

**TESTIMONY OF
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HEALTH & CLINIC CEO OF THE LOWER SIOUX INDIAN COMMUNITY, AND,
BOARD MEMBER OF THE GREAT LAKES AREA TRIBAL HEALTH BOARD
ON**

S. 1397, To amend the Public Health Service Act with respect to the collection and availability of health data with respect to Indian Tribes and Tribal organizations for other purposes. Also known as “Tribal Health Data Improvement Act of 2021”.

**BEFORE THE
COMMITTEE ON INDIAN AFFAIRS
U.S. SENATE**

MARCH 23, 2022

Hahanna Waste’ (good day), Chair Schatz, Vice-Chairman Murkowski, and Members of the Committee. Thank you for the opportunity to speak to you about “Tribal Health Data Improvement Act of 2021” – S. 1397. I am Dr. Darin Prescott; an enrolled citizen of the Lower Sioux Indian Community or, *Cansayapi*’ (where they paint the trees red), in Southwest Minnesota. I am the Health & Clinic CEO of the Lower Sioux Indian Community and a Board member of the Great Lakes Area Tribal Health Board (GLATHB). I am here today with the support of both, the Lower Sioux Indian Community and the Great Lakes Area Tribal Health Board. I am an advanced-degree registered nurse and here today speaking in support of Senate bill 1397.

The Lower Sioux Indian Community is the largest of the four Dakota Communities, and one of 11 Federally Recognized Tribes in Minnesota. The GLATHB covers Indian Health Service (IHS), Tribal and Urban (ITU) health services in the State of Minnesota, Wisconsin, Michigan, Northern Indiana and the Indian Health Board of Chicago, IL.

The Lower Sioux Indian Community is committed to improving the standard of living and quality of lives for our citizens. Access to land, water, utilities, safety initiatives, programming, and business are critical to an equitable quality of life. Data is an imperative component for tribes to support these requisite accesses. As I reviewed the proposed changes in S. 1397, I’m identifying a potential improvement that is long overdue. The following are ongoing concerns of the current system and an opportunity to support tribal data sovereignty.

1. Need for meaningful data

Most data reported to the U.S. Government relies on elective, self-reporting of tribal affiliation instead of tribal enrollment data; much of which has been collected to satisfy the administrative needs of the U.S. Government and not the needs of the individual tribes.¹ Data collection for tribes in the U.S. typically revolves around programming and cost centers. This binary data is not particularly useful especially for smaller tribes.

Tribal citizens are storytellers by nature. Our stories, passed down from generation-to-generation reflect a qualitative approach to data. Oftentimes this is supported by current quantitative data to identify resource needs. Most data collected by the U.S. government is quantitative. “Indigenous data is information, in any format, that impacts indigenous lives at the collective and individual levels.”²

As a registered nurse working in a tribal health system, collection of tribal citizenship data is part of our processes. In my previous work within three major health systems, the impetus for a patient to identify as a tribal citizen falls almost exclusively on the patient. One private-sector health system that asks about tribal affiliation is Yale University Medical Center in Connecticut, during the patient registration process. Kudos to them for asking this when caring for one of our relatives recently. The specificity of tribal affiliation oftentimes is not specified or may be generalized to either Caucasian or more than one race. The classifications do not support determination of tribal data.

To complicate data collection, Indian tribal citizens may not identify themselves as belonging to a tribe. This is done with concern for receiving substandard treatment or a fear of discrimination. S. 1397 may provide additional assurances to further define the protection, importance, and obligations from the U.S. Government of data to tribal citizens.

2. Need for data sharing agreements between U.S. Government agencies, States with tribes, tribal health boards and epidemiology centers

Lower Sioux Indian Community’s tribal constitution identifies that the Tribal Council (government) is responsible for the health and wellbeing of the tribe. Tribal use of data goes back further than colonization. Data was used to make decisions on survival. Identifying the season’s population of deer and bison, helped determine how many could be taken for survival and maintain the game populations for future. Another example was which type of corn grew the strongest and some of the corn would be kept as seeds for the upcoming season. Data was, and continues to be collected and analyzed for survival and harmony.

What I’ve seen over the past 8 years in my journey from the private to the tribal health sector is a parental role taken by the U.S. Government over tribes. The most recent example I can share with you is from 2021 when we began receiving COVID-19 vaccines. Tribes agreed to report their data with regard to vaccinations being administered through the Minnesota Immunization Information Connection; a repository for immunizations and vaccinations given in Minnesota. On a call with tribal health leaders, a staff member at Minnesota Department of Health very abruptly identified that tribes would be monitored that we were giving the vaccines and not hoarding them. When asked if other entities receiving vaccine through MDH, such as retail pharmacies, county public health agencies and private clinics would be equally monitored; the subject quickly changed. Data is also used as a pass/fail grade for tribes. This was seen early on with the State Health Improvement Program or SHIP outcomes. It took a fair amount of time to come to understanding what success looked like in a tribal community versus County.

Fast forward to today, the need to make data-driven decisions and set policy could not be better identified than the COVID-19 pandemic response. Tribes rely on their area Tribal epidemiology

centers (TEC). TEC's, such as the Great Lakes Inter-Tribal Epidemiology Center were denied access to COVID-19 data what was made available to States. Tribal epidemiologists were denied access to requisite data on testing and infection rates to inform, direct and make tribal, data-driven decisions. Much of our information was based on county and State data which oftentimes was received from mainstream news streams. The concern was identified with sharing data with tribes from the CDC was data-privacy issues.³

Over the past year, about half of the 11 tribes have a data-sharing agreement between the Minnesota Department of Health and tribe. Other tribes are currently in consultation regarding the data-sharing agreement. I attribute two reasons for this success. Minnesota Department of Health elevated the priority of American Indian public health by creating it's first Office of American Indian Health. Tribal data-sharing agreements was one of the first objectives of this department.

Our TEC's consist of experts parallel to State health departments and the CDC. TEC's play various roles for tribes in the data sharing whether it's a pass through to tribal health departments or a more collaboration where some tribes do not have the professional staff in place to review and refine the data. Data sharing with a TEC brings data to the tribe in a way they may use this.

S. 1397 identifies the opportunity for development of tribal data-sharing agreements in a government-to-government consultation. Each tribe is unique and a data-sharing agreement will need to be individualized. I'm proud to share that the Minnesota Department of Health is an example of what can take place when tribal-State relationships are prioritized and fostered. This example and others can serve as a framework to CDC, States and other organizations working with tribes.

3. Need for data that is accurate regarding birth and death records in a tribe

Accuracy of tribal affiliation on death certificates is a unique phenomenon to American Indians. In studies regarding white, black and Hispanic populations, they do not experience the same level of error as does the death certificate of American Indians. Reliability on appearance or peripheral exposures by persons completing death certificates is at cause for close to 50% of inaccuracies in reporting Caucasian versus American Indian.⁴

The Lower Sioux Indian Community consists of approximately 1,200 citizens. Approximately half of that number is 18 or under. Birth records are important as part of the tribe's planning. For example, Lower Sioux Indian Community supports its tribal children through supporting equity from pre-school through high school and higher education. We monitor these numbers to assure we plan to support our relatives from their start. In death, we look for data to help identify causes that may be impacted by disparities. Some examples include chronic illness, diseases, and suicide. It's difficult to cite errors when one does not have access to a birth and death certificate.

- ¹ Bruhn, L. (2014). Identifying useful approaches to the governance of Indigenous data. *The International Indigenous Policy Journal*, 5(2). Doi: <http://dx.doi.org/10.18584/iipj.2014.5.2.5>
- ² Kimmerer, R. (2002). Weaving traditional ecological knowledge into biological education: A call to action. *BioScience*, 52(5). Doi: [http://dx.doi.org/10.1641/0006-3568\(2002\)052\[0432:WTEKIB\]2.0.CO;2](http://dx.doi.org/10.1641/0006-3568(2002)052[0432:WTEKIB]2.0.CO;2)
- ³ Rothermich, E. (2021). Pandemic strengthens calls for Indigenous data sovereignty. *The Regulatory Review*. Retrieved March 21, 2022 from: <https://www.theregreview.org/2021/02/11/rothermich-pandemic-strengthens-calls-indigenous-data-sovereignty/>
- ⁴ Wheeling, K. (2017, June 14). How mortality data fails Native Americans. *Pacific Standard*. Retrieved March 19, 2022 from: <https://psmag.com/news/how-mortality-data-fails-native-americans>