Building Healthy Tribal Nations

Building Healthy Tribal Nations in Montana and Wyoming Through Collaborative Research and Development

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We describe a collaborative approach to reducing health disparities affecting Montana and Wyoming tribal nations while promoting health-protective practices and interventions among these populations.

Under the auspices of the Montana-Wyoming Tribal Leaders Council, a consortium has undertaken activities to (1) establish the research infrastructure necessary for conducting ongoing health disparities research, (2) develop a target research agenda that addresses tribally identified priority health issues and tests the feasibility of interventions, (3) develop increased research skills and cultural competency through mentoring activities, and (4) develop effective collaborative relationships. All research projects are user-defined and -authorized, and participation is voluntary. (*Am J Public Health.* 2005;95:784–789. doi:10.2105/AJPH.2004.051032.)

THE POOR HEALTH STATUS OF the American Indian/Alaska Native (AIAN) population, relative to the US population overall, has been well documented.[1] The AIAN population has a lower life expectancy and higher age-adjusted mortality rates, and the prevalence of several specific health indicators is dramatically higher than for the overall US population.[1]

There are also great disparities in health among AIAN subpopulations.[2] For example, American Indians served by the Indian Health Service (IHS) Billings Area (Montana and Wyoming) exhibit even poorer health status and lower life expectancy than the average for the overall AIAN population.[3] From 1994 through 1996, average US life expectancy was 75.8 years, average life expectancy of all American Indians and Alaska Natives was 71.1 years, and life expectancy for Billings Area IHS Indians was 67.2 years.

The lower life expectancy for Billings Area IHS Indians reflects the higher prevalence of and death rates associated with many serious health conditions (Table 1). The age-adjusted death rate from all causes is 83% higher than the US rate for all races, and 34% higher than the rate for all American Indians and Alaska Natives.

TABLE 1—Disparities in Death Rates for American Indians in the Indian Health Service (IHS) Billings Area (Montana and Wyoming): 1998–1999[3]

	Age-Adjusted Death Rate[a]	Percentage Above "All US" Rate	Percentage Above IHS Adjusted Total[b]
All causes	923.0	83	34
Suicide	24.3	117	26
Homicide	19.3	105	26
Firearm injury	24.8	78	31
Injury and poisoning	5.0	316	108
Pneumonia and influenza	30.6	137	39
Heart disease	206.4	49	32
Cerebrovascular disease	43.0	61	41
Malignant neoplasm	173.3	33	49
Lung cancer	69.7	82	120
Breast cancer	20.7	98	43

[a]Per 100 000 population.
[b]IHS adjusted totals include all IHS areas.

In 2002 a collaborative consortium was formed to address many of the health disparities affecting Montana and Wyoming tribal nations. This initial partnership comprised 3 organizations: the Montana-Wyoming Tribal Leaders Council (TLC), the Project HOPE (Health Opportunities for People Everywhere) Center for Health Affairs, and Black Hills State University (BHSU). Other collaborators have since joined. Here we describe the consortium partners, our approach to and objectives for AIAN health, and our progress.

A COLLABORATIVE APPROACH TOWARD RESOLVING HEALTH DISPARITIES

The Consortium Is Born

The TLC, located in Billings, Mont, is composed of elected tribal leaders from 9 land-based, large-population, federally recognized tribes, and 1 non–federally recognized tribe, all located in Montana and Wyoming (Table 2). The TLC's mission includes a commitment to uniformly promote the common welfare of all

TABLE 2—Members of the Montana-Wyoming Tribal Leaders Council

Reservation	Tribes	Location
Fort Belknap	Assiniboine, Gros Ventre	North Central Montana
Wind River	Northern Arapaho, Eastern Shoshone	Central Wyoming
Rocky Boy	Chippewa Cree	North Central Montana
Flathead	Kootenai, Salish, Pend d'Orielles	Western Montana
Northern Cheyenne	Northern Cheyenne	Southeastern Montana
Crow	Crow	South Central Montana
Blackfoot	Blackfeet	Northwest Montana
Fort Peck	Sioux divisions of Sisseton/Wahpetons, Yantonais, and Teton Hunkpapa; Assiniboine bands of Canoe Paddler and Red Bottom	Northeast Montana
NA	Little Shell Tribe of Chippewa [a]	Northwest Montana

NA = not applicable.
[a]The Little Shell Tribe of Chippewa is not a federally recognized tribe. Thus, they do not reside on a reservation.

the Indian reservation peoples of Montana and Wyoming. The TLC incorporates the Montana-Wyoming Indian Health Board, linking all tribal health directors and providing representation to the National Indian Health Board.

The TLC executive director, his staff, the TLC Subcommittee on Health, and the tribal health directors are key participants in our collaborative efforts to reduce health disparities. The TLC's role is to serve as a research partner and liaison between the Montana and Wyoming tribal leaders, tribal health directors, and tribal colleges, as well as researchers from partnering organizations. The TLC serves as the focal point for present and future collaborative activities, and guides the evolution and growth of the collaborative partnership.

The Project HOPE Center for Health Affairs is a nonprofit organization that originally provides objective research and policy analysis on both foreign and domestic health systems. Domestic activities associated with Project HOPE have been discontinued, and center staff no longer participate in the consortium. However, Project HOPE center staff from the Lead, SD, office were the principal participants in the original consortium. The center provided expertise and support in the areas of research design and methodology, as well as statistical and data analyses, and played a lead role in pilot research study design.

BHSU, located in Spearfish, SD, is a public 4-year liberal arts institution. Staff from the areas of health services administration, exercise physiology, and business, from the Center for American Indian Studies, and from the Grants and Special Projects Office participate in consortium activities. BHSU's role is to provide the administrative structure for the original project, to ensure that processes are in place to maintain effective communication among the partnering organizations, and to provide technical and financial management of grant funds. Faculty members serve as investigators for several research projects.

Growth of the Consortium

One of the major collaborators to join the consortium has been the Billings Area IHS. The Billings Area IHS director provides an IHS staff member to serve as a liaison between non-AIAN researchers and local IHS clinics and hospitals. Both the Billings Area Office and several local IHS clinics and hospitals are actively engaged in research and educational projects aimed at reducing health disparities. The Billings Area IHS Research and Publications Committee reviews all research projects involving human subjects. IHS senior staff members serve on several oversight committees and attend planning, evaluation, and informational meetings.

Early in the collaborative process the partners identified a need for 1 or more clinicians to assist with clinical research, and the president of the Black Hills Center for Indian Health (BHCIH), a Lakota Sioux physician and board-certified internist and epidemiologist, became involved with the consortium. Similarly, the Yellowstone City-County Health Department in Billings provides the TLC with epidemiologists to support research, data collection, and analysis for existing and future studies.

We continue to hold ongoing discussions with tribal college presidents and faculty, with the goal of mentoring, supporting, and involving tribal college faculty in health disparities research. We believe that expanding the involvement of tribal college faculty will help the tribes build the infrastructure to conduct their own health disparities research.

Consortium Objectives

The consortium began its work by applying for and receiving $1.05 million in grant funding from a new program established by the National Center on Minority Health and Health Disparities of the National Institutes of Health to establish Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities, and Training (Project EXPORT). The grant, received in fall 2002, provided funds to support the development of the research infrastructure, methodologies, and collaborative working relationships that could provide the foundation for future efforts; those efforts include ongoing, sustainable research and programs on health disparities, and effective strategies for addressing those disparities.

The consortium targeted several specific courses of action to establish the research infrastructure necessary for conducting ongoing health disparities research, evaluation, and programs: (1) develop and implement standardized data collection protocols to assess

community health needs across tribal populations in Montana and Wyoming and allow the identification of high-priority health areas for community outreach and information dissemination; (2) develop and implement standardized data collection protocols for collecting epidemiological data on a periodic basis to establish a database for ongoing research and evaluation; (3) create a centralized database to provide background data for designing and conducting health disparities by all project team members; (4) design and implement community outreach and information dissemination projects to target specific health needs identified by the Montana and Wyoming tribes; (5) establish effective working relationships and joint projects (including mutual and interactive mentoring activities) between faculty at various tribal colleges and BHSU to aid the transfer of the research knowledge, grant management skills, and cultural competency; and (6) design a health disparities research agenda, pilot test the feasibility of various strategies for implementing the agenda, and evaluate specific health disparities research topics chosen as highest priority by the tribal leaders, the TLC Subcommittee on Health, and the tribal health directors.

RESULTS

Several aspects of the partnership bear mentioning. First, all research projects are user-defined and user-authorized, and are developed upon consensus of what is most important to tribal health improvement. The TLC Subcommittee on Health determines the priorities for research, with the TLC executive director and the researchers involved giving guidance as to the relevance of the project to the specific grant, and the feasibility of conducting the project within the budgetary and time constraints of the grant. Second, each tribal health director, in consultation with his or her respective tribal leaders, may elect or decline to participate in any of the pilot studies or ongoing projects. In the event that more tribes desire to participate than is possible given budgetary and human resource constraints, the TLC executive director, in consultation with the tribal health directors, ensures that participation is equitably and fairly distributed. Finally, the partnership is committed to developing increased collaboration among additional organizations.

TABLE 3—Collaborative Health Disparities Initiatives Undertaken to Address Health Disparities for American Indians in the Indian Health Service (IHS) Billings Area (Montana and Wyoming)

Pilot Research Studies
- Develop educational intervention to increase seat belt use on reservations
- Conduct consumer health services satisfaction survey using a modified Consumer Assessment of Health Plan Survey
- Evaluate alternate technologies for diagnosing diabetic retinopathy and other eye disease
- Design and pilot test a suicide prevention for young adults
- Examine disparities in access to emergency medical services
- Design and pilot test a transition program to provide health and substance abuse treatment services to young adult offenders
- Design and implement a pilot program for community-based residential assessment for at-risk adolescent female drug users
- Examine the direct and indirect economic costs of methamphetamine use on a reservation
- Develop a "Healthy Reservations" model and a tribal work plan to implement it
- Examine factors affecting screening rates and follow-up of abnormal findings for breast and cervical cancer
- Develop and test a methodology to use a consumer satisfaction survey for performance improvement in IHS facilities

Community Outreach and Information Dissemination
- Develop a diabetes self-management education curriculum
- Train tribal community health representatives to teach diabetes self-management education courses
- Develop and implement a standardized community health assessment tool and methodology

Mentoring
- Develop and publish a cultural and mentoring research design guide for use by non–American Indian/Alaska Native researchers
- Conduct grant-writing workshops for tribal health directors and tribal diabetes educators

Database and Information
- Develop a shared-resource research database
- Develop a Web-based inventory of American Indian/Alaska Native health research, pilot programs, and best practices

Fetal Alcohol Syndrome Disorder
- Establish a Center for Fetal Alcohol Syndrome Resources and Technical Assistance

Several current and near-term projects have resulted from the collaborative efforts discussed here (Table 3). These initiatives were made possible by several months of trust building, working to enhance communications, and discussing cultural differences among the partners.

The Blackfeet, Wind River, Crow, Northern Cheyenne, Fort Peck, Fort Belknap, and Little Shell reservations/tribes have participated in consortium-sponsored initiatives. All of the consortium partners have worked diligently to solve organizational and administrative difficulties, remove communication barriers, develop collegial relationships, and respect each organization's culture. Here we describe each of these projects in more detail.

Pilot Research Studies

Six pilot research studies are currently being completed. Each study is funded by a 3-year grant under Project EXPORT.

In the first pilot study researchers developed and tested a pilot program to increase seat belt use on 2 reservations and thereby reduce injuries and deaths associated with motor vehicle crashes. Baseline data were collected on seat belt and child safety restraint use, and on the number and rates of motor vehicle crashes involving injuries or deaths in the previous year. An information and education campaign is under way, and comparative data will be collected and analyzed after 1 year.

In the second pilot study team members developed and tested a modified Consumer Assessment of Health Plan Survey (CAHPS) for IHS users. The IHS CAHPS was adapted from the CAHPS 3.0 Adult Core Questionnaire and the CAHPS 3.0 Child Core Questionnaire.[4] It provides information on user experiences with providers, processes of care, and access to care. The objective of this pilot study was to provide tribal leaders, tribal health directors, and IHS managers with a way to collect data that can inform and guide the design of strategies for improving access, services, and health outcomes. Data have been collected on 2 reservations, and the tribal health staff and principal investigators are discussing performance improvement initiatives.

Researchers in the third pilot study examined the use of digital photographs to detect specific eye disease in American Indians. The BHCIH president serves as the principal investigator for a clinical study on diabetic retinopathy. The project soon expanded, and BHCIH entered into a collaborative relationship with the director of the IHS/Joslin Vision Network (JVN) Teleophthalmology Program at the Phoenix, Ariz, Indian Medical Center. The JVN is affiliated with the Joslin Diabetes Center of Harvard University, and allows remote-access retinal imaging of diabetic patients, with no need for pupil dilation. Phoenix IHS staff read and analyze JVN digital images transmitted from the IHS Optometry Clinic located on the Crow Reservation. The purpose of the pilot study was to document and characterize the sensitivity and specificity of the JVN system in identifying specific nondiabetic ophthalmic pathology of the anterior segment and fundus of the eye in a group of older American Indians with type 2 diabetes mellitus.

In the fourth pilot study investigators designed and implemented a culturally appropriate community-based intervention for suicide prevention and follow-up services among youth. The objectives of this study included (1) improving surveillance and monitoring the collection of data on suicide attempts, demographic characteristics, and timing; (2) increasing knowledge and awareness among youth peers of behaviors that may indicate suicidal thoughts; and (3) designing, implementing, and evaluating a procedure for providing follow-up services and support for people who have attempted suicide.

In the fifth pilot study researchers performed a preliminary analysis of disparities in access to emergency medical services. This pilot study documented the emergency medical services available to AIAN and non-AIAN residents of Northern Montana, compared access to and timeliness of services for both populations, and identified factors that contribute to documented differences in access.

Team members on the sixth pilot study designed and implemented interventions to improve access to physical and mental health services for juvenile offenders in transition to the community. This study documented unmet needs for health and substance abuse treatment services among juvenile offenders transitioning from incarceration, and designed and implemented a pilot program to link these young people to needed services. In subsequent studies researchers will (1) design and implement a pilot program for community-based residential assessment for at-risk adolescent female drug users, (2) design and conduct a pilot study of the direct and indirect economic costs of methamphetamine, and (3) develop a "Healthy Reservations" model by adapting the Healthy Communities model promoted by the US Department of Health and Human Services to reflect unique aspects of reservations, and create a tribal work plan to implement the model.

Two additional pilot studies are currently under way. These studies are funded by a second grant won in 2003 by the TLC, from the Agency for Healthcare Research and Quality Minority Research Infrastructure Support Program (AHRQ-MRISP). The first study seeks to address factors affecting breast and cervical cancer screening and follow-up among American Indian women residing in Montana and Wyoming. The results will provide preliminary information and evidence to develop an in-depth research program to address several significant research questions.

Investigators with the second pilot study are using the revised CAHPS instrument to survey IHS users on 6 reservations, and are developing quality performance improvement initiatives to address respondents' concerns about IHS health care.

Community Outreach and Information Dissemination

Two Project EXPORT–funded community outreach and information dissemination projects are under way. The first project involves the development of a diabetes self-management education curriculum. The curriculum is based on the existing IHS Diabetes Education Curriculum and an existing curriculum at Rapid City Regional Hospital, and is tailored to meet the specific cultural and programmatic needs of the tribes involved in this project. The second project involves training tribal community health representatives to teach their local constituents diabetes self-management as part of an ongoing health program. A third project to develop and implement a community health assessment tool and methodology standardized for AIAN populations is scheduled to begin later in 2005.

Mentoring

Project EXPORT funding is also being used to develop and publish a cultural and mentoring research design guide for use by non-AIAN researchers. The cultural guide includes a history and background provided by the participating Wyoming and Montana tribes, offers guidance on how to ask questions of AIAN study groups that show respect for specific tribal cultural characteristics and beliefs, discusses culturally sensitive techniques to gather and analyze data, offers an ongoing mentoring program component, and includes a bibliography of recommended reading and Web sites.

In addition, 2 grant-writing workshops have been conducted to assist tribal health directors and their staffs in identifying grant opportunities, writing successful responses to funding agencies, preparing budgets, and managing the grant-writing process. Approximately 50 people attended these workshops. More workshops will be offered if needed.

Additional Projects

As an offshoot of these efforts, the TLC was awarded a 15-month planning grant from the Robert Wood Johnson Foundation for building community support mechanisms for diabetes care. This project involves the design and implementation of interventions to reduce barriers to diabetes self-management. Specific components include (1) developing guides to tribal cultures and conducting workshops on cultural barriers for IHS providers and staff, (2) developing training programs for tribal diabetes educators and their staffs on effective methods for helping people with diabetes to adopt positive health behaviors, (3) conducting diabetes wellness classes and activities for people with diabetes, and (4) evaluating the effects of the program on the knowledge, attitudes, and health behaviors of people with diabetes and on selected clinical outcomes. The planning grant was successfully completed and a phase II implementation grant awarded.

In another project funded by the AHRQ-MRISP grant, TLC and BHSU staff have prepared 5 background papers geared toward tribal health directors, tribal health program managers, and health care providers interested in specific topics. The papers synthesize research on the following selected health topics: suicide prevention in AIAN youth; barriers to Medicaid, State Children's Health Insurance Program, and Medicare enrollment among AIAN populations; education, health, rehabilitation, and independent living for American Indians with disabilities; choosing exercise certification programs for tribal staff; and rural emergency medical services. These papers identify best practices for prevention, treatment, and management of specific health conditions, and have been placed on the TLC Web site to assist tribal health directors and service providers.[5]

Finally, in 2003 the Centers for Disease Control and Prevention awarded BHSU a grant to develop strategies for training and providing technical assistance for children and youth with fetal alcohol syndrome disorder. An implementation grant was received in 2004.

CONCLUSION

The objective of the collaborative initiative we have described is to improve the health of Montana and Wyoming Indian tribes and tribal nations. Because we have less than 2 years' history building the infrastructure to accomplish this objective, our data do not yet provide empirical evidence of tribal member health improvement. However, the collaboration has resulted in several significant projects, and our research and intervention efforts have grown rapidly.

Tribal data collectors have been trained, grant-writing workshops conducted, epidemiological expertise expanded, best practices identified for 5 focal areas, and videoconferencing capabilities developed. Through the assistance of the Tribal Subcommittee on Health, tribal health directors, and the TLC, a 3-year research agenda has been established. Through the pilot research studies discussed herein, we are in the process of testing the feasibility of various strategies for implementing the research agenda. Contacts with tribal college presidents have been made on 4 reservations, and we are currently working to include tribal college faculty as junior researchers in conducting health disparities research. The expansion of our collaborative partnership, the trust building that has taken place among the partners, and the joint research programs undertaken during the past 22 months reflect substantial progress in attaining this long-term objective.

However, to fully establish the research infrastructure for conducting ongoing research, evaluation, and program development, we will need to successfully complete the following initiatives: (1) obtain government and private grants to fund a series of pilot research projects that have the potential to meet specific health needs; (2) build a robust, public database to assist in identifying health disparities and conducting future health services research and epidemiological studies; (3) train tribal health directors and community health representatives in educating Montana and Wyoming AIAN populations regarding critical health issues, while maintaining cultural sensitivity and respect for traditional tribal models of health care; (4) educate and assist non-AIAN researchers in better understanding the cultures of Montana and Wyoming tribes so that health research can be conducted in a manner that respects the rich tribal cultures; (5) develop the ability among tribal college faculty and tribal members to conduct basic health research; (6) identify, publicize, and replicate best practices for addressing health issues among tribal members; (7) develop tribal institutional review boards that can take responsibility for approving, guiding, and assessing health research conducted on behalf of their constituents; (8) apply

for funding from the IHS for an area epidemiology center for the tribal nations of Montana and Wyoming (considering the Billings Area IHS's large land base and population—with commensurate high-incidence and high-prevalence disease burdens—the lack of such a center is notable); (9) conduct tribally driven epidemiological studies on public health threats such as hepatitis C, West Nile virus, methamphetamine use, and others; and (10) establish a research presence at the American Public Health Association annual meeting and the annual IHS Research Conference.

During the coming months and years we will strive to collaborate further with organizations that share our objectives, so that we can effectively leverage the shared resources of our partners to improve the health of Montana and Wyoming tribes. ■

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Contributors

S.R. Andersen led the writing of this article and synthesized the analyses. G.M. Belcourt wrote the sections of the article pertaining to tribal information, provided information on the tribes, conceptualized the collaborative model described in the article, and reviewed and edited drafts of the article. K.M. Langwell conceptualized the original Project EXPORT grant and study, produced the health disparities data included in the article, and conceptualized the pilot research studies and their objectives.

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Human Participant Protection

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References

1. Keppel KG, Pearcy JN, Wagener DK. *Trends in Racial and Ethnic-Specific Rates for the Health Status Indicators: United States, 1990–1998.* Hyattsville, Md: Centers for Disease Control and Prevention, National Center for Health Statistics; 2002. Healthy People Statistical Notes 23.

2. Young T. Recent health trends in the Native American population. In: Sandefur GD, Rindfuss RR, Cohen B, eds; Committee on Population, National Research Council. *Changing Numbers, Changing Needs: American Indian Demography and Public Health.* Washington, DC: National Academy Press; 1997:53–75.

3. US Department of Health and Human Services, Indian Health Service. *Regional Differences in Indian Health, 1998–99.* Washington, DC: US Department of Health and Human Services, Indian Health Service, Office of Public Health; 1999.

4. CAHPS Survey Users Network. Available at: http://www.cahps-sun.org/cahpskit/inc/savedocs.asp. Accessed August 1, 2004.

5. Montana–Wyoming Tribal Leaders Council. Available at: http://tlc.wtp.net/index.html.htm [password protected].