

The Story of Indian Health is Complicated by History, Shortages & Bouts of Excellence

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Abstract: One of the primary goals of the U.S. government's entry into health care was to protect soldiers by isolating tribal populations and inoculating them against infectious disease. When tribes signed the legally binding treaties, the United States promised them doctors, nurses, facilities, and basic health care. Yet this promise has never been fully funded by Congress. The Indian Health Service, which includes tribal and nonprofit health agencies, is tasked with defying gravity, and this has led to a regular cycle of heart-breaking stories about a system that fails American Indian and Alaska Native patients. Yet, at the same time, the Indian health system has achieved remarkable innovation and excellence.

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Every so often, the “story” of Indian health is told by a news organization. For example, *The Wall Street Journal* reported the death of several Native American patients in Pine Ridge and Sisseton, South Dakota, and Winnebago, Nebraska: “In some of the nation’s poorest places, the government health service charged with treating Native Americans failed to meet minimum U.S. standards for medical facilities, turned away gravely ill patients and caused unnecessary deaths, according to federal regulators, agency documents and interviews.” The report adds that the Indian Health Service (IHS) “operates a network of hospitals and clinics, much like the Veterans Health Administration. Under U.S. treaties that date back generations, the service is legally responsible for providing medical care to about 2.2 million tribal members. But that system has collapsed in the often-remote corners of Indian Country, where patients live hours from other medical providers, often have no insurance and depend on the federal service.”¹ A few days later, at a budget hearing on Cap-

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itol Hill, a number of senators weighed in on *The Wall Street Journal* report. “The stories are heartbreaking,” said Senator Lisa Murkowski, R-Alaska, chair of the Appropriations subcommittee that funds Indian health programs. She added that though the then-Acting Director of IHS, Mary Smith, had indicated that “the agency was committed to doing ‘whatever it takes’ to deliver quality care,” Murkowski still found that serious problems continued, including hospitals operating without having received recertification from the Center for Medicare and Medicaid Services despite an additional \$29 million approved to address these problems.² Murkowski stated that she was “very concerned” that the Trump budget request

does not adequately meet the needs for health care in Indian Country. The disparities between health outcomes for American Indian and Alaska Native people compared to the population at large are staggering. For example, American Indians and Alaska Natives are three times more likely to die from diabetes. The drug-related death rate for Native Americans has increased 454 percent since 1979 to almost twice the rate for all other ethnicities. And, the suicide rate among our First Peoples is roughly twice that for the rest of the population. In order to improve health care delivery, the IHS must do a better job at hiring and retaining an adequate number of qualified doctors and nurses. The IHS must also do a better job of maintaining a large facilities infrastructure that serves 2.2 million American Indians and Alaska Natives. This requires significant resources. Currently, the vacancy rate for Indian Health Service doctors, dentists, and physician assistants is roughly 30 percent. The backlog of facilities maintenance at IHS hospitals is over half a billion dollars, and according to the agency’s own budget documents, the average age of its facilities is roughly four times that of its private sector counterparts. Additional resources are

not the only answer – the agency must also do more to improve the quality of its existing work force.³

Mark N. Trahant

Another member of the subcommittee, Jon Tester, D-Montana, was frustrated by the administration’s budget request and the refusal of the agency’s current acting head, Michael Weakhee, to admit whether there would be an increase or a decrease in the agency’s ability to hire staff. When questioned directly about the budget, Weakhee replied only that the IHS was prioritizing “maintaining direct care services.”⁴ But this was not an isolated incident; there has been a long history of Indian Health Service directors who were unable or unwilling to answer that question. If we consider the Senate exchanges as a story, it becomes one that tells of incompetence, poor management, too few doctors, and, most certainly, not enough money.

Because we only have sparse evidence about Indian health problems prior to European contact, this story of Indian health begins with European colonization, when serious health challenges such as smallpox reached catastrophic proportions. As history of medicine scholar and physician David S. Jones has written, “Estimates of pre-contact American populations vary between 8 and 112 million (2 to 12 million for North America), and estimates of total mortality range from 7 to 100 million. Whatever the exact numbers, the mortality was unprecedented and overwhelming.” Europeans introduced several diseases, including smallpox, measles, influenza, and malaria, to Native populations from the sixteenth to nineteenth centuries. “Populations often decreased by more than 90% during the first century after contact. As recently as the 1940s and 1960s, new highways and new missionaries brought pathogens to previously isolated tribes in Alaska and Amazonia.”⁵ It’s impossible to over-

state the consequences of a 90 percent mortality rate. This is the root of historical trauma: the collective memory of a people nearly wiped off of their homeland.

Greg Bourland, then-chairman of the Cheyenne River Tribe in South Dakota, shared in *The New York Times Magazine* a personal familial history of epidemic. He wrote about his great-great-grandmother Blue Earnings:

She was a powerful Lakota medicine woman. They say that she drank water all the time. She got sick from smallpox, and when she was getting ready to die, she asked for a bowl of water. She said, "I'm going to show you part of my powers, and why I'm sick." They put the bowl in front of her, and she spit into it, and out of her mouth flew four little water creatures. Here in the Dakotas, around the edge of lakes, there are these insects. They look as if they can walk on the water. They skitter. Three of them were jumping around in the bowl, and the other was dead. She pointed and said: "See, that one got sick from this white man's disease, from smallpox. If that one can't live, I can't live, either." And she died.⁶

Indeed, it was the epidemics that defined the early public health initiatives of the United States. The Army sent doctors to military posts in order to protect soldiers from infectious diseases, leading Army doctors to care for tribal communities, at least on an irregular basis. In 1832, the War Department negotiated a treaty with the Winnebago Tribe in Wisconsin that promised two physicians as partial payment for ceded acres. The cost was budgeted at \$200 per year. (As a comparison: an Indian agent's salary in that region was \$800 per year and that was considered low. Missouri River agent John Sanford wrote to Superintendent of Indian Affairs William Clark and asked for a \$400-a-year salary increase because he deserved a job with less risk and

better pay.) Not every treaty was as specific, but most of the nearly four hundred treaties that Congress ratified included the promise of doctors. Some spelled out the construction and operation of hospitals as a part of the deal. But treaties only made the promise. Congress still had to appropriate the money, and that has never happened.

By 1880, there were seventy-seven physicians serving the entire American Indian population in the United States and its territories. Commissioner of Indian Affairs Thomas J. Morgan urged Congress shortly before the turn of the century, "in the name of humanity," to fund hospitals and every agency because their absence was a "great evil that in my view amounts to a national disgrace." Morgan calculated the disparity in resources, finding that the Army spent \$21.91 per soldier and the Navy \$48.10 per sailor, while the government only appropriated \$1.25 per Indian patient.⁷

The first direct appropriation for Indian health programs was made in 1911 for the "relief of distress and prevention of diseases" among the Indians. President William Howard Taft said it was not enough: the conditions were "very unsatisfactory" and the Indian death rate was more than twice that of the general population. He asked Congress to increase wages because the "smallness of the salaries" affected the qualifications and ability of the physicians in the Indian Service. The average salary was \$1,186 per year, less than half of the average salary for a government employee. "As guardians of the welfare of the Indians," the president told Congress, "it is our duty to give the race a fair chance for an unmaimed birth, healthy childhood, and a physically efficient maturity."⁸

The Bureau of Indian Affairs (BIA) created a health division in 1921. But poor funding, low salaries, inadequate supplies, and deficient facilities contributed to an unsatisfactory health care system. "All we re-

ally need,” Michael J. Pijoan, a doctor at the Navajo Medical Center, wrote in 1951, “are good doctors, facilities and pharmaceuticals. I am weary.” A month later, he resigned, saying, “the system is no longer medical. It is only bureaucratic. No more ceremonies are allowed in hospitals. Indians are now numbers, not people. We are machines. This is intolerable. We leave.”⁹ In 1955, Congress recognized at least part of the problem and transferred health programs away from the BIA to the new Indian Health Service. Ray Shaw, the IHS’s director at the time, promised Congress that he would make improvements. While working at the BIA, he noted that Congress had appropriated \$30 million to treat tuberculosis, but the money was never used for that purpose. According to Shaw, the director of the BIA said he needed the money for other things. “I never forgot that,” Shaw said. As a new agency, the Indian Health Service budget increased from \$10 million per year to \$17.7 million. This is where the story gets complicated. The new Indian Health Service was ambitious and innovative despite being underfunded.

In 1976, Congress proposed a sweeping new authorization for Indian health programs. The Indian Health Care Improvement Act “declares that it is the policy of this Nation, in fulfillment of its special responsibilities and legal obligation to the American Indian people, to meet the national goal of providing the highest possible health status to Indians and to provide existing Indian health services with all resources necessary to effect that policy.”¹⁰ The legislation called on Congress to appropriate at least \$1.6 billion in new funding for Indian health, spending resources on improving staffing, facilities, access to care for urban Indian populations, and, for the first time, opened up Medicare and Medicaid revenue. “While there have been improvements in health status of Indians in the past 15 years, a loss of momen-

tum can further slow the already sluggish rate of approach to parity. Increased momentum in health delivery and sanitation as insured by this bill speed the rate of closing the existing gap in age at death,” White House advisor Ted Marris wrote in support of the legislation. “In 1974 the average age at death of Indians and Alaska Natives was 48.3. For White U.S. citizens the average age of death was 72.3. For others, the average age was 62.7.”¹¹ For Marris, the “bottom line” was an unavoidable connection between “equity and morality” when there is a more than twenty-year differential in age at death between Indians and non-Indians. Yet this idea – the improvement of Indian health programs – divided the Nixon and later the Ford administrations.

Marjorie Lynch, Undersecretary of Health and Human Services, sent a letter to Republicans in the House saying the administration “strongly opposed” the legislation because of the costs: “scarce Federal health dollars are directed to the areas of greatest need, and that the Congress will agree that existing authorities are sufficient to continue addressing the health needs of American Indians and Alaska natives.” She added that having Medicaid fund Indian health programs would be unfair both in terms of cost and equity. States’ reimbursement rates range from 50 to 83 percent. “To provide a 100 percent match for services to Indians would be inequitable to other poor recipient groups, and to those States with many families and individuals at poverty levels, who happen not to be Indians.”¹²

Marris pressed President Gerald R. Ford to sign the bill into law. “Admittedly, I am biased as a physician in favor of equity in length of life so you will have to excuse my considering the humanitarian aspect along with the budgetary, pragmatic and political,” he wrote. “Failure to adjust the present course is in my opinion a flagrant deprivation of human rights in a measurable as well as dramatic way.” Marris’s pitch

worked. On October 1, 1976, President Ford stated:

I am signing S. 522, the Indian Health Care Improvement Act. . . . This bill is not without its faults, but after personal review I have decided that the well-documented needs for improvement in Indian health manpower, services, and facilities outweigh the defects in the bill. While spending for Indian Health Service activities has grown from \$128 million in FY 1970 to \$425 million in FY 1977, Indian people still lag behind the American people as a whole in achieving and maintaining good health. I am signing this bill because of my own conviction that our first Americans should not be last in opportunity.¹³

While the federal government has, from time to time, recognized that the system is underfunded and it cannot improve without adequate revenue, professional staff, and facilities, serious money always lags behind health care spending for the general population. IHS is expected to defy gravity.

So what happened after the Indian Health Care Improvement Act became law? According to pediatrician Abraham Bergman and colleagues:

Few bright spots exist in the shared history of the American Indian and the federal government. . . . A notable exception is the sustained campaign by a little-known agency, the Indian Health Service, to improve the health of this population. Except for the intractable problems associated with the abuse of alcohol, the health status of Indians has been raised to approximately the level attained by the rest of the U.S. population. This achievement is amazing when one considers the appalling poverty and harsh physical environment in which many Indians live.

But there remain huge challenges related to diabetes, obesity, and mental health. “We do not mean to present a rosy pic-

ture. . . . We wish to emphasize, however, that given their isolation and harsh living conditions, many health status measures are better than might be expected, in large measure owing to the efforts of the IHS.”¹⁴

The story needs to account for the IHS successes as well as the challenges. Consider infant mortality rates. In 1955, infant deaths were nearly three times higher than that of the general population and accounted for one-quarter of all early deaths among infants under one year of age. But over the next twenty-five years, infant mortality rates dropped by 82 percent, outpacing the health gains of other disadvantaged populations.

The Centers for Disease Control and Prevention reported that, in the United States, from 2004 to 2008, 84 percent of American Indians and Alaska Natives have a “usual place for health care.” That compares with 86 percent for White Americans, 85 percent for African Americans, and 72 percent for Hispanics. And Native Americans are living longer. “The AIAN population has a life expectancy at birth that is 2.4 years less than that of all U.S. populations combined.”¹⁵ There is not a health care parity with the general population, not by a long shot, partly because of the chronic nature of so many diseases that afflict Indian Country. But efforts to close the existing gap in age at death have certainly been improving over the last four decades.

The 1976 Indian Health Care Improvement Act created a new statutory authority for the Indian Health Service to direct funds to urban populations in which most American Indians and Alaska Natives live. A 2007 report by the Urban Indian Health Commission called this “a population in crisis”: “Reliable health statistics on urban Indians are scarce because this demographic has been studied so little and its members are often misclassified on vital records as belonging to other races or ethnicities. But what we do know about

urban Indians' health is enough to warrant immediate action." The report cited dismal statistics: the infant mortality rate among urban American Indians and Alaska Natives was 33 percent higher than that of the general population; the death rate due to accidents was 38 percent higher; the death rate due to diabetes was 54 percent higher; the rate of alcohol-related deaths was 178 percent higher; up to 30 percent of all American Indian and Alaska Native adults suffer from depression, and there is strong reason to believe the proportion is even greater among those living in cities; and cardiovascular disease, now a leading cause of death, was virtually unheard of among American Indians and Alaska Natives as recently as forty years ago. The report concluded: "Urban Indians have less access to health care than other Americans. Often, their living conditions are literally sickening. Persistent bias against them and their mistrust of government keep many from getting the health care they need."¹⁶

Only about 1 percent of the Indian Health Service budget is spent on urban Indian health. There is another underappreciated impact from the growth of Indian health programs following the Indian Health Care Improvement Act. Around 1996, the Indian Health Service became Indian Country's largest employer. Indian health was once a small slice of the Bureau of Indian Affairs. But by 1996, the agency's budget was larger than the BIA's and there were likely more workers as well. In 2017, for example, the BIA employed approximately 6,770 full-time workers compared with the 15,119 at the Indian Health Service (including 1,928 uniformed Public Health Service officers). This makes sense and reflects what is happening with health care generally: clinics, hospital systems, and university medical centers are often a region's largest employer. But there is another story that has largely been missed by both policy-makers and the

public: the shift of the Indian Health Service from a federal, government-operated health care system to one that's more than 60 percent operated by tribes, intertribal organizations, and nonprofits.

This is where the story gets lost in translation. Both the government-operated system – which includes the facilities profiled by *The Wall Street Journal* at Pine Ridge, Sisseton, and Winnebago – as well as the tribally operated health care initiatives do not have enough resources. The system as a whole spent \$3,688 per capita on its user population compared with \$9,523 for the U.S. population.

Don Berwick, who ran the Centers for Medicaid and Medicare, has called the Indian Health Service a model of efficiency: "The Indian Health Service can and will be one of the leading prototypes for health care in America. The Indian Health Service is trying to deliver the same or better care with half the funding of other systems in the United States." Berwick added that the very nature of the agency's underfunding has resulted in a discipline that's "an example for us all."¹⁷

That discipline goes hand in hand with innovation. The Southcentral Foundation in Anchorage set out to reinvent its program by surveying its patients. "Are you sure you want to do that?" CEO Katherine Gottlieb was asked. "I was, like, delighted because I knew what the answers were going to be. I was not surprised at all when the answers came back. Long waits. Everybody hated waiting." Most of the primary care back then was in the hospital's emergency room where they handled everything from "heart attacks, broken arms, strep throat, to you name it, and here we were coming in with our baby for just an appointment," Gottlieb said. "I personally waited up to seven hours, waiting for an appointment, just to get in the door."

The Southcentral Foundation set out on a new course, starting with a change in

the language. The phrase “patients” was swapped for “customer-owner”: “We are literally customer-owners, Alaska Natives. Our board of directors are all Alaska Natives.”¹⁸ When people are hired, they are told this system is customer-owned. That’s part of the deal: every patient is one of those owners.

The Alaska Native Medical Center was designed with a team-based approach to health care that uses smaller waiting rooms, so many people can be seen without long waits. The medical team approach is different, too. The team sits together without hierarchy. Members include doctors, medical assistants, nurses, care coordinators, and often a behaviorist. Customer-owners can choose their own team and make changes if they are unhappy. The ideal is an integrated system and a relationship with the patients, resulting in less return visits.

In most cases, expenses increase at the end of a person’s life in terms of health care dollars spent. What if that were reversed? What if dollars instead were invested early on prevention, focusing on early root causes of diseases to prevent the development of heart disease, diabetes, depression, or domestic violence? And the treatment of root causes can reduce the health disparities that are so much a part of the Native American experience. Gottlieb described this model as especially necessary because, as the baby boom generation ages, those costs will be unaffordable.

The Southcentral Foundation calls this the “Nuka” model, and the data back up their experience. There has been a 40 percent reduction in emergency room and urgent care visits; a 50 percent decrease in specialty care visits; a 20 percent decrease in primary care visits; and more than a 35 percent decrease in admissions. Staff turnover has dropped dramatically and the overall rating by customers of their care stands with a score of 91.7 percent. The Nuka model is not about money. “We still have a poor-

ly funded IHS system. We are not fully funded,” claimed Gottlieb. In fact, she said, the government has not fulfilled its treaty-trust obligations to American Indians and Alaska Natives. Southcentral’s system is about 45 percent funded by the Indian Health Service, 50 percent from “aggressive” billing of third-party insurers or Medicaid, and the remaining 5 percent from foundation or other government grants.

“You won’t find anything in Indian Country like this campus,” said Douglas Eby, the Alaska Native Medical Center’s vice president for medical services. There is less direct funding from IHS, and this is by far the biggest, most sophisticated campus in the Indian health system. It’s also far better off than most for a variety of reasons ranging from leadership to the structure and resources of Alaska Native corporations. “We were smart enough to say we need to optimize revenue, and we’ve done very well at doing that,” Eby said. But the growth in population, people moving in from the villages, flat funding from IHS, and health care being such a “wasteful” business drove a rethinking of the business model. “Our real hope lies in controlling costs, doing things smarter, better and avoiding high care cost as much as possible.”¹⁹

When you consider historical trauma, coupled with persistent underfunding by the federal government, it’s remarkable to think of any health facility accomplishing innovation. The Indian Health Service, tribal health centers, nonprofits, and urban centers are tasked with delivering health care at a fraction of the cost spent anywhere else in America. And yes, sometimes that falls short, sometimes dramatically so, as in the case at the Winnebago Hospital. But that story has been told so often we forget there is another one: the narrative of excellence, innovation, and creativity in a system that remains critically underfunded.

ENDNOTES

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