Speaking Truth to Power: Using Research to Inform Indian Health Care Advocacy

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SUMMARY

This case study highlights how the California Rural Indian Health Board (CRIHB) advocacy efforts have benefited from its research infrastructure. With support from The California Endowment's Clinic Consortia Policy and Advocacy Program, CRIHB has been able to secure grants to fund research staff, create and analyze databases, and publish findings. Several key findings emerge from this analysis:

- Partnering the Research Unit with the CRIHB leadership has allowed CRIHB to effectively translate its research findings into valuable products to educate policymakers, such as evidence to help justify a 13 percent increase in the Indian Health Services 2010 budget;
- By establishing itself as a credible researcher with an aim to help all California American Indian/Alaska Natives (AI/ANs), CRIHB was able increase support from tribal leaders and government agencies; and
- As a result of CRIHB research that identified disparities in Medicaid funding of the health care of American Indians in California, CRIHB's Executive Director and the Research Unit are now designated by the national Tribal Technical Advisory Group to the Centers for Medicare and Medicaid Services to research Medicaid and Medicare data for American Indian/Alaska Natives (AI/ANs) nationwide.

INTRODUCTION

In 2001, The California Endowment provided funding to 15 local and regional community clinic associations and four statewide community clinic organizations (referred to as "consortia") through the Clinic Consortia Policy and Advocacy Program to strengthen the capacity of consortia to engage in advocacy on behalf of their member clinics. Clinic consortia are statewide, regional, and local associations of primary care clinics that undertake activities that individual clinics may not be able to do on their own. In 2004 and 2007, 18 grantees were refunded for three years to undertake or continue a similar set of activities.

To achieve their goals, clinic consortia engaged in multi-year initiatives during the grant period to:

- Expand coverage (insurance and/or services) to low-income adults and/or children;
- Strengthen the local or regional health care delivery system; and
- Target policies to strengthen California's safety net.

The California Rural Indian Heath Board, Inc. (CRIHB) was formed in 1969 to promote and improve Indian health in California and develop improved communications between Indians and all agencies of government concerned with Indian health. CRIHB is responsible for planning, advocacy, funding, training, technical assistance, coordination, fund-raising, education, and development on behalf of member tribal organizations. Its primary role is to promote unity and formulate policy on Indian health care issues. CRIHB is a tribal organization with 11 member Tribal Health Programs (THPs) formed by 25 tribes, with 27 clinics that serve 47,000 AI/AN clients annually.

METHODS

In 2009, UCSF staff reviewed background documents, conducted open-ended interviews with CRIHB leadership and research staff, as well as the Executive Director of one of CRIHB's THPs. Informants were asked to describe their involvement in the effort, challenges encountered, and benefits to clinics and their target populations. *(Please note that the Darrell Hostler Fund paid for any lobbying activities*.)

FINDINGS

THE ISSUE: AI/AN HEALTH PROBLEMS, LACK OF FUNDING AND DATA

California's 27 THPs with clinics are owned by individual tribes or consortia of more than one tribe. They operate clinics that deliver a range of community-oriented, primary preventive and therapeutic medical and dental services. Not only has the federal Indian Health Service been chronically under funded, but California's AI/AN population also receives the least amount of Indian Health Service specialty and hospital care Contract Health Services and Contract Health Emergency Funds funding of any of the 12 Indian Health Service funded regions. As a result, the THPs have had to rely on other funding sources, such as the state Indian Health Program, Medicaid, Medicare and some private insurance and special projects funding. Many of these programs have been threatened over the years as California struggles with budget problems. In 2009, funding for the state Indian Health Program was slated to be eliminated in the Governor's budget.

CRIHB has long used research to strengthen its advocacy work to justify the need for additional funding for health services for AI/AN populations. However, California's AI/AN populations are often misclassified in health-related databases. For example, death and hospitalization rates reported by the state and Indian Health Service underestimate disparities for AI/ANs relative to other Americans because they cannot track all deaths or hospitalizations of AI/ANs in their populations. Consequently, there are no reliable data on deaths, diseases, injuries, or health behaviors for this population to help advocate for additional funding to help meet their health needs. CRIHB was able to overcome these challenges through the creation of a research infrastructure that enabled it to link state and Indian Health Service databases to overcome the limitations of the individual databases, and more completely document AI/AN health status and health services.

PROMISING SOLUTION: EXPANDING RESEARCH EXPERTISE TO ATTRACT PUBLIC FUNDING

CRIHB long recognized that an internal research infrastructure could improve the quality of the information on AI/AN health status and health services. From 2001-03 CRIHB conducted research that was published in the journal *Medical Care*. It compared hospitalization and avoidable hospitalization rates for a rural AI/AN user population with those of non-Indians living in the same counties where both groups use the same hospital system, regardless of the expected source of payment. It found that hospitalization and avoidable hospitalization rates were both higher for the AI/AN user population than for the non-Indian general population. These disparities were previously undetected by either federal Indian Health Service or state hospital discharge data. CRIHB concluded that at least some of the disparities are likely reducible with improved access to care. This early research established the need for expanded capacity to conduct additional and expanded data analyses.

Building on the success of this study, CRIHB was able to secure federal research grants to establish two research centers: the Native American Research Center for Health (NARCH) and the California Tribal Epidemiology Center (EpiCenter). They are both focused on assessing the need for and effectiveness of innovative preventive and primary care programs to reduce disparities in health. The NARCH projects are designed to determine how health outcomes for clinic patients depend on performance and funding of the clinics using existing datasets. The EpiCenter studies engage California's AI/AN communities in collecting and interpreting health information to establish health priorities, monitor health status, and develop effective public health services.

MAJOR MILESTONES: CONDUCTING POLICY RELEVANT RESEARCH

The NARCH and the California EpiCenter have produced numerous studies that have been published in reports and peer-reviewed journals since 2005. Key research accomplishments include:

American Indian Medicaid Health Care Services Use and Health Care Costs in California: In February 2006 CRIHB researchers published an article in the *American Journal of Public Health* showing that AI/AN had significantly lower use of Medicaid-paid ambulatory visits, prescriptions, emergency room visits, and hospitalizations and lower associated costs than Caucasians. This research was widely regarded and led to the expansion of CRIHB's role as a national leader in Medicaid funding research.

Gaps and Strategies to Improve AI/AN Data in Medicare, Medicaid and SCHIP Data Bases: Working with the Tribal Affairs Office and its Tribal Technical Advisory Group of the national Centers for Medicare and Medicaid Services, CRIHB examined statewide as well as Contract Health Service Delivery Area data on Medicaid enrollment, service use, and payments. This research demonstrated that a low percent of Indian Health Program Active Users are enrolled in Medicaid (52 percent in California) due to barriers to enrollment. Moreover, research findings revealed lower average payments to California Indian Health Programs enrollees for Medicaid services.

Causes of Hospitalizations of AI/ANs in California**:** In October 2007 CRIHB documented the high disparities in hospitalizations for a number of health conditions including asthma in *American Indian Health in California*. The report demonstrated that AI/ANs have either higher health status needs compared to Caucasians, or they have less access to preventive services than Caucasians in rural areas of California. The report was used to advocate for improved policies and health initiatives.

Indian Health Service Funding of THPs Linked to Lower Rates of Hospitalization**:** In January 2009 CRIHB published research showing that the rate of hospitalizations for ambulatory care sensitive conditions

for users of THP clinics dropped 12 percent for every 10 percent increase in THP funding.

Partnerships: CRIHB's success in creating its research infrastructure for advocacy has relied in part on partnerships with others. CRIHB receives continual guidance in planning, designing, and implementing its studies from member Tribal Health Program clinics, tribal leaders, Tribal EpiCenters nationally, university researchers, and others. For example, CRIHB research is being integrated with efforts of the Yurok tribe in Humboldt/Del Norte Counties and with the California Center for Rural Policy research at Humboldt State University on a number of projects. CRIHB has partnered with the Fred Hutchinson Cancer Research Center in Seattle, the Northwest Portland Area Indian Health Board, and the Northwest Tribal Epidemiology Center. The CRIHB Institutional Review Board oversees all research activities of CRIHB staff for protection of tribal participants in California studies.

Overcoming Challenges: One of the challenges of establishing the research center was recruiting non-CRIHB THPs to be part of the EpiCenter. Once trust was established, CRIHB was able to develop data sharing agreements with each THP.

Accomplishments and Benefits

The primary purpose of CRIHB research is to support California THPs and improve the funding of health services to meet patient health needs and improve health status. Using the grant Logic Model, the short and long-term outcomes of CRIHB's research-based advocacy include:

Expanded CRIHB advocacy capacity*:* CRIHB's research infrastructure has allowed it to collect new data that has strengthened its advocacy efforts. Research is now a vital activity at CRIHB and 6 FTE and 4 PTE staff gather, analyze, and report data on the health needs, services and status of California Indians. CRIHB has developed a sustainable financial model, raising 100 percent of its funding from a diversified mix of funding sources including research grants and contracts, private foundations, Indian Health Service, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Centers for Medicare and Medicaid Services, and National Institutes of Health.

Increased policymaker awareness of safety net and clinic policy issues: Using its research findings, CRIHB has educated state and federal policymakers. For example, IHS funds to California have been traditionally low because the IHS lacks hospital and death data on California Indians that it has for other regions. CRIHB developed a model documenting hospitalization rates by IHS region. This is often used in advocacy visits of California tribal leaders to advocate for their rightful share of IHS funds. The model has become the most often requested information from CRIHB.

Increased policymaker support of safety net and clinic policy issues*:* CRIHB research used positive findings from the study of Indian Health Service funding of THP to advocate for improvements in public policies that fund the services that THPs provide. From 2006-2009 CRIHB's Executive Director and Research Director conducted advocacy visits to the Office of the Management of the Budget to recommend that the IHS fund THPs at a level of at least 60 percent of the health care costs of the AI/AN who use the programs, instead of the current 40 percent. This increased policymaker support for increased funding for THPs as evidenced by acknowledgement of the research findings and passage of a 13 percent increase in the 2010 IHS budget.

> ***Clinic Perspective:*** For years, we have been traveling with CRIHB leaders to Washington DC to testify about the status of AI/AN health. We had to fight to get our feet in the door. Even when we managed to get our feet in the door, we had no information to share. We were frustrated because IHS was only using aggregated California data, which did not examine the status of our AI/AN population, thus masking their specific needs. Once CRIHB was able to secure funding for the EpiCenter, we were able to produce reliable information about the true needs of AI/ANs. -- *United Indian Health Services*

Strengthened clinic operations*:* Individual THPs lack sufficient funds to conduct research on the needs of their populations. CRIHB is able to produce and share research that THPs can use in their grant applications to bring more resources to all the community clinic systems. For example, in 2005 CRIHB published *Community Health Profiles* of health related indicators for the 24 THPs with clinics, which helped the clinics to develop funding proposals.

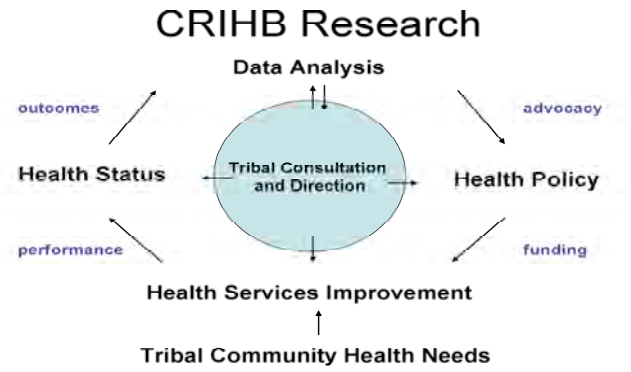
The CRIHB Research Unit also wrote a grant proposal in partnership with the CRIHB Health Systems Development Department and three member THPs to the Agency for Healthcare Research and Quality that funded clinic licenses for the implementation and use of a commercial ambulatory care Electronic Health Record (EHR) in 8 sites. The joint research project used the EHR for quality improvement of clinical care and reporting of clinical population data. CRIHB provided an evaluation of the implementation efforts that has been used as a model by private foundations funding the use of EHR in community clinics elsewhere.

Increased services for the underserved and uninsured*:* Published documentation of disparities in access to or use of specific treatment services is necessary to secure changes in the services. For example, CRIHB is working with the Fred Hutchinson Cancer Research Center in Seattle to determine whether there are disparities in use of cancer care among AI/ANs in Washington, Oregon, and California. In addition, CRIHB collaborated in a study that determined that there is no disparity in cardiac procedure rates among AI/AN compared to Caucasians hospitalized in California for acute myocardial infarction or unstable angina.

Improved health outcomes for targeted communities and populations: Although it is too early to document the impact of these efforts on health outcomes, increased funding enables THPs to improve the type and quality of health services they provide.

FACTORS FOR SUCCESS

The following diagram depicts CRIHB's research and advocacy model. It strives to conduct data analysis on health status and health policy that can be used to advocate for improvements in public policies that fund the services that THPs provide. The use of this diagram has helped CRIHB "sell" its research internally, and keep its efforts focused on policy-relevant research.



Another important factor for success is to have a "champion" leader who understands the value of data and how to use it in advocacy. CRIHB attributes its success over the years to the commitment of the tribal leaders and Board Members to research-based advocacy efforts. It attributes its recent success in part to the change in Administration and the new IHS Director who understands the role of health services research data in policy-making.

> ***Clinic Perspective:*** You hope that policymakers will change out of the goodness of their hearts, but the reality is that you need a weapon to change policy -- and research becomes your sword. You know you've scored when policymakers use your data and arguments when they defend their votes. -- *United Indian Health Services*

LESSONS LEARNED

CRIHB's research expertise can be used in other venues and by other agencies. For example, the Centers for Medicare and Medicaid Services has contracted with CRIHB researchers since 2007 to analyze Medicare/Medicaid data for AI/AN and to give guidance on how to use this data in policy and funding decisions. Moreover, there is extensive clinic data to document the effectiveness of funding health programs and the unmet needs of specific target populations. Other advocacy organizations might consider either establishing in-house research expertise, or commissioning an outside entity (such as a university-based or private research organization).

Last, it matters how research findings are communicated. For example, policymakers are particularly receptive to concise handouts with streamlined bullet-points of solid health services/health research data and information. These are most effective when they are backed up with published articles from peer-reviewed journals.

THE FUTURE

CRIHB will continue to produce research findings that can be used to advocate for the reinstatement of the state Indian Health Program. Other specific policy goals are to reinstate Medicaid optional benefits (including Denti-Cal) through a demonstration project to demonstrate the extent to which costs of care increased for Medicaid recipients denied optional benefits. CRIHB is also working to maintain the substance abuse prevention, treatment and recovery programs. CRIHB is focusing on implementing the Children's Health Insurance Programs Reauthorization Act (CHIPRA) and American Recovery and Reinvestment Act (ARRA) in California, which amended Medicaid and CHIP statutes as they apply to AI/AN. The amendments require states to increase outreach and facilitate enrollment for eligible AI/AN, and eliminate cost sharing in state Medicaid and CHIP programs. CRIHB will also be collecting Medicaid and Healthy Families data for California to see whether the programs stopped cost sharing for AI/AN using a THP.

CONCLUSIONS

Researchers at CRIHB now conduct health services, health policy, and epidemiology studies on public health and personal health care. The use of effective non-biased research greatly strengthens the role that state and federal governments play in addressing the unmet health needs of American Indians in California. Research is a vital activity at CRIHB. It has been able to gather and analyze data on the health needs, health services and health status of AI/AN and turn that data into action at every possible opportunity in its advocacy efforts.

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