

THE HARVARD PROJECT ON AMERICAN INDIAN ECONOMIC DEVELOPMENT

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Northwest Portland Area Indian Health Board The 43 Federally Recognized Tribes of Oregon, Washington, and Idaho (Portland, OR)

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Launched in the early 1970s by a group of tribal leaders who recognized the value of intertribal coordination, the Northwest Portland Area Indian Health Board (NPAIHB) plays a critical role in improving the health status of Indian nations located in Idaho, Oregon, and Washington. Through a wide range of activities that include policy advocacy, health promotion and disease prevention, and data collection and management, NPAIHB empowers its forty-three member tribes to create and manage effective health care systems that are designed to meet community needs.

In order to improve the health status of American Indian and Alaska Native peoples, tribal leaders must understand the nature and extent of the health problems facing their communities. For many tribal leaders, however, obtaining even the most basic tribe-specific data is an enormous challenge. While it is commonly known that American Indians suffer some of the highest levels of diabetes, Sudden Infant Death Syndrome, infant mortality, cardiovascular disease, and obesity in the US, data about these diseases are rarely available at the tribal level. Oftentimes the tribe-specific data that do exist are incomplete, inaccurate, or insufficient. This lack of accurate data cripples tribes' ability to manage health services on several levels. Without tribe-specific data, health care professionals are unable to identify important risk groups for intervention and may repeatedly fail to recognize or implement appropriate public health measures. They also struggle to assess the success or limitations of existing health promotion or disease prevention programs to determine whether these programs should be continued, altered, or expanded. Furthermore, in the absence of tribe-specific data, tribes must rely on widely available regional and national data samplings. Inaccuracies in these data lead to the underestimation of the disease burden borne by tribal populations. As a result, tribes are generally unable to direct their limited resources in a strategic manner, lobby for needed funding, or press for effective health legislation.

In 1972, a group of tribal leaders from Idaho, Oregon, and Washington came together to discuss their nations' health problems and to contemplate how they might work together to address them. Recognizing the need to generate tribe-specific data and the desirability of sharing information and resources, they decided to create an intertribal organization that would serve each of the federally recognized tribes in the tri-state region. As a result of their vision, the Northwest Portland Area Indian Health Board (NPAIHB) was born.

From its inception, NPAIHB focused on several specific responsibilities on behalf of its member tribes. First, the organization invested in its capacity to collect, analyze, and manage data, activities that its member tribes were unable to implement effectively on their own. In turn, NPAIHB trained its member tribes in data management and, under the direction of member tribes, also designed health promotion and disease programs that addressed the most pressing and prevalent health needs for these communities. Finally, it worked closely with tribal leaders and health care professionals to develop a shared policy agenda so that NPAIHB could advocate for and implement health care policy on tribes' behalf at the regional and national level.

A strong organizational structure enables the Northwest Portland Area Indian Health Board to undertake these important responsibilities. NPAIHB is governed by a forty-three-member board of directors that is comprised of representatives from each of the forty-three tribes it serves. Although NPAIHB's member tribes are all different sizes their populations range from sixty-five to ten thousand individuals each tribe enjoys equal representation on the board of directors. This structure keeps the organization focused on concerns and problems that are broadly shared among its membership. Member tribes' confidence in NPAIHB is further bolstered by the board's professionalism and expertise: directors are typically elected tribal officials or health program managers with years of experience. Their high standard of professionalism contributes to NPAIHB's stability. In fact, since the organization's founding in 1972, it has had only three chairpersons. NPAIHB also benefits from clear decision-making processes. The organization holds an annual planning meeting that allows its membership to come to consensus on institutional priorities. It maintains a five-year strategic planning cycle (revised every three years) to address institutional priorities. Additionally, NPAIHB's board meets quarterly to review policies and procedures, resolve pressing issues, learn from tribal programs, and discuss pending health legislation.

Since its creation, the Northwest Portland Area Indian Health Board has played a crucial role in improving the health status of its member tribes as well as tribes throughout Indian Country. Its successes are the direct result of NPAIHB's steady and effective execution of its responsibilities. Paramount among these is NPAIHB's highly successful effort to generate and manage information. NPAIHB has been a key player in the conceptualization of tribal epidemiology centers. In 1997, NPAIHB established the Northwest Tribal Epidemiology Center, or EpiCenter, to facilitate data collection, analysis, and management. In turn, NPAIHB has relied on its increased and improved data to work with tribes in the design and implementation of effective health promotion and disease prevention programs. Today, NPAIHB offers more than two-dozen programs addressing health concerns such as diabetes, the non-ceremonial use of tobacco, women's health, elder's health, suicide, and injury prevention. The EpiCenter enables local sites to continue the work of the projects independently; tribes evaluate and customize their own programs to best suit the needs of their members. NPAIHB's capacity to generate and manage information also makes it a formidable advocate in policy arenas. NPAIHB plays a critical role in drafting and lobbying for health legislation that benefits Indian County generally. Responding to the expectation of member tribes that it will accept a leadership role in Indian health care issues, NPAIHB does not shy away from wielding its expertise in guiding national Indian health policy.

These successes in data collection, health program implementation, and policy advocacy are most importantly measured in the improved health of the Northwest tribal communities. In the Northwest region, mortality rates from infectious diseases, gastrointestinal diseases, and tuberculosis among Indians have fallen dramatically. Deaths from Sudden Infant Death Syndrome have declined. The growth of other diseases including diabetes, HIV/AIDS, cancer, and tobacco related illnesses has been slowed through the implementation of effective health promotion and disease prevention programs.

The Northwest Portland Area Indian Health Board's remarkable successes confirm that, in health services management, information is power. NPAIHB's Northwest Tribal Epidemiology Center is the first and still the largest tribal epidemiology center in the nation. Through the EpiCenter, NPAIHB trains member tribes in appropriate data collection, the proper use of relevant statistical analysis software, and data management. The EpiCenter regularly implements innovative information programs that enable tribes to work increasingly independently. Now, member tribes' ability to cite sound statistical evidence regarding disparities in health status between their own people and surrounding populations allows them to garner needed funding and implement effective health services.

While information is power in the hands of tribes, it is NPAIHB's organization as an intertribal entity that ensures its members' continuing access to information. Member tribes can tap into NPAIHB's expertise not only in data collection and management, but also in a host of health-related services including health promotion and disease prevention program operation, billing, the administration of Medicare and Medicaid, and third party reimbursements. Through NPAIHB, individual tribes hold

influence that they could not wield alone: NPAIHB keeps abreast of developing trends in health care so that its members have a voice in shaping those trends. NPAIHB facilitates consultation between its member tribes, the Indian Health Service, and state and federal agencies. Without question, the ability of NPAIHB's member tribes to defend their sovereignty is strengthened because of their participation in such a powerful alliance

NPAIHB understands that its credibility and long-term effectiveness depend on its own capacity. To this end, NPAIHB works hard to attract and retain highly qualified and experienced staff renowned for their knowledge and advocacy work on Indian health issues. The staff's expertise allows them to interact productively with other experts in the field of health care. NPAIHB's staff 85 percent of whom are American Indian or Alaska Native has formed lasting peer relationships with top experts in academia, medicine, and government. NPAIHB is similarly committed to enhancing the health expertise of individual member tribes. It partners with area universities to offer internships to Native and non-Native students in epidemiological methods training. To date, NPAIHB has sponsored fifteen interns and is confident that many will continue to work with tribal communities as needed health experts. Such investments in staffing and relationship building assure NPAIHB's long-term institutional effectiveness.

Most impressively, NPAIHB has wielded its expertise on behalf of Indian Country broadly. NPAIHB's efforts to reach beyond its member tribes have been a core part of its health promotion and disease prevention agenda. NPAIHB works assiduously to establish comparable health boards and regional epidemiology centers elsewhere. It works with tribes across the nation to disseminate its effective health programs and policies. Moreover, it is able to influence health policy legislation at state and national levels. All tribes have benefited from NPAIHB's involvement in policy debates surrounding Medicaid, welfare reform, and the Indian Health Service. NPAIHB was a major author of the 1992 amendments to PL 93-638, the Indian Self-Determination Act. The Board also participated in the drafting of PL 94-437, the Indian Health Care Improvement Act (IHCIA), and was active throughout 2002 and 2003 to gain the IHCIA's reauthorization. NPAIHB has also benefited all tribes through its analysis of and advocacy for an enhanced Indian Health Service budget.

The Northwest Portland Area Indian Health Board is the result of forty-three individual tribes' determination to assert their sovereignty over tribal health. It is an excellent example of how tribes with shared concerns can come together to create an organization that serves its constituents with greater effectiveness than would be possible if the tribes acted independently. Although American Indians continue to suffer the highest levels of ill health in the US, NPAIHB has proven itself to be a leading force in closing the gap.

Lessons:

- By working for the good of Indian Country while maintaining strong ties to their representative
 nations, inter-tribal organizations can facilitate knowledge-sharing between tribes, build
 consensus across Native organizations, and gain credibility as national experts in critical areas
 of public policy.
- With appropriate capacity, training, and support, tribes can collect, analyze, and store their
 own health data that can be used for health planning and program evaluation. The
 establishment of a central data resource organization (e.g., epidemiology center) can create
 opportunities for tribes to develop their own training, advocacy, and technical support
 programs.
- Inter-tribal organizations should establish predictable and accepted processes for communicating needs and setting priorities. Health boards (and other organizations) can accomplish this by ensuring broad representation at meetings, establishing guidelines, and by maintaining open lines of communication among its members.