

# Urban Indian Community Responds to an Information Crisis

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Over the past three decades in the United States, American Indians and Alaska Natives (AIAN) have steadily relocated from rural and reservation communities to urban centers throughout the nation. Urban living may provide more opportunities for American Indians and Alaska Natives, but their departure from the reservation has typically resulted in the loss of health care. Historically health care was provided by the federal Indian Health Service, which has only a handful of facilities in urban areas. Although 61 percent of American Indians and Alaska Natives live in urban areas, according to the 2000 Census, only 1 percent of the Indian Health Service budget goes to address urban AIAN health. This lack of support is evident in all aspects of resources dedicated to urban AIAN, including incomplete and fragmented data collection systems that handicap urban Indian health organizations from effectively describing health needs and advocating for resources to address those needs.

In an effort to address the problem of inadequate data, the Seattle Indian Health Board established the Urban Indian Health Institute ([www.uihi.org](http://www.uihi.org)) in July 2000. The Institute's mission is to provide centralized, nationwide management of health surveillance, research, and policy considerations regarding the health status of urban American Indians and Alaska Natives.

Economic, cultural, social, and historical factors have led to severe health disparities among urban American Indians and Alaska Natives. According to 2000 US Census data, compared to all races combined, this urban group experiences higher death rates from accidents (38 percent higher), chronic liver disease and cirrhosis (126 percent higher), and diabetes (54 percent higher). Alcohol-related death rates are 178 percent higher. (Existing national data sources grossly underestimate the extent of health needs among urban AIAN as a result of inadequate data collection and racial misclassification on official documents.)

The Seattle Indian Health Board is one of 34 nonprofit, community-based urban Indian health organizations that contract with the Indian Health Service to provide assistance to off-reservation and urban American Indians and Alaska Natives. Similar to community health centers but with an expanded focus, most of these organizations provide medical and dental care, and lab, pharmacy, nutrition, and mental

health services within a primary care model. However, these programs go beyond primary health care. Most also offer an array of public health and community health activities designed to improve the overall health status of urban American Indian and Alaska Native people. These services include traditional healing and access to culturally specific and appropriate care.

## Building a research database

The Urban Indian Health Institute is unique in that it provides a mechanism to focus attention on the work of the 34 urban Indian health organizations so that a unified set of data can be acquired to address the urban AIAN health needs and clarify health disparities. Unifying data from 34 different agencies is no small task, but it is made possible by using Web-based technology as the primary data-gathering tool. Data collected by the Institute include service description, utilization of the services, patient-specific data, and population disease prevalence. This information is crucial for describing the health status of the population. To establish its infrastructure, the Institute solicited financial support from local foundations to purchase hardware, and pursued software donations to build the data-gathering platform.

The Web-based data collection system demonstrated its effectiveness in early 2001

when an inquiry was made about the activities of the 34 urban Indian health organizations operating under a new diabetes initiative. The organizations were asked to provide data on the success of the initiative's interventions, which enabled them to offer services to address the burden of diabetes in the population. Within days after the request, 30 of the 34 organizations submitted program service and disease prevalence information via the Web-based survey tool.

The information allowed the Institute to deliver a data-supported response, demonstrating the success of the initiative. This demonstration of success helped reinforce the value of the urban Indian health organizations as effective means to address the diabetes epidemic in Indian Country. It also resulted in additional resources for the urban Indian health organizations. The success of this approach illustrates the importance of using centralized data collection by an organization that understands the scientific, cultural, and political characteristics of inquiry and that can respond rapidly and effectively.

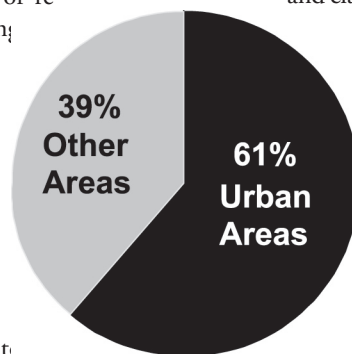


Figure 1. US AIAN population living in urban areas. (US Census, 2000)

After completing its first major demonstration, the Institute continued pursuing an information baseline necessary to conduct systematic studies of health and social conditions of urban AIAN that can be compared to other groups.

Because no definition of program scale existed, the first challenge was to determine the size of the urban AIAN population to establish a denominator for future calculations. Taking into consideration what data would be most accessible, the Institute started by asking the 34 urban Indian health organizations to define their service areas by using US counties, so that the resulting data could be compared to other US populations. Through this approach, the Institute determined that the 34 organizations offer assistance to American Indians and Alaska Natives living in 94 US counties in 19 states.

Since its inception, the Institute has completed a number of studies necessary to understand the health disparities experienced by urban American Indians and Alaska Natives. These studies include identifying the long-term care needs of urban AIAN elders, identifying the prevalence of urban AIAN adult tobacco use, and determining the screening barriers for breast and cervical cancer (*for a complete list of studies and projects, visit [www.uihi.org](http://www.uihi.org)*).

## Building a community-driven research agenda

The Institute was created out of frustration with existing research efforts and the lack of government attention to the needs of this special population. All too often, research fails to offer information useful to the community. Urban American Indian and Alaska Native communities tend to be small in population and highly diverse in both geographic and tribal affiliation.

The Institute's research model differs somewhat from what is typically considered community-based participatory research in that communities serve as true partners, identifying the areas of research and ensuring that the findings from those projects are used to help communities meet their self-identified needs. By design, the Institute is located in a community health and social service organization. This unorthodox location facilitates the Institute's participatory approach by ensuring that the sponsoring organization's obligation is directly to the community being served. Governed by an AIAN-majority community board of directors and directed by an urban American Indian, the goals and mission of the Institute directly reflect the needs and concerns of the urban American Indian and Alaska Native community.

The Institute's research model is based on the fundamental need for communities to play an active role in determining their health status. American Indians and Alaska Natives recognize the importance of participating in appropriate and meaningful research among their people, especially when it means they can live healthier and fuller lives. The Institute's approach emphasizes the need for community involvement at all stages of the research process. It also creates learning opportunities that foster the equitable exchange of knowledge and ideas between communities and researchers. Examples include establishing community advisory boards, steering committees, and workgroups

with community member leadership and decision making authority. In addition, the Institute uses qualitative research methods, such as focus groups, cognitive interviewing, surveys, pilot tests, and discussions to solicit community input

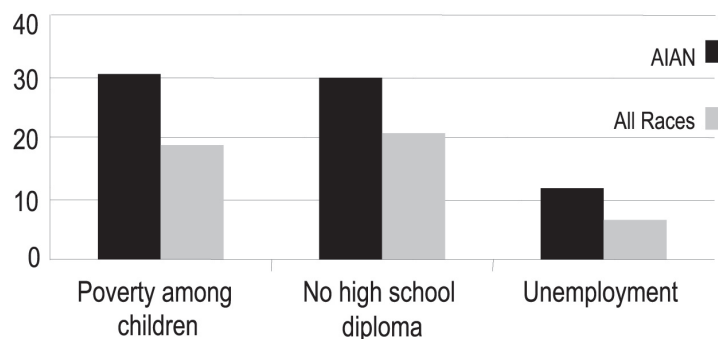


Figure 2. Percent of socioeconomic disparities among AIAN and all races in counties with urban Indian health organizations (US Census 2000)

on project designs, materials, and methods. Any initiative that is community-responsive must ensure an authentic community voice. The Institute is fully engaged in a collaborative approach to its research in which the community representatives participate directly in the research.

The need for research and public health surveillance must include an understanding of the cultural and anthropological aspects of communities if effective solutions to health disparities are to be discovered. The Urban Indian Health Institute has successfully demonstrated that science and culture can be merged. The Institute strives to meet the needs of the urban AIAN community and the organizations that serve them, while using acquired information to help define a national agenda to address health disparities that afflict urban AIAN across the nation.

Community-based research efforts are time and resource intensive. However, despite limited resources and faced with the overwhelming requests for help, the Institute has successfully implemented innovative strategies and techniques that meet the needs of the communities and certainly raise awareness of the value of using research to guide program and service delivery. With greater awareness to the plight of urban American Indians and Alaska Natives and their health needs may come more resources and support. With more resources, the urban Indian health organizations will be able to deliver a broader array of assistance to the American Indians and Alaska Natives who need them the most. ■

### Authors

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### Resources

Indian Health Service Fact Sheet. US Department of Health and Human Services. [www.ihs.gov/PublicInfo/PublicAffairs/Welcome\\_Info/ThisFacts.asp](http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/ThisFacts.asp).

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