY

Top Mortality Causes

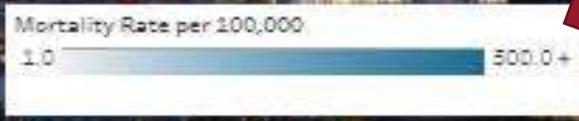
Let's Compare
1. Select Race, Gender and Category options on each side below
2. Select a Geography above
3. Select the same or a different value in the "Compare to" option

Geography

Table with columns: Cause, Rank, Mortality Rate. Data for Dallas (deaths per 100,000, 2010-2014). Top causes: Vascular disease (432.6), Cancer (58.2), Flu and pneumonia (17.2), Chronic liver disease and cirrhosis (10.8), Intentional self-harm (6.2).

Compare to

Table with columns: Cause, Rank, Mortality Rate. Data for All UIH Service Areas (deaths per 100,000, 2010-2014). Top causes: Vascular disease (254.3), Cancer (189.6), Chronic lower respiratory disease (45.1), Alzheimer's disease (35.3), Diabetes (19.1).



Geography

All UIH Service Areas

Compare to

non-Hispanic Whites

MATERNAL & CHILD HEALTH

Births by C-Section



Almost 1 in 3 women in the US give birth by cesarean section.

While medically necessary cesarean sections can prevent maternal and infant mortality and morbidity, there is no advantage for women who have the procedure electively. Possible complications include infection, hemorrhage or increased blood loss, injury to organs, and extended hospital stay.

Births by C-Section, All UIH Service Areas, 2008-2012

AI/AN

28.1%

NHW

31.3%

The proportion of AI/AN mothers in all UIH service areas who gave birth by C-section was 10.2 % lower than for NHWs.

MATERNAL & CHILD HEALTH

Maternal Smoking

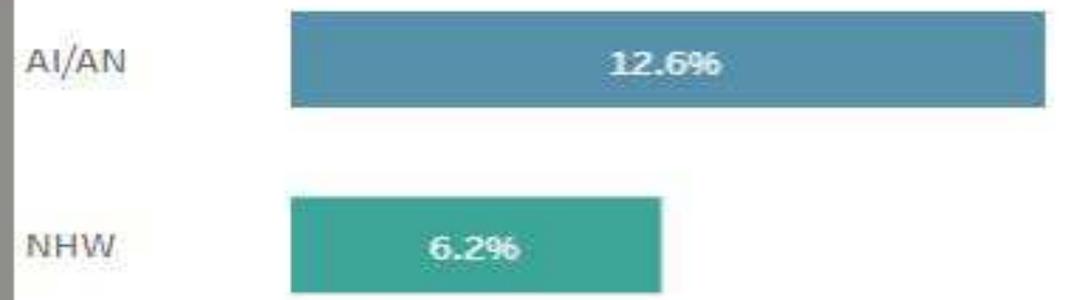


Smoking before and during pregnancy is the single most preventable cause of illness and death among mothers and infants. Maternal smoking can result in complications during the delivery for the mother and her newborn, and may result in adverse outcomes for the infant.

Complications include low birth weight, preterm birth, ectopic pregnancy, miscarriage, stillbirths, slow fetal growth, placenta previa and abruption, severe vaginal bleeding, intrauterine growth restriction, sudden infant death syndrome (SIDS), and birth defects.

The proportion of AI/AN mothers in all UIH service areas who smoked while pregnant was 2.0 times higher than for NHWs.

Maternal Smoking, All UIH Service Areas, 2008-2012



Data source: National Vital Statistics System



MATERNAL & CHILD HEALTH

Maternal Smoking

RANK
25
of 27



Smoking before and during pregnancy is the single most preventable cause of illness and death among mothers and infants. Maternal smoking can result in complications during the delivery for the mother and her newborn, and may result in adverse outcomes for the infant.

Complications include low birth weight, preterm birth, ectopic pregnancy, miscarriage, stillbirths, slow fetal growth, placenta previa and abruption, severe vaginal bleeding, intrauterine growth restriction, sudden infant death syndrome (SIDS), and birth defects.

The proportion of AI/AN mothers in the Albuquerque service area who smoked while pregnant was 41.3 % lower than in the Bakersfield service area

Maternal Smoking, AI/AN, 2008-2012

Albuquerque

3.7%

Bakersfield

6.3%

Sexually Transmitted Diseases

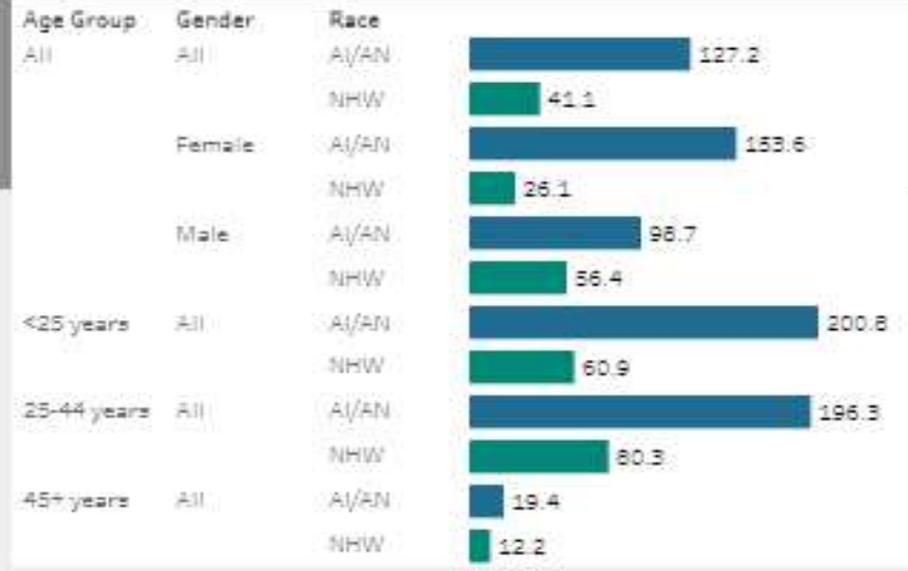


Sexually transmitted diseases (STDs) are an essential component of reproductive health and wellbeing. STDs impose a significant burden on the U.S. healthcare system, estimated to cost as much as \$16 billion annually. In addition, STDs do not affect the population equally; gender, age, and racial disparities are well-documented. The CDC estimates that more than 20,000 women in the U.S. become infertile each year due to undiagnosed and untreated STDs.

Gonorrhea is the second most common sexually transmitted disease reported in the US and shares many of the same epidemiologic patterns as chlamydia; the disease disproportionately affects minorities and infection may cause permanent reproductive damage in women.

The rate for AI/AN females was 1.6 times higher than AI/AN males. However, among NHWs, infection rates for males were over two times higher than their female counterparts.

Gonorrhea Infection Rate per 100,000, All UIH Service Areas, 2010-2014



Data source: National Notifiable Disease Surveillance System

SUBSTANCE USE

Alcohol Use



A causal link between alcohol and over 60 medical conditions has been found, with alcohol having a negative effect in most of those cases. According to the National Survey of Drug Use and Health (NSDUH), from 2009-2014, among AI/ANs living in urban areas, 44.2% reported using alcohol in the past month, which is significantly lower than 59.5% of NHW. While the stereotype that AI/ANs consume more alcohol than Whites is widespread, national survey findings have actually shown that AI/ANs report greater abstinence from alcohol and lower numbers of light/moderate alcohol use.

Alcohol Use in the Past Month, 2009-2014



Data represents NSDUH Urban Areas.
 Data source: National Survey on Drug Use and Health



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UIHI

A Division of the Seattle
Indian Health Board

Dashboard Survey

1. Name

50 characters left.

2. Your office phone number

50 characters left.

3. Your email address

50 characters left.

4. The agency you work for

50 characters left.

5. Your job title

50 characters left.

6. How would rate your overall experience with the data dashboard?

Very Poor

Poor

Fair

Good

Excellent



Comment:

Funding for dashboard development was provided by:

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(Grant # **AIAMP120015**)

and by the Epidemiology Program for American Indian/Alaska Native Tribes and Urban Indian Communities through the Indian Health Service
(Grant # **HHS-2016-IHS-EPI-0001**)

Next Steps...

Reclaim narratives of indigenous health and well-being



Thank you!
Questions?



**Urban Indian
Health Institute**

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