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**American Indian Culture and Research Journal**

**Title**

The Changing Landscape of Health Care Provision to American Indian Nation

**Permalink**

<https://escholarship.org/uc/item/9rs7h9n1>

**Journal**

American Indian Culture and Research Journal , 39(1)

**ISSN**

0161-6463

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**Publication Date**

2015

**DOI**

10.17953/aicr.39.1.j1u030g668113403

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# The Changing Landscape of Health Care Provision to American Indian Nations

*Stephanie Carroll Rainie, Miriam Jorgensen, Stephen Cornell, and Jaime Arsenault*

In the 2010 US Census, 5.2 million Americans reported American Indian or Alaska Native (AI/AN) heritage; of these, 2.9 million reported AI/AN ethnicity alone.<sup>1</sup> While often referred to as a single minority group, AI/AN populations are enormously diverse—culturally, regionally, and historically. Furthermore, many self-identified AI/AN American citizens also are citizens of individual indigenous nations whose governments have a substantial degree of sovereignty. In 2010, the Indian Health Service (or IHS, the US government agency charged with providing health-care services to citizens of federally recognized tribes) served 565 federally recognized tribal nations, more than two hundred of which are located in Alaska.<sup>2</sup> This paper is concerned primarily with the tribal citizen population, but because available data for AI/AN health status is limited, statistics for the general AI/AN population may sometimes be presented instead.

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Health status indicators for the AI/AN population show consistent inequities when compared with the US population as a whole. While AI/AN health conditions have improved in recent decades, particularly in terms of infectious disease and infant and maternal mortality, and while health problems vary across AI/AN communities, aggregate data continue to paint a bleak picture.<sup>3</sup> A 2001–02 study indicated that AI/ANs bear the greatest chronic-disease burden compared to other ethnic and racial groups, with the highest prevalence of cardiovascular disease and diabetes and striking rates of hypertension and elevated blood cholesterol. Chronic-disease risk factors also were prevalent for American Indians in the study: 80 percent had at least one risk factor and 30 percent had at least three.<sup>4</sup>

Chronic diseases of the heart, malignant neoplasm (cancerous tumor), unintentional injuries, and chronic lower respiratory diseases were the top four causes of death for AI/AN persons within the IHS service population from 2006 to 2008. The 2006–08 AI/AN all-causes mortality rate exceeded that of the 2007 US population as a whole by 20 percent, and AI/AN life expectancies are 4.2 years fewer than those of the US all-races population. The IHS AI/AN population age-adjusted mortality rate was 368 percent higher than the all-races rate due to chronic liver disease and cirrhosis, 177 percent higher due to diabetes, 138 percent higher due to unintentional injury, 82 percent higher from assault (homicide), 62 percent higher from intentional self-harm (suicide), and 59 percent higher for chronic lower respiratory disease.<sup>5</sup> The AI/AN population living in IHS Contract Health Service Delivery Area counties for 1999–2009 had infant mortality rates 61 percent higher than the US population as a whole, with neonatal mortality 16 percent higher and post-neonatal mortality 149 percent higher.<sup>6</sup>

Health-services research has continuously shown a link between health-care service organization structures, processes, and financing mechanisms, on the one hand, and access to and quality of health-care services on the other. In turn, changes to organizational structures and financial mechanisms have been shown to improve access to and quality of health-care services and, ultimately, health outcomes.<sup>7</sup> This paper explores the historical and policy changes affecting provision of health-care services to AI/AN citizens of federally recognized tribes and discusses the literature on tribal management of health-care services. Unfortunately, there is no commensurate comparative research that tracks what effects these changes may have on health outcomes over time.<sup>8</sup>

Health-status indicators for AI/AN populations are not created in a vacuum. What has shaped health services to citizens of federally recognized tribes? What is the postcontact history of health services provision to AI/AN peoples who are citizens of federally recognized tribes? How has the trend toward *tribal* management, which has major implications for organizational structures, processes, and financing, changed the provision of health-care services offered to citizens of federally recognized tribes? What are some of the challenges to tribal management? This paper addresses these questions in turn.

## THE EVOLUTION OF AMERICAN INDIAN HEALTH-CARE PROVISION

An examination of the last two hundred years of federal policy shows a government neglecting the health of AI/AN peoples while at the same time attempting to dismantle their cultures and governments through assimilation policies that included removals from original homelands, resource-takings, suppression of Native religions, forced attendance of children at boarding schools, and other means.<sup>9</sup> This policy history is marked by periods of little to no federal involvement in the health of AI/AN peoples, despite acknowledgment of a government-to-government relationship between the federal government and the governments of American Indian nations. Since the 1970s, however, federal policy has shifted to recognizing tribal self-determination. Concurrently, tribes have staged a quiet revolution, reclaiming sovereign rights and determining the course of tribal community development, including reasserting management control over tribal health care. These tribal solutions to health-care management challenges reveal the benefits of tribal control—benefits that may ultimately lead to improvements in health outcomes.

### *Early Days*

Article I, Section 8 of the US Constitution (adopted in 1789), subsequent treaties, case and statutory law, and executive orders acknowledge a special government-to-government relationship between the US federal government and tribes and create a general US government trust responsibility for AI/AN peoples and their resources—an obligation to act in their best interests. The provision of health services by the US government to citizens of federally recognized American Indian tribes stems from this relationship and responsibility.<sup>10</sup> For example, the treaties between the US government and Indian tribes, through which the United States procured its land base, often included stipulations for medical services, physicians, and hospitals.<sup>11</sup>

However, the extent of the federal government's responsibility for providing health services to AI/ANs is not clear. Court decisions have found that the federal trust responsibility does not entitle AI/ANs to services nor does it provide a basis for claims against the government, and that congressional appropriations, specifically the dollars allocated for activities and services such as the IHS, are publicly owned by all US citizens, not belonging to only AI/AN peoples.<sup>12</sup> Rights are not explicit or specific, nor do they cover all AI/AN individuals. In fact, IHS and any IHS-funded services are typically only available to citizens of federally recognized American Indian nations living within areas that IHS serves.<sup>13</sup>

Some of the earliest medical assistance offered by the US government to AI/AN nations came in the form of vaccines to help control the spread of infectious disease. Yet these vaccines, and other single-incident congressional appropriations, may have been an attempt at self-preservation and diplomacy as much as they were an attempt to practice preventive medicine.<sup>14</sup> In 1804, President Jefferson ordered the Lewis and Clark expedition to utilize the smallpox vaccine as a method of diplomacy. In 1832, Congress (4 Stat. 514) first appropriated funds for health services by instructing Indian agents to purchase smallpox vaccine for army physicians to administer to AI/

AN peoples. These events exemplify the United States' participation in the global eighteenth- and nineteenth-century foreign policy practice of providing medicine and health services to indigenous peoples to further imperial goals.<sup>15</sup>

Missionaries also used medicine as a tool, which the federal government often supported as a cost-effective way to simultaneously address AI/AN health and accomplish assimilation. On the Navajo reservation, for example, evidence demonstrates that the US government invited or allowed missionaries from a variety of religious denominations to provide health services, often with the end goal of wiping out traditional healing practices.<sup>16</sup> Overall, however, AI/AN health conditions were not a primary concern of the US government in the early and mid-nineteenth century.<sup>17</sup>

### *The Reform Movement*

Advances in medicine and the increasing role of government in public health in the late nineteenth century—part of an overall “progressive” or “reform” movement in government—led to changed attitudes toward the provision of AI/AN health care. Both Congress and the Department of the Interior Bureau of Indian Affairs (BIA) attempted to improve health-care delivery for AI/AN peoples. Through their efforts, funds were provided to build facilities and hire medical staff to serve on-reservation American Indian populations.<sup>18</sup>

The Snyder Act of 1921 (42 Stat. 208) allocated federal funds to the BIA to treat and preserve the health of AI/AN citizens of federally recognized tribes. Nonetheless, few improvements occurred. In the 1920s, AI/AN peoples' health was poorer than that of the general population, including higher rates of infant and infectious-disease mortality. Often, diseases that were of no consequence to the rest of the United States presented major challenges for AI/ANs.<sup>19</sup>

In the late 1920s Secretary of the Interior Hubert Work commissioned Lewis Meriam and the Institute for Government Research (later renamed the Brookings Institution) to survey American Indian health services, among other BIA programs. The resultant Meriam Report remains widely cited today, as it provided a comprehensive summary of American Indian health-care issues and through suggested changes, ultimately had a positive impact on future policies.<sup>20</sup> The report concluded that almost all federal government health services and programs provided to AI/ANs were substandard.<sup>21</sup> Its authors took the federal government to task on multiple grounds, among them insufficient appropriations, inadequate medical facilities, nonexistent preventive-medicine programs, the absence of adequately trained physicians and nurses, a lack of understanding of American Indian cultural knowledge and ideas about health, and the need for reliable data-gathering on American Indian health conditions. Recommendations for more and better hospitals, increased professional standards and pay rates for physicians and nurses, and reduced cultural barriers to care and racism were among those that had a positive impact on later policies and health services.

The Meriam Report (and several successors, including reports by the Hoover Commission in 1948 and the American Medical Association in 1949) helped motivate the shift of American Indian health care from the BIA to the IHS, an agency of the

US Public Health Service under the Department of Health, Education, and Welfare, later renamed the Department of Health and Human Services.<sup>22</sup> In 1955, the Act for the Transfer of the Indian Health Facilities to the Public Health Service (P.L. 83-568) moved more than 2,000 BIA personnel, 40 hospitals, and 130 health clinics to the newly created IHS. At the time, conditions in these facilities were below the average level found at most US health-care facilities.<sup>23</sup>

Many of these problems continued under IHS, which with scarce funds struggled to reform the system it inherited from the BIA. In the 1970s staff reported that IHS constraints limited their ability to provide adequate and quality care, including instances where no health-care staff existed to care for those in need, ultimately resulting in deaths.<sup>24</sup> Congress enacted the Indian Health Care Improvement Act (IHCIA, P.L. 94-437) in 1976 to address these issues and further improve conditions in AI/AN health. In so doing, the IHCIA also strengthened the United States' statutory responsibility to provide health services to AI/AN peoples.

### *Self-Determination Policies*

In the 1960s, in response to the federal government's termination policy (which sought to end the government-to-government relationship between tribes and the federal government and to assimilate AI/AN peoples into mainstream society) and in an era of increased civil-rights activism, American Indian nations, American Indian activists, and local and national AI/AN organizations fought for tribal self-determination and self-governance.<sup>25</sup> In 1970 President Nixon called for a policy change from termination to self-determination and recognition of tribes' rights to self-govern. Subsequently, tribes lobbied for, and Congress approved, a series of acts that make it possible for federally recognized tribes to set their own priorities and assume management of services, including health care. Today, tribal involvement varies across the country, depending on each tribal government's ability and desire to assume specific health-services management functions.<sup>26</sup>

### *Tribal Voice*

One of several ways the IHCIA of 1976 attempted to improve IHS-funded care was to set forth methods for involving tribes in the planning and provision of care for tribal citizens eligible for IHS services living on federally recognized American Indian reservations or other tribal services areas in Alaska and Oklahoma.

### **638 Contracts**

The Indian Self-Determination and Education Assistance Act of 1975 (ISDEAA, P.L. 93-638) made it possible for tribes to manage some aspects of otherwise federally managed health care themselves. Commonly known as "638 contracts," agreements pursuant to this act transfer the administration of agreed-upon health services from the IHS to tribes.

While this was an important advance, some tribes struggled with the limitations of 638 contracts. The contracts are administrative mechanisms, rather than routes to priority setting or program development: they are defined-service agreements that

obligate tribes to complete tasks formerly performed by the federal government.<sup>27</sup> A specific criticism of 638 contracts has been that implementation and monitoring vary geographically by IHS area. Some tribes report, and some members of Congress concur, that IHS has at times asserted inappropriate control of (micromanaged) 638 contract services.<sup>28</sup>

### ***Self-Governance Compacts***

Such concerns were among the reasons for amendments to the ISDEAA in 1988 (P.L. 100-472) and for the Indian Health Care Amendments of 1992 (P.L. 102-573). P.L. 100-472 not only allowed the Department of the Interior to transfer management of formerly federal activities and associated funds to tribes, but also provided qualified tribes with broad discretion in spending through a practice called “self-governance compacting.” Compacts resemble block grants and are used to give tribes the ability to exercise decision-making power over federal funds, control the design of services, and have flexibility in program administration.<sup>29</sup> P.L. 102-573 extended those management and spending activities to the IHS, and the Tribal Self-Governance Amendments of 2000 (P.L. 106-260) made this option permanent.<sup>30</sup>

### ***The Results of Congressional Action***

The ISDEAA and the 1992 amendments initiated a substantial shift in control over health-care services from IHS toward tribes.<sup>31</sup> By 1996, most tribes operated *some* type of health-care service and a number offered extensive treatment and preventive programming, such that tribes operated 77 percent of ambulatory facilities and 25 percent of hospitals on tribal lands.<sup>32</sup>

The shift in control continued through the next decade, strengthened by the 2000 amendments (P.L. 106-260). By 2003, tribes or tribal consortiums managed over half of the IHS budget.<sup>33</sup> As of 2010, IHS continued to transfer more than half of its \$4.05 billion budget to tribes and tribal consortiums through seventy-six compacts representing 330 tribes and through “638 contracts” with 232 tribes or tribal consortiums.<sup>34</sup> Increased transfers of funds to tribes resulted in tribes and tribal consortiums controlling health-care facilities. Table 1 traces the shift in tribal control of health-care facilities from 1998 and 2010.

The Patient Protection and Affordable Care Act (ACA, P.L. 111-148) of 2010 amended and permanently reauthorized the IHCIA, providing heightened involvement for tribes through consultation with IHS and states regarding Medicaid changes that may affect tribal citizens. The ACA also provides tribes with the ability to purchase insurance for tribal citizens and defines urban AI/ANs by their tribal enrollment status.<sup>35</sup> These changes underscore tribes’ status as sovereign nations by requiring consultation and recognizing AI/ANs’ tribal citizenship even when they live off-reservation—and encourage still more tribal control.

### ***Tribal Funding***

Clearly, federal policy change was an important factor in increased tribal control over health-care management from 1975 to 2010. Increased tribal resources were

TABLE 1. IHS AND TRIBALLY OPERATED MEDICAL FACILITIES, OCTOBER 2010.

	OPERATED BY <b>IHS</b>		OPERATED BY <b>TRIBES OR CONSORTIA OF TRIBES</b>				
	Direct IHS	% of Total Facilities	638 Contract <sup>a</sup>	Compact <sup>b</sup>	Other Contract <sup>c</sup>	% of Total Facilities	% of Change 1998-2010
<b>Hospitals</b>	28	62	3	14	0	38	51
<b>Health Centers</b>	58	20	116	119	0	80	20
<b>School Health Centers</b>	2	13	11	2	0	87	44
<b>Health Stations</b>	31	25	52	40	0	75	32
<b>Alaska Village Clinics</b>	0	0	8	125	6	100	10

**a** P.L. 93-638 Self-Determination Contracts  
**b** P.L. 106-260 Tribal Self-Governance Amendments  
**c** Local government standard procurement contract for Alaska Native Villages

Source: modified and updated from a table in *The State of Native Nations: Conditions Under US Policies of Self-Determination* (2008), Harvard Project on American Indian Economic Development (Oxford University Press, 2008), 225, based on data from US Indian Health Service and US Department of Health and Human Services.

another factor. The self-determination policies freed tribes not only to manage their own health-care services but also to have greater say over the course of economic development in their nations. In the 1990s, largely as a result of self-determined economic choices, AI/AN nations' economies grew three times faster than the US economy.<sup>36</sup> During the 2000s, while the United States economy constricted, many tribal economies continued to grow in terms of per capita income, household income, and female labor force participation.<sup>37</sup> This growth provided many tribal governments with discretionary public funds, which they could spend on projects and services of their choosing (note that both the availability and amount of such funds vary among tribes). As tribes have taken on more management and funding responsibility, they also have had the incentive to develop other new sources of funds, and many have done so, seeking grants, in-kind sources of support, and third-party reimbursements



for services provided. All of these “tribal sources” of funds are used to supplement health-care resources provided by the federal government, giving tribes still more say over the administration of health care in their communities.<sup>38</sup>

## EXPERIENCES IN TRIBAL MANAGEMENT

While tribal government health-care management through 638 contracting, compacting, and budget supplementation with tribal funds resulted in a shift from purely federal management of IHS services to a mix of tribal and federal management, few research efforts have examined this shift or experiences in tribal management. What research does exist is outdated; only a handful of studies appear in the literature since the 1990s, and none have been published since 2002.<sup>39</sup> Nonetheless, the research provides insight into the factors associated with health-care management decisions and into the benefits and challenges that tribes face in taking control of health-care delivery in their communities. Six comparative studies, summarized here, were published between 1996 and 2002. The research in these studies includes secondary data analysis, surveys, and interviews with individuals representing the tribes, tribal organizations, and the IHS.<sup>40</sup>

Adams’ study of 107 tribes—one of the few quantitative studies of tribal management—compared the characteristics of IHS direct-service tribes with those that had switched to tribally managed care using IHS, BIA, and census data from 1974 and 1980. Tribes were more likely to stay with the IHS if they felt it was responsive to their concerns, if they had limited financial resources, and if they shared an IHS service unit with at least one other tribe. Tribes were more likely to self-manage if the tribal government was large relative to the size of the local federal bureaucracy, possibly indicating experience with tribal management in other areas (such as education).<sup>41</sup>

In 1995 the Office of the Inspector General in the Department of Health and Human Services conducted interviews on how the IHS could best support and enhance 638 contracting with seventy American Indian tribes, twelve tribal organizations, forty-four IHS area and headquarters staff, and ten Indian health boards. Three-quarters of the interviewees wanted to increase the scope and number of their contracts. They had access and quality concerns about IHS health care and administrative services and felt that more contracting would lead to easier access to health-care services, expanded coverage, and improved quality.<sup>42</sup>

Noren, Kindig, and Sprenger’s 1996 on-site survey of thirty-nine Indian health-care clinics and multi-clinic organizations addressed organizational challenges, management needs, and the relationship between Native-managed health services and the IHS. The respondent group was representative both in terms of geography (ten states) and management regime (IHS operated half of the respondent organizations, tribes one-third, and tribes or regional health boards that governed urban programs and worked in collaboration with the IHS operated the remainder). Survey findings identified funding, staff morale, the perceived ease or difficulty of transitioning to tribal control, the quality of IHS-local clinic relationships, changes in federal programs (such as Medicaid), and cultural competence as important issues in tribes’ decisions to

self-manage. The authors point to the need for ever-increasing management capacity at the tribal level—yet they also correctly predict the aggregate shift toward tribal self-management of health programs.<sup>43</sup>

Dixon, Bush, and Iron's 1996 study assessed the factors affecting tribal choice of health-care delivery organization using twenty-seven interviews with tribal leaders, tribal health directors, IHS area directors, and IHS area planners from nine tribes in four IHS areas. Factors that affected a tribe's decisions were its legal, historical, and political context; management, planning, and negotiating capacity; basic beliefs concerning health care; available choices; and perceived outcomes. Tribal leaders underscored the importance of a separate health-care delivery system for Indians; acknowledged that decisions regarding health-care management involve risks that affect lives; highlighted the importance of quality care; called for holistic solutions; emphasized the need for long-term decision-making; identified a need for more information and communication between tribes and the IHS; and underlined the federal government's trust responsibility. Advantages of tribally operated health services included improvements in quality and types of care, financial management opportunities, and community ownership benefits. Challenges identified by Dixon, Bush, and Iron include inadequate funding, retention of providers, and issues related to economies of scale, small population sizes, and geographic isolation.<sup>44</sup>

The National Indian Health Board's 1998 report presented the results from a financial analysis of data through 1997 and surveys of tribal leaders and health directors at 210 tribes and tribal organizations engaged in 638 contracts and compacts. Survey questions focused on barriers and opportunities to tribal management, and the impact of tribal management on services, facilities, and quality of care. Analysis of high response clusters identified chronic IHS underfunding, unwieldy federal funding mechanisms, and concerns regarding trust responsibilities as barriers to tribal management. Other results showed that 638 contracting and compacting tribes tended to focus on preventive services and offer more integrated service delivery—changes that may improve the quality of care.<sup>45</sup>

Joe reports on findings from twenty-two interviews conducted in 2001 with tribal leaders and representatives of IHS, tribal, and urban health programs. While interviewees reported difficulties with the retention of skilled providers and the need to ration Contract Health Services by limiting the expenditure of these dollars to situations that could result in permanent disability, loss of a limb, or death, they also described health service quality improvements once tribes assumed health-care management through compacting or 638 contracting.<sup>46</sup> One reason may be greater attention paid to local needs; interviewees noted that tribal management often resulted in new or rebalanced service offerings and in terminating providers who did not meet quality-of-care standards. However, interviewees also reported fears of federal cuts as more tribes take over management of health services and observed that tribal elections have the potential to change tribal health-care programming and the delivery of quality health care.<sup>47</sup>

All together, these studies suggest that tribes often are eager to take over management of IHS health-care services, recognizing the opportunity to manage according to

their own priorities, bring their own assets to bear on service delivery, and potentially improve the quality of care. But the research also emphasizes that the decision is a complicated one, requiring tribes to wrestle with challenges that in and of themselves deserve further consideration.

## CHALLENGES OF TRIBAL MANAGEMENT

The literature identifies five significant challenges to tribal management of health care: (1) the funding challenge, or how to patch together and sustain adequate funding for tribal health care in a world of constantly changing costs and a history of inconsistent support for American Indian health; (2) the institutional challenge, or how to create tribal-governance environments capable of supporting and sustaining quality health-care delivery; (3) the treaty and trust challenge, or how to preserve the treaty and trust relationships on which federal funding of health care is based; (4) the information challenge, or how to remedy the scarcity of information about tribal-management options and their effects on health-care access; and (5) the access challenge, or how to provide needed services and ensure that people use those services. Significantly, the literature also points to strategies that tribes have utilized to minimize or overcome the challenges.

### *The Funding Challenge*

Funding for American Indian health care is largely a matter of congressional will. In federal budgets, the IHS competes with other priorities and other constituencies—from other health-care interests to national defense—to gain the attention of policymakers. The result has been deteriorating support for American Indian health, as evidenced by static budgets,<sup>48</sup> at the same time as the IHS service population and per-patient demand for services have grown and goods and labor costs have increased.<sup>49</sup> Numerous studies have documented historic and current inadequate and massive underfunding of the IHS.<sup>50</sup> For example, in 2003 the US Commission on Civil Rights reported that federal government per-person spending on AI/ANs eligible for IHS services was less than half that of per-person spending on any other group receiving publicly funded health care, including prisoners and Medicaid recipients, resulting in rationing of health-care services to eligible AI/ANs.<sup>51</sup> In its subsequent 2004 report, the commission concluded that while IHS and others have identified solutions to AI/AN health disparities, Congress does not provide the resources to implement such solutions.<sup>52</sup> Even a supportive executive branch may not help: President Obama's fiscal year 2014 budget request sought to change the federal self-governance process by placing caps on the payment of contract support costs without consulting with tribes, the IHS, or the BIA.<sup>53</sup>

The chronic underfunding of IHS limits health-care services and makes the further establishment and expansion of IHS-funded health-care facilities in Indian country nearly impossible. It also presents imposing obstacles for tribes that want to increase their control over health-care delivery. Some tribes, having taken up the management task using IHS funds, have subsequently found the financial burden insupportable,

returning management to IHS as they neared bankruptcy. Other tribes have chosen not to take on management because they lack the financial resources to make already underfunded programs work.<sup>54</sup>

Decentralization of management from the federal IHS system to tribal management also has led to the loss of economies of scale that result from being part of the IHS system. However, some tribes have instituted practices to better realize economies of scale or further supplement their funding, such as asking for discounts; creating intertribal partnerships; offering care to non-citizens; billing third parties (such as Medicare, Medicaid, Veterans Affairs, or private insurance); seeking grant awards from federal agencies and other public or private foundations; and partnering with nontribal governments, organizations, or educational institutions.<sup>55</sup>

There is a consensus among many government officials and health-care providers that, as health-care costs continue to rise nationwide, it will take a multifaceted and creative approach to provide all AI/AN citizens with access to quality care. For example, long-term cost savings will require more aggressive and better-funded preventive programs as well as increased utilization of telemedicine and other technology. Some have argued that if technology were better utilized, it would save money while providing quality care, especially for isolated, rural populations.<sup>56</sup>

### *The Institutional Challenge*

Prior research on governance and development in Indian country indicates that tribal health care cannot be treated simply as a stand-alone program, existing in a programmatic silo unaffected by the organization of tribal government. Tribal health-care capacities reflect, to a significant degree, the characteristics and capacities of that larger organization. Governmental effectiveness and efficiency affect whether or not a tribe can successfully deliver services.<sup>57</sup> Tribes with poor organizational infrastructures potentially face challenges when moving toward tribal management.<sup>58</sup>

Certainly, the histories of tribal governments have complicated the tribal-governance task. The current governments of many AI/AN nations were created in a context of invasive paternalism on the part of the federal government. Many tribes' governing systems were designed by federal bureaucrats in the 1930s and were not conceived as expressions of the will and values of the communities they served. Instead, these tribal governments were intended simply to organize events, endorse federal initiatives, and administer local programs according to federal guidelines. Such governments had limited freedom and capacity either to take over major decisions about the future of their communities or to design and implement ambitious programs intended to address persistent problems such as poverty and ill health.<sup>59</sup>

As they have been able, and particularly in the self-determination era, many American Indian nations have moved aggressively to reshape their own governing institutions, recognizing the need for governing tools capable of supporting their own goals and of improving the quality of life of their peoples.<sup>60</sup> Through constitutional and other governmental reforms, they have been reorganizing tribal governments in diverse ways, introducing dispute-resolution mechanisms, insulating day-to-day administration from

political interference, bringing cultural considerations into governmental structures and program management, and so forth. This has allowed many of them to do much more than simply replicate and administer programs designed by federal bureaucrats. Some tribes have initiated new relationships with other, nontribal governments; some have developed innovative funding strategies to support their own programs of change; and some have come up with solutions to problems long viewed as intractable.<sup>61</sup>

Such improvements in the quality and capacity of tribal governance can have multiple direct effects on health care. Citizens are more likely to support programs that they believe are responsive to their own concerns. Professional staff are more likely to be attracted to environments where overall governmental administration is competent, politics are kept in their place, and commitment and quality performance are rewarded. Funders are more likely to invest in programs managed by governments with reputations for probity, prudence, and effectiveness. The different pieces of tribal government are more likely to act collaboratively to address leading concerns.<sup>62</sup>

In short, the institutional challenge for American Indian nations moving into health-care management is to create governance environments in which social-service programs—including tribally managed health care—are more likely to succeed and to sustain themselves in the long run. Of note, the institutional challenge augments the funding challenge: long-term effectiveness with health-care management will require significant near-term investments, both by tribes and by the federal government, in tribal governance and management capacity.

### *The Treaty/Trust Challenge*

A third challenge is finding a balance between tribal management and preservation of treaty and trust relationships, which are the basis of federal health-care provision for citizens of federally recognized tribes. As tribes take increased responsibility for delivering health-care services through 638 contracts, compacts, and supplemental funding, they do not want to find the federal government stepping away from its trust and treaty obligations to support health care.<sup>63</sup>

This is a particular possibility in the cases of cost savings and supplemental funding. As American Indian nations innovate and invest, will they find the federal government *further* reducing its financial commitments? Will the federal government come to expect that tribes will supplement federal American Indian health funds? Will tribes with fewer citizens and larger land bases, who may find it more difficult to move toward tribal management, be shortchanged as a result? Others worry that self-determination and self-governance will lead to the dissolution of IHS and will allow the US government to abrogate the trust responsibility, abandon the provision of health care for American Indians, and dismiss the idea as a “historical” commitment.<sup>64</sup>

These questions and concerns regarding the federal government’s responsibility to provide health-care services to citizens of federally recognized American Indian nations are of ongoing importance. However, our review finds the promising result that some tribes have asserted indigenous control over health-care management while at the same time continuing to urge federal action on AI/AN health care.

## *The Information Challenge*

AI/AN nations lack information about health-care management. Many tribal efforts are based on data from the 1990s and earlier. Tribal control is clearly expanding, but the research to understand its effects has not kept pace; surely, there are unknown insights and lessons in the growing body of tribal experiences.<sup>65</sup> Determining the effects of policy on health outcomes can require long time frames, but changes in access to quality care should be quickly identifiable. However, identifying these changes and linking them back to policy initiatives in ways that can inform tribal and federal policymakers will require a systematic effort that has not been conducted to date.

Some field leaders have called for the creation of a national network to disseminate existing information and encourage discussion regarding tribal control of health-care services.<sup>66</sup> Self-Governance Communication and Education, a tribally based group that seeks to educate tribal, federal, and other governments as well as individuals on the purpose and tenets of federal self-governance policies, has created a website, an email listserv, and an annual conference that facilitate communication, information dispersion, and a national self-governance strategic plan for all self-governance activities.<sup>67</sup> This is helpful, although a comprehensive effort specific to tribal control of health-care services would be even more so. In particular, a means of sharing ideas and strategies about what works—in terms of service development, funding, and management challenges, among other issues—could provide critical strategic guidance for current and potential tribal managers.

This lack of information is symptomatic of broader AI/AN health-care data challenges. Indian country needs greater data availability and quality, more evaluation of policy effects, and improved dissemination of information. Evidence of these needs is diverse. For example, in 2007 Westat, a private statistical consulting firm contracted by the Department of Health and Human Services (DHHS), investigated the quality of DHHS American Indian, Alaska Native, and Native Hawaiian health data and identified numerous data reliability and validity issues. These resulted from small population sizes (many tribes do not have large enough populations to allow for precise statistical estimates); the geographic dispersion of many AI/AN individuals to urban areas and the concentration of many reservation populations in rural areas; misclassification of race resulting in underreporting; the lack of or inconsistent collection of race identifiers; and inadequate racial representation due to limited survey response rates and issues with survey question interpretation. The authors proposed changes such as oversampling of AI/AN people, revising statistical methods, and aggregating datasets to improve data availability and quality, many of which DHHS and others are investigating or adopting.<sup>68</sup>

The post-2000 transition from the decennial census as the means for collecting socioeconomic data on the US population to the American Community Survey (ACS) further complicates the data landscape for the AI/AN population. Although the ACS provides a more timely view of the American population, it undercounts the “AI/AN alone” population (the population that identifies solely as AI/AN, not in combination with any other race). This has caused reservation-based data to change significantly

and without explanation for some key socioeconomic characteristics, which increases concern about the reliability of AI/AN data, and reservation-level data is provided only with the five-year data aggregates.<sup>69</sup>

These data challenges present an argument not only for advocacy concerning the usefulness of and possible improvements to federal data collection, but also for tribes to consider building internal capacity and infrastructures to generate, manage, and analyze their own data. Much data already exist within tribal enrollment offices and programs. Comprehensively collecting and analyzing these data allow for their use in setting tribal priorities, decision making, grant writing, and more reliably describing the community's health status.<sup>70</sup>

The complications surrounding data availability and quality discussed here, along with others not mentioned, present research challenges. Simply put, it is not easy to know what is going on. Nonetheless, American Indian nations need more evidence of what's working in tribally managed health care and information on whether and how American Indian nations are improving access to effective health services under difficult conditions. Yvette Roubideaux, the IHS director from 2009–2015, has called for data on the provision of health-care services for AI/ANs that would allow measurement of the impact of the shift to tribal management.<sup>71</sup> Systematic research on these issues could provide concrete, usable insights to nations faced with major health-care management policy decisions.<sup>72</sup>

### *The Health-Care Access Challenge*

A primary determinant of AI/AN health outcomes is *access* to health care. American Indians and Alaska Natives are less likely to use available health-care services, are less likely to be satisfied with the care they do access, have less confidence in the quality of their medical care, and have more difficulty in communicating with their health-care providers than non-Natives.<sup>73</sup>

No single explanation can fully capture the reasons that AI/AN do not or cannot access health care. Among others, specific barriers cited in the literature include language and cultural incompatibilities, problems with provider communication, some patients' low education levels, poverty and the associated inability to pay for services, geographic isolation and long distances to health-care facilities, transportation difficulties, dissatisfaction with care, long wait times, poorly staffed facilities, limited availability of services, under-insurance, and rationing of care.<sup>74</sup> Broadly, however, access problems affecting AI/AN populations can be characterized as sociocultural, structural, and financial.<sup>75</sup>

### *Sociocultural Factors Limiting AI/AN Health-Care Access*

One important sociocultural factor that inhibits some AI/AN patients from accessing available care is discomfort with the Western health-care system. There is, at times, a divergence between what the Western biomedical community designates a best practice and what AI/AN people may desire from health-care providers. The long history of colonialism and external control over AI/AN communities, poorly conceived and conducted academic and government research projects, and the history and current

practice of genomic research on minority populations have spread distrust and even fear in some AI/AN communities.<sup>76</sup> Failure to address this sociocultural barrier to accessing available care is evidence of a lack of cultural competence.<sup>77</sup>

Integrating indigenous culture and health care is not easy. Most health-care professionals are non-Native, and the US health-care system is not organized to deal easily with cultural diversity as it relates to AI/ANs.<sup>78</sup> In general, Western-trained, non-Native health-care providers never learn the history of tribes as part of their formal education and as many as half of physicians have no training in cross-cultural care. Dixon and Iron's study of cultural-orientation programs revealed that about two-thirds of IHS-funded AI/AN health programs lack an associated, tribally run cultural-training program for health-care providers.<sup>79</sup>

Nonetheless, connecting health care to culture might have substantial payoffs. In the literature, the most frequently mentioned strategies for increasing cultural competence in health-care services to AI/AN communities are fostering the use of traditional medical models and healing practices, increasing cultural-competence training, and increasing the number of AI/AN caregivers. Pursuing such changes would focus greater attention on the cultural and spiritual dimensions of health care and increase the likelihood that AI/AN citizens will take advantage of the medical services currently available to them.<sup>80</sup>

The strategy of hiring more AI/AN health professionals is hindered by a further hurdle—the lack of availability of such personnel. In 2013 and 2014, American Indian, Native Hawaiian, and Alaska Native students constituted a disproportionately low 0.2 percent of all medical school graduates, while Whites accounted for 58.6 percent of graduates, Asians 20.3 percent, Blacks 5.6 percent, and Hispanics 5.0 percent.<sup>81</sup> The shortage results from a mix of issues: extreme poverty and social issues in reservation communities that make preparation for higher education and paying for college difficult, the cultural disconnect experienced when leaving the reservation community to pursue college, and the lack of culturally appropriate training programs.<sup>82</sup>

The personnel shortage requires diverse solutions, only some of which are currently being implemented. Tribal colleges, for instance, offer a unique opportunity to train AI/AN nurses and often put special emphasis on cultural competence.<sup>83</sup> Nontribal colleges, private organizations, and corporations also offer programs to encourage American Indian students to pursue careers in medicine.<sup>84</sup> Unfortunately, because of the difficult economic environment of the late first decade of the 2000s, many of these programs have experienced funding cuts or been discontinued altogether.<sup>85</sup>

Notably, tribal innovations such as the award-winning Tohono O'odham Nation's Archie Hendricks, Sr. Skilled Nursing Facility and the Lac du Flambeau Band of Lake Superior Chippewa Indians' Peter Christensen Dental Campus demonstrate how health-care facilities can connect to educational institutions, create jobs, and retain staff even in geographically isolated communities, and provide workplace training and educational opportunities for Natives and non-Natives within a culturally relevant environment.<sup>86</sup>



### ***Structural Limits on AI/AN Health-Care Access***

Over the last century, access to clinical services and infectious-disease prevention measures, including sanitation and environmental health, resulted in reduced infectious-disease incidence rates in the AI/AN population. But the scarcity of IHS resources has meant that these investments in services and infectious-disease prevention came at a cost: many American Indian communities now lack adequate *chronic* disease-prevention services, despite the fact that conditions such as diabetes and cancer are a growing problem in Indian country and that more comprehensive prevention programs addressing both infectious and chronic diseases could significantly improve AI/AN health outcomes.<sup>87</sup> In other words, a lack of relevant health-care structures can be an important barrier to access.

### ***Financial Factors Limiting AI/AN Health-Care Access***

As compared to other Americans, AI/ANs are particularly poorly insured. Among self-identified AI/ANs, as much as 30 percent of the population under sixty-five is uninsured: they do not carry individually purchased or employer-provided benefits, they are not enrolled in Medicaid or the Children's Health Insurance Program, and they are not eligible for Medicare.<sup>88</sup> Among the subset of AI/ANs who are tribal citizens (again considering only the population under sixty-five), 16 percent were totally dependent on the IHS in 2006–07.<sup>89</sup> The Affordable Care Act provides expanded Medicaid coverage in some states and creates a new opportunity for AI/AN individuals or tribes to purchase insurance. However, coverage is not mandatory for tribally enrolled AI/ANs, and the provisions and exceptions for AI/ANs (for example, the provision allowing a change in plans on a monthly basis and exemptions to cost sharing) are confusing.<sup>90</sup> Because health insurance is an important financial mediator of access to health care in the United States, this demonstrated lack of insurance is a significant barrier to access for many AI/ANs.

Direct service provision by the IHS is an important—but limited—backstop for poorly insured AI/ANs.<sup>91</sup> In 2009, for example, the IHS used its \$3.58 billion budget to serve approximately 1.9 million people—some 65 percent of the single-race AI/AN population.<sup>92</sup> But because 67 percent of the single-race AI/AN population does not live on tribal lands,<sup>93</sup> and only one percent of the IHS budget is dedicated to health-care centers outside IHS or tribal service areas,<sup>94</sup> access for many came at the cost of a long trip home to a reservation-based facility. Access may have been impeded further by a patient's need to reestablish IHS eligibility following a move from one service area to another.<sup>95</sup>

Certainly, part of the access issue is that not all self-identified AI/ANs are citizens of federally recognized tribes—the group the US government is obligated to serve under its treaty and trust responsibilities—through direct IHS service provision, tribal contracting, or compacting. Yet often, because of IHS underfunding, even tribal citizens' access options are reduced to emergency-room care. Cost constraints often mean that care can be provided only when there is a direct threat to life or limb.<sup>96</sup>

## CONCLUSIONS

This paper has provided a brief overview of the relationship between American Indian tribes and the federal government with respect to health-service provision over the past two hundred years and described how that history led and related to the shift in health-care services management from federal to tribal governments over the past thirty years. The field of tribal management of health care is ripe for research, as the sparse and aged array of existing research demonstrates. Extant research has focused on how tribes approach tribal management and on the challenges of underfunding, institutional requirements, federal treaty and trust responsibilities; how tribes share and acquire information; and how they address access to health-care services. The overall discussion demonstrates that in many instances, tribes have found innovative ways to address these challenges. For many, the solutions reveal the benefits of tribal management—benefits that may ultimately lead to improvements in AI/AN health-care outcomes. Questions for future research include: Can tribal management lead to better health-care delivery than direct Indian Health Service management? What is the relationship between the changes in management of health-care services and health outcomes over time? In what ways are tribes addressing the challenges identified in this paper? In what other ways are tribes working to improve the health of AI/AN communities?

### *Acknowledgments:*

We would like to thank Alyce Adams for her insights and advice; Ariel Mack for graphics; Denise Lum, Sara Shuman, and Erin Suelmann for research assistance; and Emily Dellinger McGovern, Jennifer Lee Schultz, Rachel Rose Starks, and Renee Goldtooth for editing assistance. This research was made possible by a grant from the Nathan Cummings Foundation; the Morris K. Udall and Stewart L. Udall Foundation; the University of Arizona; and the W. K. Kellogg Foundation.

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74. Pfefferbaum, et al., "Providing for the Health Care Needs of Native Americans," 211–58; US Commission on Civil Rights, *Broken Promises*, 28–29, 70–71; US Indian Health Service, "IHS Fact Sheets: Indian Health Disparities"; Zuckerman, et al., "Health Service Access, Use, and Insurance Coverage," 54–55; Angus Deaton, "Policy Implications of the Gradient of Health and Wealth," *Health Affairs* (March/April 2002): 20–22; *Unequal Treatment*, ed. Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson (Washington DC: The National Academies Press, 2003), 1, [http://www.nap.edu/openbook.php?record\\_id=12875 &page=R3](http://www.nap.edu/openbook.php?record_id=12875 &page=R3). Note: Pfefferbaum, et al., in "Providing for the Health Care Needs of Native Americans," 252, define rationing as "the process for determining who receives particular goods and services and who does not. . . With respect to health care, medical need may form the basis of rationing, as is the case with medical priority rationing for the IHS contract services program."
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76. Indigenous Peoples Council on Biocolonialism, "Indigenous People, Genes and Genetics: What Indigenous People Should Know about Biocolonialism" (June 2000), 19–25, <http://www.ipcb.org/publications/primers/htmls/ipgg.html>; Jeffrey Shepherd, "At the Crossroads of Hualapai History, Memory, and American Colonization: Contesting Space and Place," *The American Indian Quarterly* 32, no. 1 (Winter 2008): 17–18; Donald Warne, "Traditional Perspectives on Child and Family Health" (paper presented at the 3rd International Meeting on Indigenous Child Health, Albuquerque, New Mexico, March 6–8, 2009), 2. For an in-depth discussion, see US Commission on Civil Rights, *Broken Promises*, 32–37.
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79. Ibid., 2, 130.

80. Davies, *Healing Ways*, 60; Tom Robertson and Dan Gunderson, "Rekindling the Spirit: The Rebirth of American Indian Spirituality—Part 7: The Healing Spirit," *Minnesota Public Radio*, 20 August 20, 2003, [http://news.minnesota.publicradio.org/features/2003/08/18\\_gundersond\\_spiritualityeigh/](http://news.minnesota.publicradio.org/features/2003/08/18_gundersond_spiritualityeigh/). Tribes that manage their own health-care services are in a unique position to enhance the quality of their care through conscious support of cultural competency. For example, per Robertson and Gunderson in "Rekindling the Spirit," the Mille Lacs Band of Ojibwe has a 638 compact for the provision of health services. Both western-trained medical staff and traditional healers hold regular office hours at their health-care facility. Through these arrangements, patients have the opportunity to access two quite different health care systems simultaneously, practitioners have the opportunity to work together across a cultural divide, and tribes increase tribal citizen support for tribal health programs.
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