MEDICAL CARE
Volume 41, Number 5, pp 579–581

Editorial

Measuring Disparity Among American Indians and Alaska Natives; Who's Counting Whom?

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During a periodic seminar on American Indian health issues, I always ask the students to guess the states in the U.S. with the largest American Indian and Alaska Native (AI/AN) populations. They rarely get the correct answer. Guess for yourself and check your answer below.* Surprise greets the answer as few people recall ever being on a sovereign American Indian (AI) nation or reservation in California. Who are the Indians of California and why are we not aware of their presence or their health concerns? Health care policy for California's AI residents highlight four key themes in United States American Indian and Alaska Native (AI/AN) demography and health policy today: tribal sovereignty and self-determination, urbanization of the AI/AN population, racial misclassification of health data, and the prevalence of health disparities. In their article "Disparities in Hospitalization of Rural American Indians",[1] Korenbrot et al touch on all four of these themes.

Disparity is the current "code" word used in the U.S. to describe inequalities in health status and health care delivery between specific populations, which are defined by income status, geography, race or ethnicity. Despite the recent emphasis on research regarding disparities, the prevalence of health status disparities for many racial and ethnic minorities is not new in the U.S., especially among America's Native American population. In its report to Congress in 1936, the U.S. Public Health Service carefully documented the marked disparities in health status between Indians living in the lower 48 states and those of the general population. Ultimately, the Indian Health Service (IHS) was created as a separate health care system for AI/AN people not only to deliver health care, but to track and eliminate the disparities that existed.[2] Today, the Indian Health Service, a $2.9 billion agency of the U.S. Public Health Service, still lists as its mission "to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level." Though the disparities have changed in type and magnitude, the IHS has little reason to change its current mission in 2003.

The movement toward tribal self-determination and sovereignty has radically altered the landscape of Indian health care in the United States over the past 20 years. At its birth in 1955, the IHS system was highly centralized and focused equal emphasis on delivering both public health and personal health care. Twenty years later, the federal authorization of the Indian Self-Determination and Education Assistance Act (1975) and the Indian Health Care Improvement Act of 1976 permitted tribes to gradually take control of the IHS hospitals

*According to the 2000 census the top three, in order, are California (333,346), Oklahoma (273,290) and Arizona (255,879). The states with the highest proportion of AI/AN in their population are Alaska (15.6%), New Mexico (9.5%), and South Dakota (8.3%).

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and clinics that had been serving them.[3] Today's IHS system is continuing to rapidly devolve into a set of independent health care systems run by tribes or tribal-consortia. Health care for enrolled AI tribal members in California is an excellent example of the "new" IHS model. California does not have any federally administered clinics or other health programs for the direct care of the IHS-enrolled population; their direct care is delivered entirely by the 31 independent tribal clinics or by contract with private providers. In 2001, California tribal health programs had a total of 107,219 registered users (a cumulative total of those that ever used services) and 66,617 active users (those that used services within the past 3 years).[4]

This arrangement contrasts sharply with care in other regions of the U.S. For example, in much of North and South Dakota, the Indian Health Service delivers both personal and public health services directly in a centralized system of clinics, hospitals and field operations.

Enhanced *tribal sovereignty* and the slow devolution of the IHS means that the central surveillance functions are at risk of weakening or even disappearing. In the traditional, vertically organized IHS system, health data flowed from the local service unit, to a regional administrative office, and then to IHS headquarters. This system resulted in the production by IHS of uniform, high-quality health surveillance reports for the population it serves, and has provided some of the broadest documentation on health status disparities for any U.S. ethnic or racial group, especially in rural areas.[5] The centralized collection of health surveillance data, especially hospitalization data, will be a greater challenge as more states begin to resemble California's system of independent tribal clinics. Some tribes may elect to opt not to report key health statistics to IHS, but for other tribes, self-determination may offer an opportunity to redefine indicators of health status and utilization for their populations. For example, the Northwest Portland Indian Health Board has an Indian Community Health Profile Project in which a core set of 15 health status indicators were developed by and for the participating tribes.†

The *urbanization* of the American Indian population in the lower 48 United States is one of the most important American Indian demographic trends of the late 20th century. Some American Indians live on or near reservations situated near metropolitan regions but still retain their access to tribal or IHS services. However, many urban American Indians either are not enrolled with a tribe or live distantly from their tribal home, making access to tribal or IHS care very difficult. There are approximately 34 urban programs at 41 sites that are funded by IHS to serve American Indians and Alaska Native clients. The collection of health surveillance data for all urban Indians, especially those residing outside of traditional IHS service areas, has never been mandated or assured. Currently, there is no mechanism for the measurement of disparities for this population.

Racial misclassification of hospital discharge data are another key theme and a major finding of the work by Korenbrot et al.[1] Racial misclassification can be a major obstacle in the health surveillance of racial and ethnic minority populations and may obscure disparities in health status measures or health care. Misclassification of race is a problem that the Indian Health Service, tribes and research investigators have recognized in mortality data, the incidence of cancer, injuries and infant mortality.[6,7] The problem appears to be greatest in certain areas of the U.S., including California. In the study by Korenbrot et al, they found that 70% of hospitalizations of IHS-enrolled patients were incorrectly classified as non-Indian. This level of racial misclassification has not only led to large errors in health statistics, but has also adversely affected the allocation of financial resources from IHS to the affected health care systems. Records of American Indians are particularly prone to misclassification in some areas, perhaps because of their relatively small numbers in those areas, or because of the absence of reservations in the same area.

The true rates of hospitalization in the report by Korenbrot et al were reported to be almost 60% higher than for the California non-Indian population. The large apparent differences between the rate of hospitalizations for Indian and non-Indians raises further questions about the sources of these disparities in hospital care. Are California Indians hospitalized inappropriately? Can we attribute the higher rate of hospitalizations to higher rates of preexisting disease or to decreased access to preventive care? The high rate of avoidable hospitalizations reported in this study provides one possible clue to this puzzle. However, the selection of

†Examples of these indicators are available at: http://www.npaihb.org/epi/ichp/ichp.html.

the study population from a group of active clinic users also raises some concern that this population may have a disproportionately high rate of underlying medical problems and thus exerts a selection bias. We cannot make any assumptions. The American Indian population is very heterogeneous, with marked regional variation in rates of mortality, morbidity and healthy behaviors throughout the U.S.

How do studies like Korenbrot's help inform health policy? First, given that self-determination is a reality and will continue to expand, the Indian Health Service will not have all of the tools to address fully the disparities that currently exist. To be fully successful, partnerships will first need to be formed between tribal health authorities, states, the IHS, other regional tribal health boards and research institutions to mutually define the salient indicators for surveillance and to devise novel data linkages to achieve these aims. The authors' report that further database linkages are planned by the California Rural Indian Health Board and the California Department of Health Services is highly commendable and deserving of close attention. In the end, the resulting surveillance data will be of higher quality, with less racial misclassification. Second, a comprehensive solution to eliminating disparities among American Indians and Alaska Natives in the U.S. will not be found if urban, tribally unaffiliated Indian and Native people are not recognized as part of the population denominator. Several studies have demonstrated that the urban Indian and Native populations are at much higher risk of poor health outcomes than others residing in the same urban area.[8] This need not continue to be a controversial issue dividing tribes and urban Indian organizations if successful collaborations are formed across governments to define the problem and solve it. Though the IHS is woefully under-funded to adequately address urban needs (currently, the IHS spends approximately $32 million, approximately 1% of its budget, on urban clinic programs), it can work closely with state and local health department analysts to systematically examine and address the health needs of this population and assist with potential solutions.

We cannot eliminate disparities for any population until we can improve surveillance systems to better define the gaps in health status and access to care. The reduction of racial misclassification is clearly one important priority in this effort; including all urban Indian people in the denominator should be another.

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