## THEMES AND DEBATES

# Health Delivery Systems in Response To Covid-19: The Need for Indigenous Led Responses in the USA

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#### **Abstract**

indigenous American Indian/ Alaskan Native (AI/AN) communities in North America have experienced inequitably higher of Covid-19 related morbidity, hospitalisation, and mortality than the majority, non-Hispanic white population. These inequalities are the result of centuries of racism and oppression. Mainstream health services have struggled financially to survive the crisis and are poorly positioned or trained to meet the needs of tribal members. The Indian Health Service, being both poorly funded and often suspect, largely failed to mitigate the impact of Covid-19 on these vulnerable communities. There is an urgent need for the expansion of indigenous led health providers.

The indigenous American Indian/Alaskan Native (AI/AN) communities in North America are experiencing inequitably higher rates of Covid-19 related morbidity, hospitalisation, and mortality than the majority, non-Hispanic white population. Infection rates among AI/AN communities are significantly higher than among non-Hispanic whites (1), and they are 3.7 times more likely to be hospitalised than non-Hispanic whites (2). The mortality rate

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among AI/AN populations is 2.4 times that of non-Hispanic whites.. Furthermore, the age profile of people in AI/AN communities dying of Covid-19 is notably different from the non-Hispanic white community. They are on average significantly younger, with research from New Mexico and Arizona noting that the death rates among AI/AN communities in the 45-54 year age groups are remarkably similar to those in the 75-84 age range in the non-Hispanic white population (1, 2). The sad reality is that the actual impact of Covid-19 on these communities may never be known. The poor state of reporting of AI/AN status in US health records is an ongoing issue that serves to hide the plight of this 'forgotten minority' (3). This glaring deficit in relation to Covid-19 has been referred to as 'data genocide' by contemporary advocates (4).

The Covid-19 pandemic undoubtedly wrought havoc across the globe. However it must be acknowledged that among indigenous communities with strong oral traditions and native languages that are critically vulnerable the impact has been all the more notable. Tribal societies have proven themselves to be been particularly vulnerable as the age profile of Covid-19 mortality and morbidity has been highest amongst the elderly, the very people most likely to be Tribal Elders, Native Language Speakers and Storytellers. The loss of such esteemed Tribal members has undoubtedly resulted in an irreplaceable loss of traditional cultural knowledge and skills, and will have a deep and profound impact on these communities (5) . As Salsman a spokesperson for the Muscogee Creek Nation in eastern Oklahoma states "It's like we're having a cultural bookburning... We're losing a historical record, encyclopaedias. One day soon, there won't be anybody to pass this knowledge down" (6).

The size of the AI/AN population in the US is significant. In 2017, 5.6 million people in the US self-identified as American Indian/

Alaska Native alone or in combination with one or more other races. This equates to 1.7 percent of the total population in the US. Across the US there are 574 federally recognized tribal nations, spread across 326 Reservations, with a total land area of 227,000 km<sup>2</sup>. It should be noted that in addition to such federally recognised tribes, there are in excess of 100 tribes that are State recognised, as well as additional tribes exist that are not recognised by either the States or the Federal Government.

In exploring health and Governmental responses to the Covid-19 pandemic, it is crucial to understand the history, treatment and position of these indigenous communities in the US. Looking firstly at the broader picture, it must be acknowledged that the treatment of AI/AN communities in North America is a litany of shame for both colonising powers and the US Government (7). Their history since colonisation is one of genocide, warfare and mass deportations. Official and unofficial policies include the deliberate slaughter, almost to extinction, of traditional food sources (8). European populations often adopted a policy to 'civilize' or exterminate indigenous AI/AN populations. The US Government policy was based on giving AI/AN populations rations to them, and relocating control them reservations, land that nobody else wanted. Under what was termed Indian Removal, whole populations were forcibly expelled and moved thousand of miles away from their traditional homelands, the most infamous being the Trail of Tears. It should also be noted that forcible relocation was not necessarily a singular event. Numerous tribes were relocated, only to be once more forcibly removed when resources were subsequently found in their reservation, or when nearby European populations expanded and demanded more land. This strategy also included the development of obligatory boarding schools designed to proselytise AI/AN children into Christianity (9). Founder of the Carlisle Indian Industrial School, Captain Richard H Pratt, is infamous for his statement "kill the Indian, and save the man" (9). Up until 1978 AI/AN children continued to be forcibly removed from their parental homes, often on dubious moral, social and religious grounds.

Turning to the health and medical field there is a history of distrust between AI/AN populations and mainstream and Government health providers. Part of this dates back to the involuntary sterilization of thousands of AI/AN

women (10, 11, 12). However the use of indigenous peoples in illicit research is longstanding. Pacheco et al. summarise this issue neatly when stating that the lack of trust from these communities towards the mainstream medical scientific community "is grounded in well-documented examples medical unethical research and clinical misconduct in the name of research. Investigators have broken implied and legally binding agreements in cases over at least the last years" (9).This unauthorised 100 experimentation has continued into the genomic era of research. The most infamous case in recent years was the Havasupai diabetes project, in which researchers ostensibly collected blood samples only to study diabetes, and yet covertly explored schizophrenia (9).

Trust in the Federal Government has been further eroded between AI/AN populations over the issue of land ownership and tribal sovereignty. This may be seen most recently in the Dakota pipeline dispute when the Federal government overrode Tribal sovereignty to approve construction of the Dakota Oil Pipeline, which members of the Standing Rock Sioux state contravenes Article II of the Fort Laramie Treaty. Earlier successful attempts to diminish tribal sovereignty occurred in the 'Termination' period from 1946 and 1964 in the US when the Government moved to rescind prior treaties and executive orders acknowledging sovereign status. During this period a total of 109 tribes lost official recognition, approximately 2.5 million acres of tribal land were lost, and 12 000 AI/ANs lost tribal affiliation. Ongoing issues around tribal ownership and sovereignty of Reservation land continue to erode trust in the Federal Government among AI/AN communities

For example, although AI/AN reservations are officially sovereign nations, most of the land held in trust for the Tribes by the US Government. Therefore permission to provide even basic services, such as housing, is extremely problematic. This difficulty, combined with poor socio-economic status, in part explains the notable proportion of AI/NA communities living as multi-generational families in cramped trailers on Tribal lands (13). Clean water and adequate shelter are basic rights that are catered for in most industrialised nations, however approximately a third of Navajo Tribe members for example do not have running water, and many others lack mains electricity (14). These gross inequities in a country which considers itself a world leader further erode trust in both Federal and State Governments.

Trust between AI/AN communities and the US Government has been further diminished through the impact of environmental racism. Reservation lands include a significant number of unremediated Superfund sites. These contaminated zones include a host of pollutants from sites including former mines for uranium, and major industrial plants. The negative impact of these toxic sites on not only people but, water , flora and fauna is significant. It is not accidental that the US Environmental Pollution Agency (EPA), which is tasked with remediation efforts at these toxic sites, has been identified by official US Government sources as failing to adequately map such sites on tribal lands (15).

The devastating impact of Covid-19 has also been facilitated in part at least by the underlying health status and socio-economic circumstances of AI/AN communities. As Yellow Horse et al. note 'structural inequalities established the architecture for COVID-19' among AI/AN communities (1). The marginal role of AI/AN communities in US society is clearly evident in their educational and employment status. Rates of unemployment and under-employment are above average, An examination in 2018 noted for example unemployment rate among AI/ANs of 6.6 percent, significantly higher that countrywide of 3.9 percent (16). The percentage of single-race American Indian and Alaska Native people who were below the Federal poverty line in 2016 was 26.2%, more than double the rate of the nation as a whole (14%) and higher than any other racial group (17). Educational achievements of these indigenous groups are also problematic with high school graduation rates being lower than the country as a whole, and the proportion educated to bachelors level or above being less than half that of the general population (17).

The crucial impact of the social determinants of health, as well as the impact of racism and exclusion is evident in the high rate of underlying medical conditions among AI/NA populations. These indigenous communities have significantly higher rates ischaemic heart disease, hypertension and stroke, diabetes, and

renal disease. They also suffer from higher rates of obesity and smoking, as well as the diseases of despair: alcohol and drug misuse, self-harm and suicide (18).

The Indian Health Service is the Federal Agency tasked with healthcare provision to AI/AN communities (19). This agency was however involved in the coercion of women into being sterilized, as well as their non-consensual sterilization (9, 10). It is also historically significantly under-funded. An examination of per capita funding conducted in 2010 noted that vis-à-vis other Federal health programs it The disparity received notably less. exceptionally stark, with the IHS receiving only \$3,000 per capital, \$8,000 less per capital than Medicare (20). The result has been the chronic and ongoing demise of an agency that even the most ardent believer would have trouble retaining faith in. The IHS is beset by problems of staffing issues and a decaying infrastructure combined with out of date equipment.

Although the IHS has responsibility to provide care for over 2.5 million citizens it has only 1257 hospital beds, a bed to potential patient ratio of 1:2000. The situation in relation to Intensive Care Beds is even more stark, with their meagre supply of just 36 ICU beds, yielding a bed to potential patient ratio of almost 1:70,000. The patchwork of reservations served by these scant resources are approximately 87,500 square miles (roughly the size of Minnesota).

Mainstream health providers in the US have themselves been struggling for financial survival in the face of the Covid-19 pandemic (21). US hospital systems rely heavily on elective procedures, which were drastically curtailed during the pandemic. Equally, the health systems were unprepared for the demands that were placed upon them by the Covid-19 pandemic.

Equally, it must be acknowledged that the Federal government preparedness system failed 22). After decades of concern over the pandemic threat, it quickly became evident that the anticipated stock piles of PPE were inadequate (23) Personal Protective Equipment (PPE) that had traditionally come from outside the country was in short supply due to the impact of the pandemic on traditional manufacturing sources and supply chains (24).

Table One Proportion of 2019 Nursing Graduates from the AI/AN Community(29)

Associate degree in Nursing	Bachelor of Science in Nursing	Master of Science in Nursing	PhD	Doctor of Nursing Practice
0.7%	0.4%	0.6%	0.6%	0.5%

Despite the health industries' rhetoric about personalised and individualised care the reality is that their focus is always on the financial bottom line. Although attention may be paid to cultural awareness and training the emphasis is on value based health (25) This is crucial because, as Teisberg et al. note

'While some descriptions conflate value-based health care and cost reduction, quality improvement, or patient satisfaction, those efforts—while important—are not the same as value, which focuses primarily on improving patient health outcomes' (25).

There are few indigenous health providers in the US, as well as notable deficits in the proportion of health and medical staff from the AI/AN community (26, 27, 28). It is an unfortunate reality that in a recent National Academies Press publication addressing The Future of Nursing 2020-2030 data from 2019 indicates that the proportion of American Indian or Alaskan Natives graduating off nursing programs varied between 0.4% to 0.7% of all graduates depending upon the level of qualification (See Table One) (29). This is significantly less than the proportion of the population that they constitute, an important factor given the importance of both the need for cultural competence and the inequitably adverse health status of AI/AN communities. Although the IHS runs programs to support individuals from AI/AN communities to train to become nurses, physicians or psychologists, it is clear that more must be done to promote a diverse workforce in healthcare. The current IHS programs to support AI/AN health workers have failed to supply adequate numbers of either physicians, nurses, or psychologists completely neglect other crucial members of multidisciplinary health teams, such as Physical Play-Therapists, Occupational Therapists. Therapists, Speech & Language Therapists, Administrators and Recreational Health Therapists.

The COVID-19 pandemic has highlighted numerous inadequacies in US healthcare systems. It has particularly highlighted the inability of mainstream health providers to grapple with the complexities of providing care to AI/AN communities. It must be remembered that although the workers of many health systems are diverse and multi-lingual the those in key leadership and decision making positions at the top of organisational hierarchies are predominantly white, male and monolingually English speaking. A particularly brutal example of interaction between services for AI/AN populations and mainstream health providers may be seen in the experience of Abigail Echo-Hawk of the Seattle Indian Health Board. As the COVID-19 pandemic rampaged through Washington State she reached out to State and Federal partners for additional Personal Protective Equipment (PPE) so that they could continue their work. Although they are not an inpatient service, they were subsequently sent a bundle of body bags through the post (30).

Working with AI/AN communities requires a respect for cultural differences, in which a mastery of the native language can be a vital factor (31). Traditional AI/AN health practices focus on promoting the health of the mind, body and spirit. When working with AI/AN individuals and communities to address health issues it is important understand the continuum of approaches that patients may desire. This can range from wholly western biomedical approaches to wholly traditional health approaches, although a combination of the two, to varying degrees, is often the preferred approach for many individuals.

In relation to COVID-19 Table 2 contains a succinct distillation of some of the best advice for mainstream health providers attempting to engage AI/AN communities in health promotion activities, and particularly around vaccine uptake and acceptance.

# Table Two Culturally Appropriate Healthcare(32)

• Define who in the tribe can promote the

- message on vaccination most effectively (Elders, Native speakers and story tellers)
- Unified messaging attuned to age groups supported by elders and healers within the tribe to include radio, facebook, public posters This is a fluid process
- Identifying how to keep traditional tribal ceremonies safe and message this
- Increase efforts to encourage vaccine acceptance
- Develop multiple contingency plans for obstacles to implementation
- Outline water access routes
- Designate isolation/quarantine sites
- Improvise as unique situations arise
- Evaluate success of efforts
- Share successes
- Secure access to telehealth for specialist to meet various medical needs
- Define delivery methods for food, personal protective equipment and medicine to individual homes
- Engage a volunteer force to assist in the informal network to meet needs
- Examine each hospital in the home application

The history of the US State may largely be characterised as the ongoing and wholescale mistreatment of AI/AN communities. The poor health status of these communities is largely due to the intergenerational trauma, racism, abuse and poverty that they have experienced in US society. Relegated to the most worthless and neglected land, these populations were variously marginalised, or subject to forced assimilation. Specific health services for these oftenimpoverished communities are notoriously under-staffed and underfunded. The IHS is also suspect through its deliberate program of the AI/AN women. Working sterilisation of positively with AI/AN populations means honouring the diversity of the myriad Nations that constitute AI/AN communities. Crucial factors here include a knowledge of the relevant AI/AN language, health beliefs and an ability and willingness to work with traditional indigenous health belief systems (3, 31). Mainstream health providers are unable to achieve such focussed and individualised care. Such mainstream health services routinely fail to even catch or record the AI/AN ethnicity of patients in many US States. These mainstream health systems also lack the required numbers of AI/AN staff. There is therefore an ongoing need for the expansion of indigenous led health

providers, as well as significantly increased funding to support AI/AN individuals to train as members of the full spectrum of health careers.

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