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REVIEW ARTICLE

Health ownership in American indigenous communities

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ABSTRACT

Introduction: Although the Indian Health Service (IHS) has adequately stifled acute infectious diseases that once devastated American Indian and Alaska Native (AIAN) communities, this system of health provision has become obsolete in the face of chronically debilitating illnesses. Presently, AIAN communities suffer disproportionally from chronic diseases that demand adequate, long-term health maintenance such as hepatitis, renal failure, and diabetes to name a few. A number of research endeavors have sought to define this problem in the literature, but few have proposed adequate mechanisms to alleviate the disparity. The objective of this study was to examine the efficacy of both the Indian Health Service (IHS) and the relative few tribal healthcare systems (PL 93-638) respectively in their sociopolitical contexts, to determine their utility among a financially lame IHS.

Methods: Domestic and international indigenous health systems were compared through analysis of the current literature on community and indigenous health. Informal interviews were carried out with indigenous practitioners, community members, and political figures to determine how AIAN communities were receiving PL 93-638 programs.

Results: Although the IHS has adequately stifled the acute infectious diseases that once devastated AIAN communities, this system of health provision has become obsolete in the face of chronically debilitating illnesses. A number of research endeavors have sought to define this problem in the literature, but few have proposed adequate mechanisms to alleviate the disparity. International indigenous health systems are noted to have a greater component of community involvement in the successful administration of health services.

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Conclusion: Reinstating notions of ownership in multiple paradigms, along with novel approaches to empowerment is requisite to creating viable solutions to the unique health circumstances in Native America. This article demonstrates the importance and need of more qualitative data to better characterize how PL 93-638 healthcare delivery is actually experienced by AIAN patients.

Key words: Indian Health Service, ownership, self-determination.

Introduction

The Indian Health Service (IHS) has been the target of much scrutiny since its inception in the mid 20th century. Designed to administer the health services that the United States was obligated to provide via the Snyder Act among other treaties and agreements, the IHS has faced a number of obstacles in its seemingly endless uphill climb to provide wellness to the service population. In spite of these obstacles, American Indians and Alaska Natives (AIAN) have better health indicators today than in the 1950s. However, current AIAN health indicators still reside well below those for the predominantly Anglo-American population and, given the shifting environment from infectious to chronic disease prevalence, this is particularly troubling for the IHS, which was largely designed to treat acute infectious diseases[1].

This article examines the causes associated with health disparities in AIAN populations, paying particular interest to political and social determinants. Further, it will examine the role of the Indian Self-Determination and Education Assistance Act (ISDEAA) of 1975 and the Indian Health Care Improvement Act of 1976 – which enabled some tribes to assume greater autonomy in the services they provide – in not only the health status of AIAN, but also how this law alleviates some of the unique burdens that AIANs carry, via feelings of ownership and empowerment. Lastly, an evaluation of community-based and community-run indigenous health services from both the United States and abroad, will illustrate that, although the access to health has seemingly improved for tribes via the implementation of new programs and new facilities as discussed by current IHS director Yvette Roubideaux[1], a crack still remains in the foundation of the relationship between federally recognized tribes and the United States government.

Stephen Kunitz argues that a shift to more autonomy has the potential to be beneficial if handled correctly[2]. However, any benefits are sure to be outweighed by the simple fact that the IHS is *chronically underfunded*[3]. It is quite apparent that health services are not being provided in a manner that either the United States or Native America could have imagined at the time treaties were signed. Marsha Lille-Blanton and Yvette Roubideaux provide a lucid reminder regarding why this issue is of great importance[4]. First, mortality data between AIAN and the general US population reveal disparities in nearly every factor; second, the system itself is a failing and underfinanced structure that contributes to these disparities; third, the United States has an obligation to AIAN, as was recognized in the phrasing of the treaties for appropriating land and other possessions from the latter.

Methods

This article is primarily based on the current literature surrounding the complex topic of Indian health. Many different sources were consulted, including those from key scholars and medical practitioners in this area of study. Of particular importance are the sources from international journals and texts. These were crucial in broadening the perspective of indigenous health issues. They offer insight into a seemingly shared experience between groups that have been colonized by the West and are continuing to struggle against imperialist relics found not only in the dominant society, but also among their own communities. Sources were obtained via multiple database searches including

PubMed and MEDLINE, using criteria that include keywords such as 'Indian, health, policy, and self determination.' Additionally, Google Scholar was used as a tertiary survey of the literature on global indigenous health and community health. As illustrated by this article, reports regarding the impact on community members at the hand of the ISDEAA are generally absent, and required careful scrutiny of both print and online resources. It should be noted that the *American Journal of Public Health* currently holds the most data on the subject.

Finally, four key individuals were contacted regarding their opinion of tribally governed health care and the Indian Health Service. For privacy, their names and tribal affiliations will not be disclosed, but will be identified by broad designations of their employment.

Sampling was not random, and the participants were chosen because of their involvement in the IHS as a patient, provider, or administrator. All interviews were conducted in person and thus proximity to the researcher was considered in selecting participants, which could pose a degree of selection bias in the data as three of the four participants had worked with a single tribal nation in their past or present. Inclusion criteria included self-identifying as a member of an AIAN nation, and having had experience with the Indian Health Service in one of the three capacities outlined above.

The first participant was a member of a former Presidential Cabinet of an AIAN nation in the Western United States. At the time of interview, this tribal member had served in tribal councils and other political bodies for over 20 years. Second, a public health researcher from a tribal-run health promotion program in the southwestern United States was interviewed regarding her understanding of health ownership among the various families and communities she presently works with. As a self-identifying AIAN, she offered a unique perspective that transcended the common divide between the native patient and the white provider. Similarly, the third informant was an AIAN academic and practitioner who shared the former's concern regarding the lack of primary care on reservations across the United States. Last, but perhaps most impactful, is a native community and tribal member in his thirties from a Southwestern reservation border town, who, like many of his peers, struggled with the daily negotiation of health maintenance in a system that he characterizes as lacking in preventive care. He was chosen to participate based on his extensive experience with predominantly non-638 IHS facilities on the reservation in managing his chronic illness and delivering preventive medicine.

Social and political contexts of the Indian Health Service

The IHS faced considerable obstacles when it took over the primary responsibility for AIAN health, such as deplorable infectious disease conditions[5]. It was fine-tuned in those early years to be able to operate on a small budget, with limited human and technological resources. Consequently, it inherited many facets of the military's health system[6], focusing on acute support for those deemed worthy to treat, while leaving patients beyond the scope of the short-staffed clinic in the hands of their pathologies. As the IHS evolved into what is observed today in large regional hospitals, a focus on infectious disease remained, while the population underwent a shift towards more complicated and expensive chronic conditions[7]. The implications of this shift are further delineated by medical sociologist Stephen Kunitz, stating the IHS 'has been effective in reducing preventable and treatable conditions such as infectious diseases but that it has not yet had an impact on certain chronic conditions such as diabetes and some cancers'[2]. This is troubling for a system that serves 1.6 million AIAN across 36 states[5].

Cross-cultural mortality studies are readily available that illustrate clear disparities between AIAN and usually the predominant society or standard population. Studies such as these are difficult to interpret as many are flawed with epidemiological issues of ambiguous population denominators. As data on AIAN are largely missing or do not scratch the surface regarding ethnicity and the relative rapid intermarrying of AIAN with other demographics, the data can indeed be misleading[5]. However, regardless of the quantity, all studies have shown a clear disadvantage in nearly every

disease, acute or chronic, in AIAN populations relative to the general population[7].

David Jones has outlined some of the proposed etiologies behind the disparities in AIAN disease frequencies[5]. They range from religion, diet, living conditions, climate, cultural practices, racial differences, and socioeconomic status. Indeed, the environment in which people live on reservations – or even as urban Indians – is unique in the United States, in that they are likely to experience heightened debt, low education potential, family history of alcoholism, and a lack of ownership[8,9]. The lack of ownership appears to be particularly detrimental, not only to the individual tribal member, but also to tribes as a whole, who may lack the ability to own the land they reside on. It is this fundamental trait in the relationships AIAN nations have with the federal government that will place any tribally administered health program in jeopardy. Additionally, the absence of appropriate funding appears to be just as malignant to the relative wellbeing of such communities.

Andy Schneider suggests that chronic underfunding is the key reason that the IHS is in such dire circumstances[3]. Schneider references the Federal Disparity Index Work Group's data in his claim that the federal government has 'undercut the capacity of the Indian Health Service, tribal, and urban Indian health delivery system to meet the health care needs of the AIAN population… The result has been health disparities as persistent as they are indefensible.' Further, Stephen Zuckerman et al have posited that a more comprehensive fiscal strategy may be required, stating, 'Because the IHS is funded through congressional appropriations rather than as an entitlement, it is subject to the constraints of the federal legislative process'[10]. In a study that compared IHS funding to other public programs such as Medicaid and Medicare, Timothy Westmoreland and Kathryn Watson report that the IHS is consistently losing monetary ground due to the more pronounced increase in money spent per capita in these programs than for IHS programs each year, extending not only the already alarming gap between the middle class and the indigent of this country, but now also sifting the indigent from the impoverished AIAN who live on reservations across the United States[11]. Additionally, Westmoreland and Watson cite IHS-published data that illustrate the extant monetary deficiencies, showing funding of only 54% of what it required[11]. Most scholars agree that this discrepancy is perpetuated simply because the federal funding that was promised to the IHS was originally classified as discretionary, or optional. Similarly, the interview with the aforementioned Presidential Cabinet member in 2007 supported this conclusion: 'The Indian Health Service is doing pretty good considering we are only operating on fifty percent of our budget' (T Frank, pers. comm., 2007). Further data on how underfunding has impacted the IHS can be found in studies by Bramley et al[12], Kunitz[7], Roubideaux[1], and Topor[13].

Tribally administered health care

After years of AIAN organization and activism, civil rights demonstrations, and courageous legal battles, the idea of tribally administered health care was suddenly propelled into reality with the passage of the ISDEAA 1975. Roubideaux[1] characterized this accomplishment as, 'One of the most significant changes in the Indian health system.' In their highly acclaimed work on AIAN health policy issues, Mim Dixon and Roubideaux explain that PL 93-638 (known as '638' on the reservation) allows for a perceived increase in sovereignty[14]. As an extension of this thought, programs that generate more autonomy in tribal health may also increase a sense of *ownership*. This measurement is beyond this article, but is research that is justified by the lingering question of what tribally run health care actually feels like to the patient.

Alyce Adams explains that 638 was met with reluctance from tribes that were suspicious of a greater American agenda to remove obligations to AIAN[15]. She mentions that the inherent problems with 638 include having to pay for services up front, to be reimbursed later – which depends on the availability of funds for reimbursement. Also, in spite of the more culturally appropriate administration of a 638 health system, the IHS remains underfunded. However, Adams concluded that those who switched from traditional IHS to 638 programs had lower poverty and higher tribal to federal employment ratios. Additionally, tribes that made the switch

often had some alternate way to support the health program. Similar to other researchers however, Adams is unable to provide *evidential* support in hopes of answering the question of 'whether tribal management has improved the quality of care delivered to American Indian populations'. Further, Adams sheds light on the problematic nature of generalization, and determines that such a heterogeneous population precludes any notions that 638 is better or worse for all of Native America, and that perhaps a more postmodernist approach would be appropriate for such a measure. Allison et al[16] have illustrated that tribes considering 638 should account for their relative size, as they feel this to be correlated with the potential benefit of such programs, further supporting the notion that heterogeneity is the rule across the AIAN landscape.

Stephen Kunitz argues that both extrinsic and intrinsic pressures of self-determination are forcing AIAN into the private sector, which in turn transfers the burden off of the federal government[2]. To some, this appears to be a conscious continuation of a high-stakes assimilation policy that began long ago, which trivializes not only native personhood and identity, but also the very geographic and social spaces that natives occupy. A minority of healthcare workers and community members alike agree that 638 could pose potential hazards that should be avoided[17]. For example, Irene Topor[13] and Dale Bramley[12] explain that the decentralized assortment of services that 638 programs may potentially provide would prevent adequate public health surveillance across a mixed bag of heterogeneous delivery systems.

Ownership

Crampton et al define ownership in terms of 'ultimate control'[18]. This is highly appealing to AIAN groups who have been essentially *controlled* since first contact, but problematic as the current relationship with the United States prevents this from ever happening. Other nations are concurrently struggling with similar issues in indigenous health. New Zealand's indigenous health disparities outweigh those observed in the United States[12], but there has been rigorous activity on the revolution of providing health and wellness to Maori and Pacific Islanders. Crampton et al found that community-governed health services reduced financial and cultural barriers, charged considerably lower patient fees, and employed more Maori and Pacific Islander staff[18]. These findings arguably illustrate that ownership via community-governed health programs 'have an important influence on access to primary care'[18].

A community-based approach to health care has been proven successful in a variety of environments. Not only in New Zealand[19], but also in Venezuela[20], Cuba, and even in the states of Montana and Wyoming, communities are partnering with local educators in hopes of improving health status research[21], and, potentially, surveillance.

Roubideaux explains that, in order for these community-based, tribally managed health systems to work, they need the full participation of tribes and communities in all places of planning, implementation, and evaluation of programs, services, and research[1]. Similar to Briggs' and Mantini-Briggs'[22] idea on *horizontal* approaches to community health, Roubideaux suggests that the responsibility must be shared equally among everyone – community members and physicians alike. This approach may, in turn, enable community empowerment and may move towards mitigating local health concerns[23]. Further, Nina Wallerstein suggests that this empowerment is precipitated by an acute response that leverages local knowledge to address immediate community issues[24].

Discussion

Even among the scores of research endeavors on indigenous health, the fundamental question remains, regarding the possibility of 638 programs providing health in more meaningful ways. An answer to this and other issues can only be found through further study; however, anecdotal evidence from informal interviews may suggest that, for certain groups, the idea of having an increase in the degree of power is an attractive option, as most of these groups have been

stripped of such. One community member related in an interview that he was unsure about his tribe's ability to govern such a complex system, and worried of its certain collapse (M Jenson, pers. comm., 2007). This was a troubling reminder of the indelible colonial/imperialist artifacts spoken of earlier, which appear to have a pervasive foothold in AIAN ideology.

The community member's sentiment is echoed by researchers such as Kunitz who believes the new programs will not be as successful as IHS has been with infectious disease over the past 50 years[2]. Further, Kunitz claims that the changing landscape of disease, coupled with increasing cost and stagnant budgets will likely result in failure; although some studies are revealing that tribally run health care programs are more able to provide new health strategies, build new facilities, and collect more third-party reimbursements than IHS management[1].

Critics such as Kunitz point to a more foundational issue, that appears to be as malignant as it is resilient, which is the insistence of the United States on maintaining a inequitable relationship with the AIAN of this country. As federal agendas continually attempt to shirk responsibility for tribes, they escape the treaty-bound accountability born from centuries of AIAN injustice. Therefore, PL 93-638 could be the next vehicle to instigate the offloading of financial burden from the federal government. Kunitz fears that such a scenario would 'likely result in a deterioration of services on many reservations'[2], which, given the already dismal health indicators, is a frightening forecast.

As complex and unwieldy as delivering Indian health in the United States continues to be, the literature is oversimplified, and lacking in qualitative analyses. Scholars such as Kunitz[2] speculate on the true intent of 638, but many have failed to capture what this novel delivery system feels like for a patient. It is the poignant, albeit anecdotal, evidence from the tertiary interviews conducted for this paper that point to a potentially greater reward through 638, one that may be worth the risk involved in allowing even more distance between the federal government and their treaty-bound obligation to AIAN wellbeing.

Summary

As well-intentioned as the ISDEAA may have been at the onset, it appears the federal government may have something other than the cultural competency of healthcare delivery in mind. As scholars now argue that its true intent is to relinquish its binding responsibility to administer health services to AIAN, it does not require much effort to imagine such a scenario, given the history of exploited land, resources, and even identity[9,25]. Unfortunately, PL 93-638 programs that took advantage of the opportunity, still maintain a broken relationship with the United States government in that treaties and agreements are broken without any repercussion. For those who have the resources to subsidize a tribally run health program, 638 *can* potentially benefit the community, as was illustrated by the community-based health systems that increased access and care in New Zealand, Venezuela, Cuba, and the United States. As was reported in a personal communication with a former IHS employee turned tribal public-health employee under PL 93-638, the program works well in her area, bringing new facilities and attracting health service workers who would rather be employed by the tribe, in spite of the potential cut in pay (R Smith, pers. comm., 2007).

Chino and DeBruyn insightfully explain that community health frameworks that are based on Indigenous epistemologies may potentially transform the hegemonic power relationships that exist in the IHS[23]. They further state that:

> *A tribal capacity-building model must therefore transcend the tendencies of the Western scientific community to adhere to a more linear, static, time-oriented format, which is likely to impede community involvement and discourage tribal ownership. Rather, it must establish a participatory process where mutual learning is taking place without the potential for abuses and exploitation and repair lines of trust between non-indigenous researchers and tribal communities.*

This description of a community-based approach has proven successful in other countries, but is seldom used in the United States. Charles Briggs and Clara Mantini-Briggs have implemented what they call a 'horizontal' approach to community empowerment in their efforts to combat health disparities in the barrios of Venezuela[22]. The horizontal approach is denoted by its contrast from 'top–down' or 'bottom–up' processes, which imply less-productive power differentials. Further, the horizontal approach is something primary care providers and community members alike can engage in immediately, even in the face of an underperforming and underfunded healthcare delivery system such as those seen throughout the IHS.

Finally, Chino and DeBruyn's[23] work suggests that tribal ownership may be at least promoted, if not attained, via more participatory processes like 638 programs, which serve to dampen the top–down power differential that has proven its deleterious nature in indigenous health access. Therefore, it is the position of this article that, although tribes are heterogeneous and complex, 638 may indeed be a step in the right direction in terms of gaining some sense of ownership. However, as Kunitz and others have pointed out, a co-requisite step must involve a change in funding.

Conclusions

Reinstating notions of ownership in multiple paradigms, along with novel approaches to empowerment is requisite to creating viable solutions to the unique health circumstances in Native America. As long as funding for indigenous health endeavors is *discretionary*, the wellbeing of AIAN will continue to be in jeopardy, empowerment will be capped, and ownership will remain the exclusive right of *almost* every American.

References

1. Roubideaux Y. Perspectives on American Indian health. *American Journal of Public Health* 2002; **92(9):** 1401-1403.

2. Kunitz SJ. The history and politics of US health care policy for American Indians and Alaska Natives. *American Journal of Public Health* 1996; **86(10):** 1464-1473.

3. Schneider A. Reforming American Indian/Alaska Native health care financing: the role of Medicaid. *American Journal of Public Health* 2005; **95(5):** 766-768.

4. Lillie-Blanton M, Roubideaux Y. Understanding and addressing the health care needs of American Indians and Alaska Natives. *American Journal of Public Health* 2005; **95(5):** 759-761.

5. Jones DS (2006) The persistence of American Indian health disparities. *American Journal of Public Health* 2006; **96(12):** 2122-2134.

6. Trennert RA. *White man's medicine: government doctors and the Navajo, 1863-1955*. Albuquerque: University of New Mexico Press, 1998.

7. Kunitz SJ. Ethics in public health research: changing patterns of mortality among American Indians. *American Journal of Public Health* 2008; **98(3):** 404-411.

8. Duran B, Sanders M, Skipper B, Waitzkin H, Halinka Malcoe L, Paine S, et al. Prevalence and correlates of mental disorders among Native American women in primary care. *American Journal of Public Health* 2004; **94(1):** 71-77.

9. Nelson M. Negotiating Navajo identity: Constructing coherence from the fragments of chronic disease. *The Artifact* 2010; **48:** 55-69.

10. Zuckerman S, Haley J, Roubideaux Y, Lillie-Blanton M. Health service access, use, and insurance coverage among American Indians/Alaska Natives and Whites: what role does the Indian Health Service play? *American Journal of Public Health* 2004; **94(1):** 53-59.

11. Westmoreland TM, Watson KR. Redeeming hollow promises: the case for mandatory spending on health care for American Indians and Alaska Natives. *American Journal of Public Health* 2006; **96(4):** 600-605.

12. Bramley D, Hebert P, Tuzzio L, Chassin M. Disparities in indigenous health: a cross-country comparison between New Zealand and the United States. *American Journal of Public Health* 2005; **95(5):** 844-850.

13. Topor IL. Indian Health Services: creating a balance between federal legislation and the vision care needs of sovereign nations. *Journal of Visual Impairment & Blindness* 2006; **100:** 877-880.

14. Dixon M, Roubideaux Y (Eds). *Promises to keep: public health policy for American Indians and Alaska Natives in the 21st century*. Washington, DC: American Public Health Association, 2001.

15. Adams A. The road not taken: how tribes choose between tribal and Indian Health Service management of health care resources. *American Indian Culture and Research Journal* 2000; **24(3):** 21-38.

16. Allison MT, Rivers PA, Fottler MD. Future public health delivery models for Native American tribes. *Public Health* 2007; **121(4):** 296-307.

17. Nelson M. Navajo Area Indian Health Service: Balancing wellness and tradition. In: *Proceedings, 6th Annual Hawaii International Conference on Arts and Humanities*; 9-12 January 2008; Honolulu, HI: Hawaii International Conference on Arts and Humanities, 2008.

18. Crampton P, Davis P, Lay-Yee R, Raymont A, Forrest CB, Starfield B. Does community-governed nonprofit primary care improve access to services? Cross-sectional survey of practice characteristics. *International Journal of Health Services* 2005; **35(3):** 465-478.

19. Papps E, Ramsden I. Cultural safety in nursing: the New Zealand experience. *International Journal for Quality in Health Care* 1996; **8(5):** 491-497.

20. Briggs C, Mantini-Briggs C. *Stories in the time of cholera: racial profiling during a medical nightmare*. Los Angeles, CA: University of California Press, 2003.

21. Andersen SR, Belcourt GM, Langwell KM. Building healthy tribal nations in Montana and Wyoming through collaborative research and development. *American Journal of Public Health* 2005; **95(5):** 784-789.

22. Briggs CL, Mantini-Briggs C. Confronting health disparities: Latin American social medicine in Venezuela. *American Journal of Public Health* 2009; **99(3):** 549-555.

23. Chino M, DeBruyn L. Building true capacity: indigenous models for indigenous communities. *American Journal of Public Health* 2006; **96(4):** 596-599.

24. Wallerstein N. Powerlessness, empowerment and public health: implications for health promotion programs. *American Journal of Health Promotion* 1992; **6:** 197-205.

25. Iverson P, Roessel M (Eds). *For our Navajo people: Dine letters, speeches, and petitions*. Albuquerque: University of New Mexico Press, 2002.

