National Indian Health Board

Testimony of the National Indian Health Board
"Empowered by Data: Legislation to Advance Equity and Public Health"
United States House of Representatives
Energy and Commerce Committee
Subcommittee on Health
June 24, 2021

Chairwoman Eshoo, Ranking Member Guthrie, and Members of the Subcommittee, thank you for holding this critical hearing *"Empowered by Data: Legislation to Advance Equity and Public Health."* On behalf of the National Indian Health Board (NIHB) and the 574 federally-recognized sovereign American Indian and Alaska Native (AI/AN) Tribal Nations we serve, NIHB submits this testimony for the record.

Background - The Reality of Broken Treaties

We continue to bear witness and experience the alarming obstacles to our everyday lives resulting from this unprecedented crisis. In a matter of weeks, COVID-19 reshaped the very fabric of our economy, our society, the way we conduct business, relationships, and our personal livelihoods – in some ways, permanently. The past year has been a profoundly uncertain and challenging time; and also, times of profound opportunity to achieve redress of hundreds of years of injustices, which are the children of colonization.

Today, our nation is confronted by the COVID-19 pandemic that continues to disproportionately ravage the most marginalized among us, and Indian Country has been right at the center of the pandemic. In order to understand how to address and overcome these challenges and realize the opportunity for transformation before us, we must first insist on an honest reckoning of our history. The challenges we face today - most recently evidenced through the impacts of COVID-19 on Tribal communicates - are the fruits of colonization. This system of exploitation, violence and opportunism is the foundation on which this Nation was constructed. Despite the poor social determinants of health most frequently found in the Indigenous and other communities of color - circumstances that proceed from hundreds of years of colonization - we are often blamed for our poor circumstances. What our communities are experiencing during this COVID-19 pandemic is simply the expected outcome of this historical truth.

Centuries of genocide, oppression, and simultaneously ignoring our appeals while persecuting Our People and our ways of life persist - now manifest in the vast health and socioeconomic inequities we face during COVID-19. The historical and intergenerational trauma our families endure, all rooted in colonization, are the underpinnings of our vulnerability to COVID-19. Indeed, we tell our stories of treaties, Trust responsibility and sovereignty – over and over – and it often appears the listeners are numb to our historic and current truths. But the truth does not change that is the ground we stand on. We hear baseless stories about how "dirty Indians" are causing the outbreaks, or how private hospitals are refusing to accept referrals to treat Our People. These same sentiments echoed across all previous disease outbreaks that plagued Our People from Smallpox to HIV to H1N1. This begs the painful question: what has changed?

The underpinnings of colonization may finally be loosening as a consequence of the exposed neglect, abuse, bad faith, and inequities AI/AN People have experienced during this pandemic. But it did not start with COVID-19. This pandemic and the way it is ravaging our Peoples is exposing the consequences of hundreds of years of US policy predicated on broken promises with the Indigenous Peoples of this land.

Health Inequities Create Additional Risks from COVID-19

The solemn legacy of colonization is epitomized by the severe health inequities facing Tribal Nations and AI/AN Peoples. When you compound the impact of destructive federal policies towards AI/ANs over time, including through acts of physical and cultural genocide; forced relocation from ancestral lands; involuntary assimilation into Western culture; and persecution and the outlawing of traditional ways of life, religion and language, the inevitable results are the disproportionately higher rates of historical and intergenerational trauma, adverse childhood experiences, poverty, and lower health outcomes faced across Indian Country.

Chronic and pervasive health staffing shortages –from physicians to nurses to behavioral health practitioners – stubbornly persist across Indian Country, with 1,550 healthcare professional vacancies documented as of 2016. Further, a 2018 GAO report found an average 25% provider vacancy rates for physicians, nurse practitioners, dentists, and pharmacists across two thirds of IHS Areas (GAO 18-580). Lack of providers also forces IHS and Tribal facilities to rely on contracted providers, which can be more costly, less effective, and culturally indifferent, at best – inept at worst. Relying on contracted care reduces continuity of care because many contracted providers have limited tenure, are not invested in community and are unlikely to be available for subsequent patient visits. Along with lack of competitive salary options, many IHS facilities are in serious states of disrepair, which can be a major disincentive to potential new hires. While the average age of hospital facilities nationwide is about 10 years, the average age of IHS hospitals is nearly four times that – at 37 years. In fact, an IHS facility built today could not be replaced for nearly 400 years under current funding practices. As the IHS eligible user population grows, it imposes an even greater strain on availability of direct care.

Tribal Nations are also severely underfunded for public health and were largely left behind during the nation's development of its public health infrastructure. As a result, large swaths of Tribal lands lack basic emergency preparedness and response protocols, limited availability of preventive public health services, and underdeveloped capacity to engage in disease surveillance, tracking, and response. And even though Tribal governments and all twelve Tribal Epidemiology Centers (TECs) are designated as public health authorities in statute, **they continue to encounter severe barriers in exercising these authorities due to lack of enforcement and education.**

When you compound the impact of broken treaty promises, chronic underfunding, and endless use of continuing resolutions, the inevitable result are the chronic and pervasive health disparities that exist across Indian Country. These inequities created a vacuum for COVID-19 to spread like wildfire throughout Indian Country, as it continues to do. Indeed, AI/AN health outcomes have either remained stagnant or become worse in recent years as Tribal communities continue to encounter higher rates of poverty, lower rates of healthcare coverage, and less socioeconomic

mobility than the general population. On average, AI/ANs born today have a life expectancy that is 5.5 years less than the national average, with some Tribal communities experiencing even lower life expectancy. For example, in South Dakota in 2014, median age at death for Whites was 81, compared to 58 for American Indians.[1]

According to the Centers for Disease Control and Prevention (CDC), in 2017, at 800.3 deaths per 100,000 people, AI/ANs had the second highest age-adjusted mortality rate of any population.[2] In addition, AI/ANs have the highest uninsured rates (25.4%); higher rates of infant mortality (1.6 times the rate for Whites)[3]; higher rates of diabetes (7.3 times the rate for Whites); and significantly higher rates of suicide deaths (50% higher). American Indians and Alaska Natives also have the highest Hepatitis C mortality rates nationwide, as well as the highest rates of Type 2 Diabetes, chronic liver disease and cirrhosis deaths. Further, while overall cancer rates for Whites declined from 1990 to 2009, they rose significantly for American Indians and Alaska Natives.

CDC reported that the presence of underlying health conditions such as type II diabetes, obesity, cardiovascular disease, and chronic kidney disease significantly increase one's risk for a severe COVID-19 illness. AI/AN populations are disproportionately impacted by each of these chronic health conditions. For instance, type II diabetes incidence and death rates are three times and 2.5 times higher, respectively, for AI/ANs than for non-Hispanic Whites. Despite significant improvements in rates of End Stage Renal Disease (ESRD) as the result of the highly successful Special Diabetes Program for Indians (SDPI), AI/AN communities continue to experience the highest incidence and prevalence of ESRD.

Increased physical distancing and isolation under the COVID-19 pandemic have led to recent and alarming spikes in drug overdose deaths, suicides, and other mental and behavioral health challenges. Population-specific data on increased drug overdose and suicide deaths during the pandemic are currently unavailable; yet if trends prior to the rise of COVID-19 are any indicator of risk, it is safe to assume that AI/AN People are experiencing serious challenges. One of the major drivers of increased mortality rates among AI/ANs overall has been significantly higher rates of drug overdose and suicide deaths than the general population. So, into this neglected and stunted health system on which American Indians and Alaska Native rely - into this system which is, collectively, the living expression of how seriously the federal government takes Treaty obligations and the Trust responsibility that requires the provision of full and quality health care for American Indians and Alaska Natives - into all of this theatre of failure comes COVID-19.

Policy Recommendations

1. **Expand and Strengthen the Government-to-Government Relationship with the Federal Government and the Tribes/Expand Self-Governance**

[1] South Dakota Department of Health. Mortality Overview. Retrieved from https://doh.sd.gov/Statistics/2012Vital/Mortality.pdf

[2] Kochanek KD, Murphy SL, Xu JQ, Arias E. Deaths: Final data for 2017. National Vital Statistics Reports; vol 68 no 9. Hyattsville, MD: National Center for Health Statistics. 2019.

[3] Centers for Disease Control and Prevention. Infant, neonatal, post-neonatal, fetal, and perinatal mortality rates, by detailed race and Hispanic origin of mother: United States, selected years 1983–2014.

The Indian Health Service (IHS) is the only agency within HHS that retains the authority to establish self-determination contracting or self-governance compacting (as those terms are defined under the Indian Self-Determination and Education Assistance Act) agreements with Tribal Nations and Tribal organizations. However, not all IHS programs are subject to ISDEAA agreements. For example, Tribes are barred from receiving IHS behavioral health grants (i.e., Methamphetamine and Suicide Prevention Initiative/Domestic Violence Prevention Initiative) under ISDEAA agreements. The federal government should commit to working with Tribes to ensure all IHS programs and funds can be allocated to Tribes under ISDEAA agreements.

Tribes also call on the federal government to expand self-determination and self-governance authority across all of HHS. In the interim, the Administration should work with Congressional appropriators to authorize interagency transfer of funds from other HHS operating divisions to IHS, given that IHS is currently the only agency with ISDEAA authority.

As background, in 2000, P.L. 106-260, included a provision directing HHS to conduct a study to determine the feasibility of a demonstration project extending Tribal self-governance to HHS agencies other than the IHS. The HHS study, submitted to Congress in 2003, determined that a demonstration project was feasible. In the 108th Congress, Senator Ben Nighthorse Campbell introduced S. 1696 - Department of Health and Human Services Tribal Self-Governance Amendments Act - that would have allowed these demonstration projects. A second study was completed in 2011 by the U.S. Department of Health and Human Services Self-Governance Tribal Federal Workgroup that noted additional legislation would be needed for the expansion. Despite these findings supporting expansion of Tribal self-determination and self-governance, Congress has yet to act legislatively.

Tribal self-determination and self-governance honor and affirm inherent Tribal sovereignty. Self-governance represents efficiency, accountability, and best practices in managing and operating Tribal programs and administering federal funds at the local level. Expanding self-governance translates to greater flexibility for Tribes to provide critical social services within agencies such as the Administration on Aging, the Administration on Children and Families (ACF), the Centers for Disease Control and Prevention (CDC), the Substance Abuse and Mental Health Administration (SAMHSA), and Health Resources and Services Administration (HRSA).

Allowing Tribes to enter into self-governance compacts with HHS and its operating divisions would mean that federal dollars are used more efficiently because resources in Tribal communities, which are often small, could be more easily pooled and would allow Tribes to organize wrap-around services to better serve those who have the greatest need. Self-governance allows Tribes to extend services to larger populations of eligible American Indians and Alaska Natives, leveraging other opportunities more efficiently than the federal government. It also leads to better outcomes because program administrators are in close contact with the people they serve, making the programs more responsive and effective.

- Enact a permanent expansion of Tribal self-determination and self-governance across all agencies within the HHS and affirm that all programs at the IHS are eligible to be contracted and compacted.

- Expand and codify all Tribal Advisory Committees (TAC) to ensure Tribes have a voice within all operating divisions that provide funding to Tribal governments and communities.
- Create direct funding to Tribes and avoid grant mechanisms which cause Tribes to compete against other Tribes or against well-resourced states, cities, and counties.
- Streamline reporting requirements to reduce burdens on Tribal nations receiving funding.

2. Create Set Aside Funding for Tribes in all HHS Operating Divisions

Tribes interact with the various HHS operating divisions on a regular basis and there should be funding dedicated to ensuring that the agencies can meet Tribal needs. In fact, honoring the trust responsibility requires the federal government to meet the needs of Tribal communities. However, the status quo often prevents this from happening. For example, Health Resources and Services Administration (HRSA) frequently gives out grants and conducts programming aimed at rural providers. Unfortunately, the existing framework forces Tribes to compete for these funds, and as a result, Tribes regularly lose out on funding when the system pits them against better resourced states or counties. The work of the various agencies can be improved if Congress allocated base funding directly for the Tribes.

- Create set aside funding for Tribes in the annual appropriation for each HHS operating division.
- Ensure funding can flow to Tribes through self-determination contracting and self-governance compacting, and that Tribes have maximum flexibility and minimum administrative burden. Ensure funding can be allocated through a formula to all Tribes, and not as competitive grants.
- Wherever possible, each agency should use administrative authorities to create set aside funding for Tribes.
- Each agency should devise a formula, through Tribal consultation, to ensure it allocates funding in an equitable manner.
- Each agency should conduct Tribal consultation on a yearly basis, at a minimum, so the agency can include Tribal requests and recommendations in the agency's budget request to Congress.

3. Ensure Tribal Access to Data and Support Tribal Data Sovereignty

Recent federal scientific initiatives throughs the National Institutes of Health (NIH) and the Food and Drug Administration (FDA), have sought Tribal leaders' endorsement of their projects in Indian Country. While Tribal advocates support the development of scientific initiatives to prevent and cure diseases, Tribes are sovereign nations and are the ultimate stewards and owners of the data collected on their Tribal citizens.

The Centers for Disease Control and Prevention (CDC) must work collaboratively with Tribes to ensure that Tribes have access to their Tribal data. Understanding and honoring Tribal data sovereignty must be the cornerstone of all CDC Tribal data collection efforts. Doing

so will improve overall public health data reporting and provide the most accurate information for developing budget and public health priorities, while allowing Tribal leaders and administrators the most accurate data in determining resource allocation and program development and evaluation.

Structural challenges in data reporting only serve to render invisible the disparate impact of COVID-19 in Indian Country. For example, TECs continue to face significant barriers in exercising their statutory public health authorities by facing major hurdles in accessing federal and state public health surveillance systems, including for COVID-19, which often has incomplete or inaccurate race/ethnicity data. In addition, not every state, city and county jurisdiction include AI/AN as a distinct demographic on health assessment and surveillance forms, often lumping them under "other." These race/ethnicity data gaps contribute to ongoing underestimates that only further obscure the true burden of COVID-19 and other diseases for AI/ANs. Furthermore, Tribes often experience significant barriers in accessing the patchwork of state infectious disease tracking and reporting systems. This must be corrected to allow the Tribes access to their own data in a timely manner.

While available data demonstrates higher rates of health disparities among AI/ANs in a variety of health conditions, estimates of disease prevalence and incidence for AI/ANs are likely to be underestimates due to high rates of racial misclassification and undercounting of AI/AN populations in state and federal surveillance systems. A comprehensive plan to address the gaps in data collection across these surveillance systems is drastically needed to improve the information readily available to Tribal leaders to better inform their public health policies and programs.

Unfortunately, because of high rates of misclassification and under-sampling of AI/AN populations in federal, state, and local public health disease surveillance systems, available data likely significantly underrepresents the impact of COVID-19 in Indian Country. To be clear, misclassification of AI/ANs on disease surveillance systems is not unique to COVID-19, however, the issue has taken a new level of urgency given the unprecedented devastation of this pandemic on underserved communities. Multiple states with large AI/AN populations including but not limited to Minnesota, Michigan, New York, and California continue to report thousands of COVID-19 cases without any information on patient race/ethnicity or categorizing cases as "other" on demographic forms. ***In California, for instance, the state noted they lack race/ethnicity data for nearly 30% of reported cases.*** Multiple studies demonstrate that surveillance systems frequently misclassify AI/ANs or omit them from surveillance systems entirely. These issues continue exacerbate health disparities including those from COVID-19.

The CDC must work with state and local health departments, community-based organizations (CBOs), Federally Qualified Health Centers (FQHCs), IHS facilities, Tribally-run health facilities, and Tribal Epidemiology Centers (TECs) to ensure that complete and accurate data is captured and shared with Tribes so they can effectively respond and recover from COVID-19, and other similar public health emergencies. Timely and accurate data play a vital role in public health decision-making, and would allow for better, data-driven Tribal public health policy, which would better protect Tribal members.

4. **Create Set-Aside Funding for Tribes Throughout the CDC and Invest in Tribal Public Health Systems**

Tribes interact with the CDC on a regular basis and there should be funding dedicated to ensuring that the agencies can meet unique Tribal needs. Unfortunately, the status quo often prevents the fulfillment of Tribal needs. For example, CDC frequently distributes funding via competitive grants and conducts programming aimed at strengthening Tribal public health infrastructure and systems, but these methods of funding do not allow for equitable funding across all Tribal public health systems.

Dedicated funding for Tribes and Tribal organizations is the most effective way to ensure that adequate resources are reaching Indian Country, while also furthering the fulfillment of the federal government's trust responsibility for health. With Good Health and Wellness in Indian Country (GHWIC) as a potential model, CDC should consult with Tribes to design and fund Tribal public health infrastructure and capacity development initiative in Indian Country with the flexibility to permit Tribes to tailor programs to their unique community priorities. The CDC must commit to these direct Tribal investments that support Tribes in addressing public health development and other issues. **There should be a minimum of 5% set-aside for Tribes across all CDC Centers, Institutes, and Offices (CIOs) to meaningfully begin to build equitable Tribal public health systems, compared to states and local health departments.** This funding will help integrate Tribal public health needs and priorities across the entire CDC and all CDC programs. For those CDC CIOs that do not send funding out as grants, **at least 5% of funding resources for internal activities should be directed and dedicated to Tribal support.**

5. **End the Competitive Grant Process for Tribes**

At the core of the federal trust responsibility to Tribal Nations is the fact that the federal government is supposed to ensure the health and welfare of Native peoples. The COVID-19 pandemic has given the federal government an opportunity to uphold their end of the bargain in a way that is perhaps unparalleled in modern American history. However, Tribes are increasingly running into systemic barriers that impede their ability to actually receive help from the federal government and this is slowing or even outright denying access to aid.

One reason is because in all but the latest COVID-19 relief packages, the federal government decided to use competitive grant making as a means of distributing funds to Tribes. To apply for competitive grants, you need staff to put together an application. Tribes that were lower resourced found themselves having to use a skeleton staff to put together applications to have access to funds that they needed to provide care for their people. If Tribes could not pull together these resources, they were excluded from being able to apply for these pots of money.

Federal trust obligations to fund healthcare and public health in Indian Country cannot, and must not, be achieved through the competitive grant mechanism. By their very design, competitive grants create an inequitable system of winners and losers. **The federal obligation to fully fund health services in Indian Country was never meant to be contingent upon the**

quality of a grant application – yet that is the construct that the federal government has forced Tribes to operate under. That is unacceptable.

Instead, a more effective way to distribute aid to Tribes would be through a fixed funding formula that ensures sufficient, recurring, sustainable funding reaches all Tribal Nations. Doing so would allow Tribes to know that the funding was coming to them, how much they were getting, and be able to plan to utilize that money to help their citizens. It would have also alleviated the burden on Tribes to use their staff to apply for grant funding and allowed them to use their limited resources to treat the issue at hand. We were pleased, for the first time, Congress provided a dedicated, standalone section to Indian health in the American Rescue Plan. This type of mechanism in the law is precisely what Indian Country has been asking for and avoids competitive grants altogether.

While Tribes may be eligible for competitive grants addressing public health and other issues, many of these programs have little penetration into Indian Country because Tribes have difficulty meeting the service population requirements, match requirements, or are under resourced to apply and/or compete for the grants. Moreover, **Tribal eligibility for funding does not equate to Tribal access,** especially when Tribes are forced to compete with states, cities, and other governments that are generally higher resourced. In short, the federal government must cease using the competitive grant mechanism to try to fulfill its trust obligations to Tribal Nations. It is essential that HHS make a major commitment to creating set-asides for direct funding to Tribal governments and organizations in a streamlined, non-competitive, sustainable, and equitable fashion.

Another issue was the insufficient notice of funding opportunities. Many Tribes were not told what opportunities were available or how they would be able to access the funding. Given the Trust Responsibility, we would expect HHS to take special care to ensure that Tribes know of these opportunities and are able to submit any required documentation within a timely manner. Tribes were also forced to deal with agencies with whom they had little experience or knowledge. For example, in the initial funding allocations, aid to Tribes was distributed through the CDC and not IHS. This, in turn, created a delay in receiving funding as the CDC had to create a mechanism to either distribute the funding themselves or transfer the money to IHS. However, in the American Rescue Plan, funds were directed to flow through IHS, who already has an existing relationship with Tribes to release these funds more efficiently and effectively.

As sovereign governments, Tribal Nations have the same inherent responsibilities as state and territorial governments to protect and promote the public's health. Tribes were largely left behind during the nation's development of its public health infrastructure and systems continue to be chronically underfunded. As a result, many Tribal public health systems remain far behind those of most state, territorial, and even city and county public health entities in terms of their capacity. This includes core services, such as disease surveillance and reporting; emergency preparedness and response; public health law and policy development; and public health service delivery. Additionally, HHS must commit the resources and CDC must continue its meaningful and sustainable direct investments into Tribal communities for public health if we are ever to close the gap in the disparities of lower health status, and lower life expectancy of AI/AN Peoples compared to the general population.

Conclusion

Our treaties stand the test of time. They are the Supreme Law of this land. If a nation's honor and exceptionalism is a measure of its integrity to its own laws and creed, then one must look no further than the United States' continued abrogation of its own treaties to recognize that its honor is in short supply. Every square inch of this nation is Our People's land. As the sole national organization committed to advocating for the fulfilment of the federal government's trust and treaty obligations for health, we will always be dedicated to bringing into fruition the day where Our People can state with dignity that the United States held true to its solemn word. Ideally, fulfillment of trust and treaty obligations should be without debate and the U.S. should honor its promises. These lands and natural resources, most often acquired from us shamefully, are the bedrock of U.S. wealth and power today.

In closing, we thank the Committee for the continued commitment to Indian Country and urge you to further prioritize Indian Country as you continue to provide relief regarding the COVID-19 pandemic. We patiently remind you that federal treaty obligations to the Tribes and AI/AN People exist in perpetuity and must not be forgotten during this pandemic. We thank you that American Indians and Alaska Natives will continue to be prioritized to receive the vaccine, have sufficient funds to build and maintain a public health infrastructure, and the full faith and confidence of the United States Government will further be committed to this nation's first citizens to eradicate this disease. As always, we stand ready to work with you in a bipartisan fashion to advance health in Indian Country.