

Research and Educational Approaches to Reducing Health Disparities Among American Indians and Alaska Natives

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Research and educational programs have the potential to improve health care. American Indians (AIs) suffer from considerable health disparities as compared with the general U.S. population, including significantly higher incidence and prevalence of preventable diseases like diabetes, alcoholism, and their complications. Underfunding of health programs, including the Indian Health Service, and lower socioeconomic status among AIs contribute to these disparities. Improvements in disease prevention and treatment potentially offered by research and health education programs could help to reduce health disparities. However, a history of nonparticipation in the research process and a history of dishonest research practices have raised barriers to conducting research in AI communities. Additional barriers are generated from a shortage of AI researchers and health care professionals. A research paradigm that includes the community as a full partner is necessary to promote research and education in AI communities and to translate health research into reductions in health disparities.

Keywords: health disparities; American Indians; Alaska Natives

The purpose of this article is to explore the role of research and education programs as a means to reduce health disparities in the American Indian and Alaska Native (AI/AN) population. Patterns of health disparities in this population will be described, and potential causes of health disparities will be discussed. Unfortunately, there is a shortage of AI/ANs in the health professions and research fields, leading to difficulty in developing culturally appropriate and acceptable systems of health education and research. A new paradigm for community-based participatory research will be described as a mechanism to promote active engagement of AI/AN communities as partners in the research process. If

successful, the potential exists to train more health professionals and researchers from these communities and to generate more knowledge specific to these communities that can be applied to reduce health disparities.

BRIEF OVERVIEW OF AMERICAN INDIAN HEALTH DISPARITIES

The AI/AN population experiences some of the most significant health disparities of any population in the United States. The overwhelming majority of disparities in health occur in the realm of preventable diseases. As a result, AI/ANs have among the shortest life expectancies of any population in the United States (see Table 1; Indian Health Service [IHS], 2001).

In Arizona, the average age of death from all causes for American Indians (AIs) is 54.7 years, whereas the average age of death for all populations is 72.2 years—a disparity of nearly 20 years (Arizona Department of Health Services, 2005). Specific disease processes that adversely affect AIs at disparate rates include diabetes, alcohol-related deaths, injuries, and suicide, among others (IHS, 2000). These diseases and causes of death are largely preventable, and the potential for interventions having a significant impact on reducing health disparities is great but only if newly identified interventions are made available to the AI population through appropriate means of translational research and education. Figure 1 shows death rates caused by type 2 diabetes comparing the U.S. population with the IHS population nationally and in the Phoenix-area IHS (which includes most of Arizona, Nevada, and Utah). The Phoenix area has among the highest rates of death caused by type 2 diabetes and alcohol in the IHS.

Figure 2 shows alcohol-related death rates for IHS populations as compared with the U.S. general population and the Phoenix-area IHS.

Both diabetes (Baer & Hanson, 2004) and alcoholism (Liu et al., 2004) have significant genetic components in terms of predisposition. However, the genetic components of the disease processes need to be placed into a larger context of socioeconomic, historical oppression, and a resultant culture of poverty.

TABLE 1
Life Expectancy for American Indians
and Alaska Natives in Years

Population	Men	Women	Total
Total U.S.	73.2	79.6	76.5
AI/AN	66.1	74.4	70.6
Disparity	7.1	5.2	5.9

SOURCE: Indian Health Service, 2001.

NOTE: U.S. = United States population; AI/AN = American Indian/Alaska Native population.

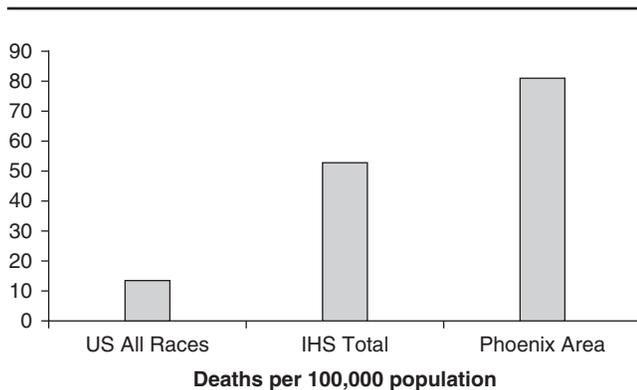


FIGURE 1. Diabetes Death Rates.

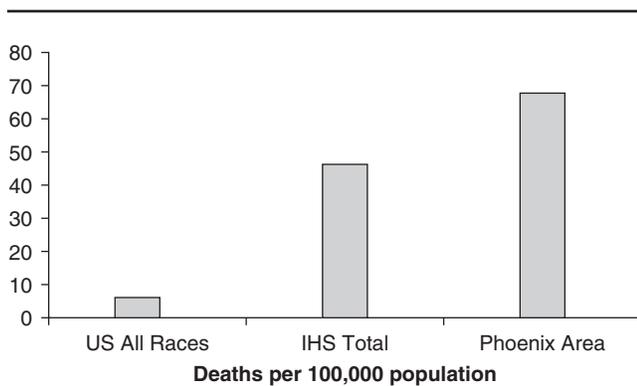


FIGURE 2. Alcohol-Related Death Rates.

There are several modifiers of disease patterns that may have an impact on health disparities. Potential causes for disparities in health include (a) genetic predisposition, (b) socioeconomic status, (c) access to and use of health care services, and (d) cultural factors (Institute of Medicine, 2003). The diversity of potential causes of health disparities necessitates a comprehensive, wide-ranging research agenda and educational approach

that is both culturally appropriate and based on community health needs.

POTENTIAL CAUSES FOR DISPARITIES IN HEALTH

Genetic Predisposition

A strong genetic component regarding risk for diseases like diabetes and alcoholism appears to exist. In addition, there may be a strong genetic influence on the development of complications of diabetes, such as end-stage renal disease (ESRD; Family Investigation of Neuropathy & Diabetes Research Group, 2003). Clinical experience demonstrates that some patients with diabetes progress more rapidly to diabetes complications like ESRD than do others, independent of blood sugar control. It is possible that genetic factors and/or other variables are at the root of the differences in the course of disease for individual patients. It will be important to identify these genetic factors and other potential variables to develop new diagnostic and screening methods as well as potential new interventions and standards of care. However, the genetic basis for these diseases is but one component of a much larger picture of Indian health that includes socioeconomic, poverty-related lifestyles, access to health care services, and cultural factors.

Socioeconomics

AI/ANs live under some of the most difficult socioeconomic conditions in the United States. Both income and educational attainment are independent predictors of health status (Deaton, 2002), and the AI/AN population has the lowest per-capita income and the lowest educational attainment in the country. Approximately 65% of the AI/AN population has a high school education as compared with 75% of the general U.S. population. Approximately 32% of the AI/AN population lives at or below the federal poverty level as compared with 13% of the non-Indian population (IHS, 2001). Figure 3 outlines these educational and income disparities.

In addition to the challenges created by reduced personal income and lower educational attainment, the system that provides health care to the AI/AN population is severely underfunded. The IHS, located within the U.S. Department of Health and Human Services, is the primary agency responsible for providing health care services to the AI/AN population. The basis for the IHS is rooted in a long history of treaties and legislation that established a trust responsibility on the part of the federal government to provide health care and other social services in exchange for land and natural resources (Bergman, Grossman, Erdrich, Todd, & Forquera, 1999). Unfortunately, the federal programs that provide services to the AI population under these treaty agreements have all been severely underfunded (U.S. Commission on Civil Rights, 2003).

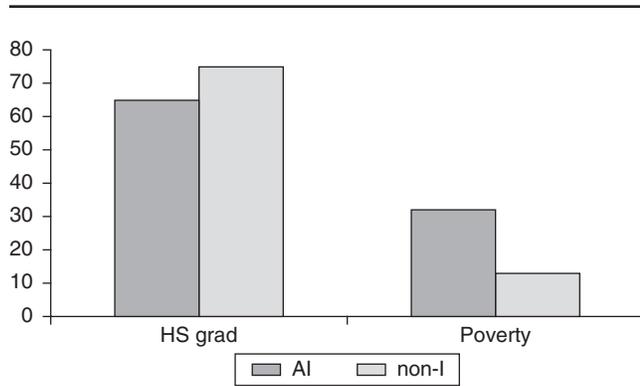


FIGURE 3. Percentages of AI High School Graduation and Poverty Compared With the Non-Indian Population.

Compared with other federally sponsored health care programs, the per-capita expenditures for the IHS are low. The 2003 per-capita funding of the IHS was \$1,805 per person as compared with \$3,501 for Medicaid, \$5,019 for Veterans Administration, and \$3,489 for the Bureau of Prisons (National Indian Health Board, 2003). This means that, on average, federal expenditures for the health care of prison inmates exceeds expenditures for AI/ANs. Ironically, based on treaties with the federal government, the only population in the United States that is born with a right to health care services is the AI/AN population. Clearly, the U.S. government is not living up to its trust responsibilities and obligations to provide adequate health care services to the AI/AN population. Figure 4 summarizes funding of several federally funded health programs.

Underfunding of Indian health programs is not exclusive to the IHS. The Bureau of Indian Affairs (BIA), an agency located in the U.S. Department of the Interior, operates many Tribal schools. Because of underfunding of BIA programs, many reservation schools do not have healthy food programs for children, and many do not have the resources necessary to provide daily physical education. This includes many of the reservations in Arizona, in which the population of children has among the highest risk for type 2 diabetes in the world.

The results of the Diabetes Prevention Program (DPP) Research Group (2002) provided scientific evidence that lifestyle interventions can prevent diabetes in high-risk populations. Again, given the inadequate financial support for key programs and poor linkages between research results and policy development, health care professionals working in AI communities are not able to implement state-of-the-art, DPP lifestyle interventions in populations that have the greatest need for diabetes prevention and health care intervention.

If the biomedical research and academic health professions communities are not made aware of these barriers to health promotion and disease prevention, tribal research agendas that are set by non-tribal members may not reflect the actual health needs of AI/AN communities.

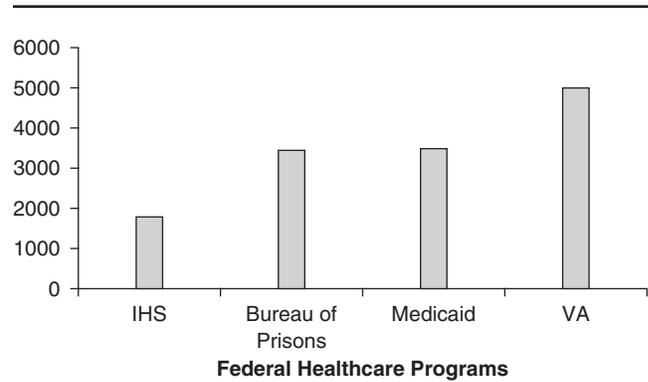


FIGURE 4. Per Capita Annual Funding.

Access to and Use of Services

Unfortunately, because of cost limitations, much of the advanced technology offered by numerous medical specialties are not available to AI/ANs (U.S. Government Accountability Office, 2005). In addition, even simple technologies that improve disease management are rarely available to AI/ANs. For example, once-a-day or long-acting medications for diabetes are typically not on the medication formulary for IHS facilities simply because of cost. The same medications in 2- or 3-time daily dosing are less expensive, and because the IHS is severely underfunded, the extended-release versions of these medications are generally not available to IHS patients. Numerous studies have shown the improved efficacy of once-a-day dosing as compared with 2- or 3-time-a-day dosing of medication, independent of the patient’s income or educational attainment (Eisen, Miller, Woodward, Spitznagel, & Przybeck, 1990). Historically, these studies have not been conducted among AI populations. Perhaps tribal leaders will identify this type of health-services research as a priority for community-based biomedical, translational, and health policy research.

Cultural Factors

Prior to 1930, there was only one documented case of diabetes (Hrdlicka, 1908) among the Southwest tribes that now suffer from among the highest rates of diabetes in the world (Knowler, Bennett, Hamman, & Miller, 1978). By 1930, dams were completed on the Salt River and Gila River in Arizona. These rivers had provided a yearlong supply of water used by the local tribes for farming (Haury, 1976). Food consisted of corn, beans, and squash; fish from the river; and wild game (Rea, 1997). Farming, hunting, and gathering necessitated increased activity levels. This healthy lifestyle came to an abrupt end with the damming of the rivers, and it was replaced with unhealthy food programs and lower activity levels. Many AI communities became dependent on federal-government-commodity food programs consisting of

refined sugar, bleached flour, white bread, lard or shortening, canned meat, peanut butter, and cheese. "Indian fry bread" is not a traditional American Indian food; it is the result of trying to make meals with commodity foods.

By the 1970s, some of the local tribes in the Phoenix area had among the highest incidence and prevalence of diabetes in the world. Clearly, this is not simply the result of a dramatic genetic shift from 1930 to 1970. Although genetic influences on predisposition to diabetes are likely, the genetic components in the AI population need to be placed in a larger context of adaptation to changes in physical environment, socioeconomically based behavioral patterns, limited opportunities for physical activity, and limited access to healthy food and health care services.

POTENTIAL BENEFITS OF EXPANDING BIOMEDICAL RESEARCH AND EDUCATION IN AI COMMUNITIES

Advances in biomedical research have the potential to reduce health disparities in populations that have poor health status; however, population-specific research also entails collective risk for these groups—including AIs (Foster & Freeman, 1998). It is imperative to include these groups and communities in research plans and discussions of the potential impact of research findings (Davis, 2000). A long-standing history of nonparticipation in research processes and in policy development for AIs has led to an undercurrent of distrust and misunderstanding regarding the motivations of researchers and policy makers (Foster, Bernsten, & Carter, 1998). To promote improvements in research and health status, AI communities need to be closely involved in the research process, including agenda setting, conduct of research, evaluation of programs, authorship, and publication (Foster & Freeman, 1998). Collaboration between individual communities and researchers is particularly important for interpreting data and disseminating results (Fisher & Ball, 2003). In addition, issues regarding ownership of data and intellectual property need to be formally addressed before initiating research projects.

It is important to recognize that there is no single AI or AN culture. More than 1,000 tribal groups exist in North America, each with a unique culture and system of beliefs. Although it is not appropriate to consider the AI/AN community as a single, homogeneous population, for purposes of simplicity, we will refer to the "community" with an understanding that tribal communities are distinctive groups with significant variations in culture, language, and beliefs. The application of research findings, or effectiveness of future health care interventions, will involve cultural issues related to treatment, recovery, and healing (DuBray & Sanders, 1999) as well as the distinctiveness of individual AI/AN communities (Hodge, Weinmann, & Roubideaux, 2000).

Historically, advances in medical science have generally resulted in health care interventions that are financially

expensive, and research results have not been linked to policy development that ensures that the populations with the greatest health disparities and the greatest need for interventions have access to new technologies. Because of severe underfunding of the IHS and other health-related programs for AI/ANs, advances in medical technology and health science typically have not been made available to AI/AN communities, which are commonly impoverished.

Albeit not an exhaustive list, some potential benefits of biomedical research for AI communities include (a) identification of markers for disease risk (e.g., ESRD), (b) new and more effective prevention strategies and treatments, (c) current treatment efficacy evaluations, (d) economic development opportunities, and (e) educational opportunities.

Although rates of diseases like diabetes are so high in some populations that essentially all community members are at risk, secondary prevention efforts such as preventing diabetes complications could be improved through biomedical and genetic research. If genetic markers are identified for diabetic complications such as ESRD, it is possible that standards of care regarding screening might be changed toward prevention and earlier identification of diabetic complications.

Unfortunately, there is a shortage of minority—and, specifically, AI/AN—health professionals and researchers. Although African Americans, Hispanics/Latinos, and AI/ANs together represent more than one fourth of the U.S. population, they comprise less than 9% of nurses, 6% of physicians, and 5% of dentists. Of the more than 16,000 new students who entered medical school in 2003, only 2,179 were African American, Hispanic/Latino, or Indian. Meanwhile, by the middle of this century, the U.S. population could be more than 50% non-White. The Sullivan Commission final report released in September 2004 brought to the fore a serious issue related to health care for minority populations: As fewer and fewer minorities become doctors, nurses, and dentists, the quality and availability of health care services for minorities will continue to suffer. Table 2 shows disparities in the numbers of health professionals for the AI/AN population.

Exacerbating the shortage of qualified health care professionals is the difficulty on the part of federal, tribal, and urban Indian health programs in recruiting and retaining health professionals in a competitive hiring market. Most Indian health facilities are located in isolated rural areas on or near reservations, making them extremely difficult to staff (www.ihs.gov). Increasing the number of AI/AN people serving their communities as health professionals and researchers has the potential to improve cultural appropriateness of care and research and to decrease shortages of providers in remote communities. Ultimately, there is an opportunity to significantly reduce health disparities through expanding educational opportunities. Clearly, educating more AI/ANs in health sciences and research needs to be a national priority.

TABLE 2
Disparities in Health Staff (per 100,000 people)

Health Professional	AI/AN	U.S.	Gap
MDs	73.9	220.6	66% lower
DDSs	24.0	61.8	61% lower
RNs	229.0	849.9	73% lower
RPh	42.8	71.3	40% lower

NOTE: MDs = medical doctors; DDSs = dentists; RNs = registered nurses; RPh = registered pharmacists.

Potential Barriers to Conducting Biomedical Research in AI Communities

Experience working in health care with AI communities reveals that trust is perhaps the most significant barrier to conducting biomedical research in such communities. As stated by Malcolm Bowekaty (2002), former governor of Zuni Indian Pueblo, "A large portion of research and researchers have been dishonest and unscrupulous when working among our American Indian and Alaska Native communities" (p. 146). Many questions are raised by the prospect of advancing biomedical and genetics research in AI communities, including the following:

1. Can the community members trust that the research team will conduct research in an appropriate manner with respect to issues like ownership of data and samples?
2. Will the research team use samples only for the purposes approved by the tribe?
3. Will the samples be handled respectfully, and will they be appropriately destroyed after a given amount of time?
4. In terms of data ownership, who will house the data set?
5. Will the community be involved in authorship and publication?
6. Will the research result in benefit to the community?

If communities do not believe that they have appropriate assurances of these and other issues, it is likely that they will not participate in research projects. The result is that the research process itself can lead to decreased research and increased health disparities if it does not include meaningful community participation. Involvement as a participating partner in all phases of research is likely to be a common goal for many AI/AN communities. This process can be reinforced by appropriate informed consent agreements at the community level to protect tribal interests (e.g., with Tribal Councils) and at the individual level to promote individual safety (e.g., with individual community members) (Burhansstipanov, 2002).

Another potential barrier to conducting research in tribal communities is the perception of benefit. If there is a perception that the tribe will not benefit directly, this might limit participation in research projects (Bowekaty, 2002). Also, the degree of direct community participation in all phases of the process can have an impact on whether a tribe agrees to participate at all in the research project. If there is

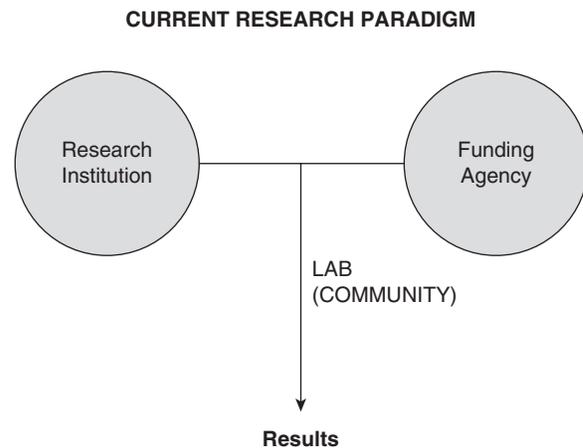


FIGURE 5. Current Paradigm for Research.

limited community participation, the people may decide not to allow the research to be conducted in their community. The historical model for research has fostered a sense of mistrust and a perception of little benefit because many communities feel that they have been treated more like laboratories and not as partners in the research process.

Proposed Paradigm for Community Participatory Research

The research paradigm itself can be a potential barrier to community participation and perceived benefit. The historical, and still current, research paradigm in most community settings is shown in Figure 5.

Under the current paradigm, the research process is essentially a partnership between a research institution (e.g., academic institution) and a funding agency (e.g., National Institutes of Health). The research institution and the funding agency work in partnership to obtain results. Research results can be defined as *publications* from the perspective of the research/academic institution, and results can be defined as expanding *scientific knowledge* from the perspective of the funding agency. In this setting, the communities being studied are often treated simply as a laboratory from which data are obtained, and the individual community members are treated as simply experimental subjects. In this setting, the community is not a genuine partner and does not play a role in setting the research agenda or in participating in the research development and implementation process.

A proposed new paradigm in which the community is treated as an equal partner in the research process is depicted in Figure 6.

In this paradigm, the community is an equal partner in the research process, and the community can define results in terms of *benefits* of research to their community. This model also allows for discussion of unique community

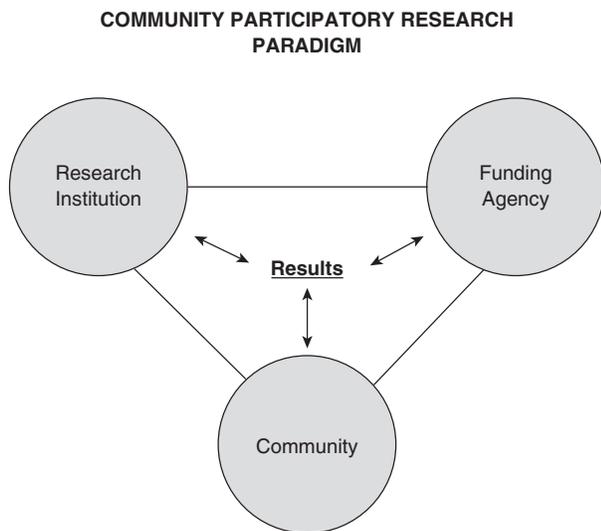


FIGURE 6. Proposed Paradigm for Participatory Research.

issues and barriers to improved health as well as those associated with research participants, their families, and the community in which they reside. Communities want to have an increased role in research agenda setting and in research design (Burhansstipanov, 2002). Providing the opportunity for communal discourse and community participation in the research process and education increases the likelihood of promoting cultural appropriateness, obtaining informed consent, and successfully completing the study.

When AI/AN communities become partners and co-researchers in the research process, potential benefits include (a) improved trust by providing communities a voice in research agenda setting and design, (b) increased benefit by involving the community in linking results to application through policy development, (c) greater understanding in the research and academic communities of cultural factors and other issues that lead to health disparities in the AI/AN population, (d) improved cultural appropriateness of research design, implementation, and characterization of results. Through advances in education, the opportunity exists to place community members not only in the community circle but also in the realms of research and academic institutions and funding agencies. This will also serve to promote culturally appropriate interactions among AI/AN communities and the biomedical community, and this can ultimately lead to reductions in health disparities.

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