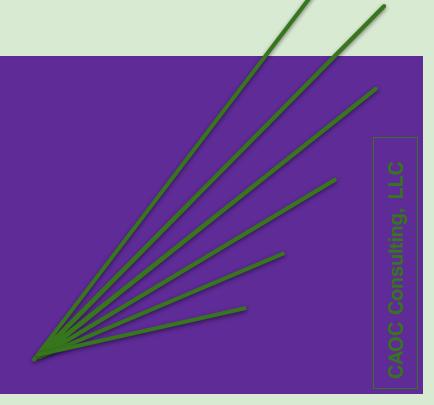
Introduction to Tribal Data Sovereignty, the Role of Tribal Epidemiology Centers, and Related Laws

Chris Alibrandi O'Connor, JD CAOC Consulting, LLC

Sarah Shewbrooks, MPH Great Plains Tribal Leaders' Health Board

March 20, 2025



What We Do

- Convene and advocate on behalf of communities that are sharing and using cross-sector data for good
- Connect to innovations, best practices, and research and funding opportunities that support ethical data sharing
- Consult with data sharing collaborations to build the human and technical capacity to share data and improve lives

Why We Do It

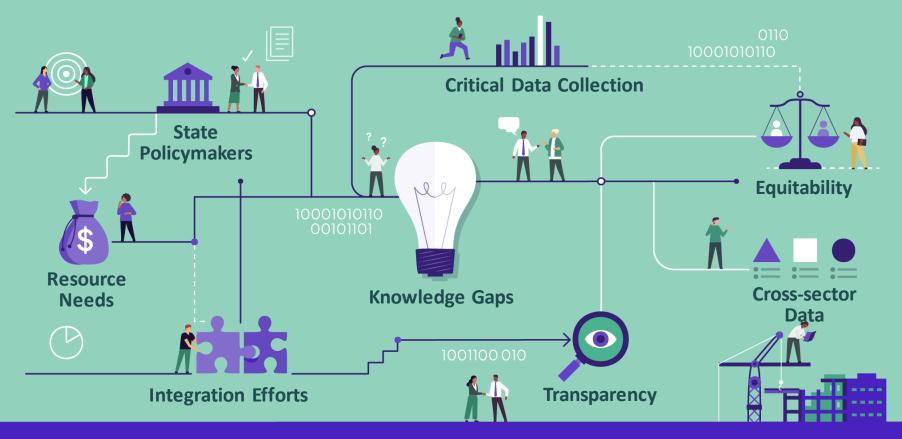
When communities bring together cross-sector data safely and responsibly, policy-makers, practitioners, and schools are better equipped to:

- Understand the complex needs of individuals and families
- Allocate resources where they're needed most to improve services
- Measure long-term and two-generation impacts of policies and programs
- Engage in transparent, shared decision-making about how data should (and should not) be used





The Data Integration Support Center (DISC) at WestEd provides expert integrated data system planning and user-centered design, policy, privacy, and legal assistance for public agencies nationwide.







Our roles





We are:

Data evangelists

Connectors, community builders, thought partners, cheerleaders, and data sharing therapists

Focused on ethical data use for policy change

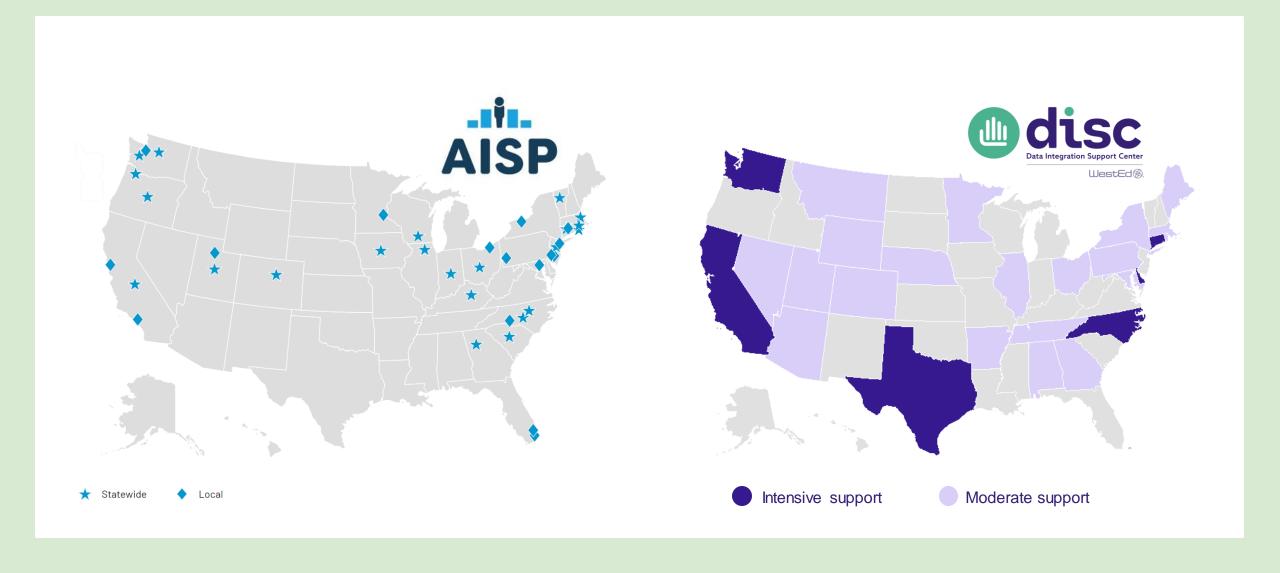
We are not:

Data holders or intermediaries

A vendor or vendor recommenders

Focused on academic research

Our Networks







Our approach

Data sharing is as relational as it is technical.

We don't just need to integrate data;

we need to integrate people.

SPEAKERS

CHRIS ALIBRANDI O'CONNOR, ESQ.

is an attorney who provides legal and management consulting services to non-profits and governmental agencies in the public health arena. Her areas of expertise include health data privacy laws and legal issues around Tribal Epidemiology Centers' and Tribes' access to health data from federal, state, and local public health agencies. Previously she was a Deputy Director at the Network for Public Health Law, HIPAA Privacy Officer, legal services attorney, and community organizer.



SARAH SHEWBROOKS, MPH

is an DCU Director and Lead Epidemiologist at the Great Plains Tribal Epidemiology Center (GPTEC), part of the Great Plains Tribal Leaders' Health Board. GPTEC provides epidemiological support and data services to the 18 tribal communities in North Dakota, South Dakota, Iowa, and Nebraska. Before joining GPTEC in 2018, Sarah served 7 years in the US Air Force as a Signals Analyst before pivoting into public health. She received her Bachelor of Public Health from University of Colorado-Denver, her Master of Public Health from the University of Edinburgh and is currently a Johns Hopkins Bloomberg Doctor of Public Health Fellow focusing on violence at the Johns Hopkins Bloomberg School of Public Health.



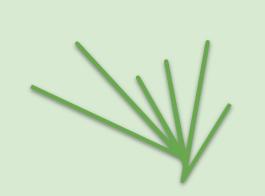
Not Legal Advice

Nothing offered in this presentation is legal advice, should be treated as legal advice, should be relied upon as legal advice, or even smells like legal advice. When the history of legal advice is written, what you hear today will not appear, as it is not legal advice. When your mother asks you tonight what you learned at work today, the proper answer will be "not legal advice, Mom!" followed by whatever recounting of the following information/ you wish to give, which, while instructive and hopefully relevant and helpful to your work, is, nonetheless, not legal advice.

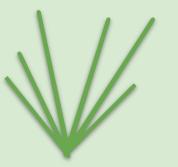
CAOC Consulting, LLC

What We Will Cover today:

- American Indian / Alaska Native healthcare
- Tribal Data Sovereignty and public health for Tribes
- Tribes and Tribal Epidemiology Centers and their public health authority
- Key barriers to Tribes' and TECs' access to public health data
- How a TEC's use of data slowed a syphilis epidemic







Your input, please:

- what questions do you have?
- what's on your mind about today's topic?

AI/AN

American Indian and Alaska Native (AI/AN) is the current Office of Management and Budget (OMB) designation for people who have origins in North, South, and Central America who maintain tribal affiliation or community attachment.

OMB sets the standards for racial designation in most data sources, which is why we will use the term AI/AN throughout this presentation.



AI/AN Healthcare

AI/AN's enrolled in a federally recognized tribe in the United States are the only group that have the right through federal legislation to access healthcare.

Why?

to American Indians and Alaska Natives

- ✓ United States Constitution
- The Snyder Act of 1921
- √ The Transfer Act of 1954
- ✓ Indian Sanitation Facilities and Services Act of 1959
- The Indian Self-Determination and Education Assistance Act (enacted 1975)
- Indian Health Care
 Improvement Act of 1976
- The Indian Alcohol and Substance Abuse prevention and Treatment Act of 1986
- ▼ The Indian Child Protection and Family Violence Prevention Act of 1990

This is not an all-inclusive list.

Indian Health Service (IHS)

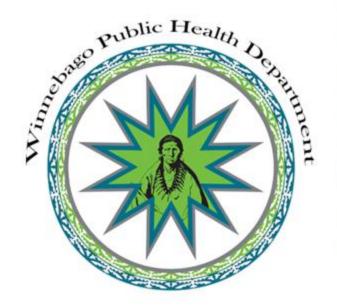


Facilities (as of June, 2023)	Operated By	
Type of Facility	IHS	Tribes
Hospital	21	22
Health Center	52	331
Health Station	25	76
Alaska Village Clinic	0	147
School Health Center	12	7
Youth Regional Treatment Centers	6	6

Public Health for Tribes

Public Health for Tribes

Tribes/Tribal Health Departments



State/Regional/Federal Health Departments



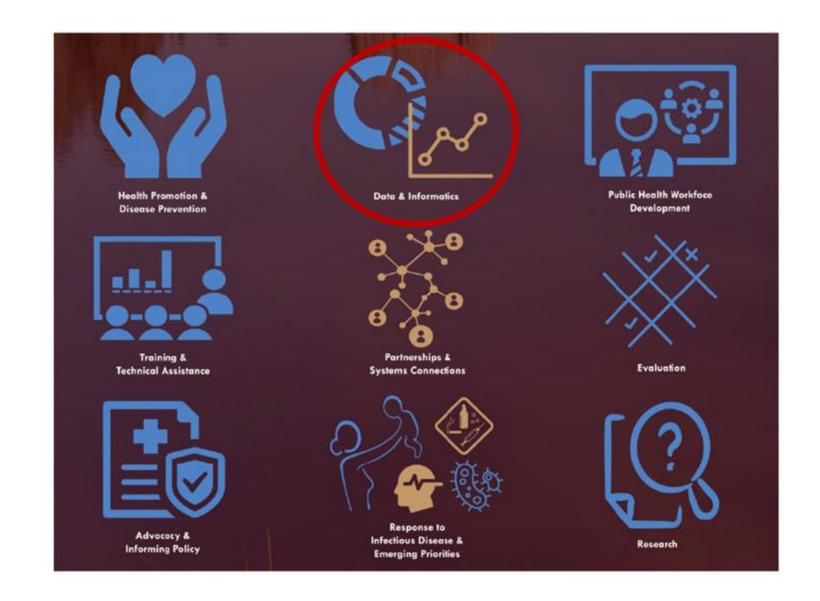
Tribal Epidemiology Centers (TECs)



TECs



Tribally-directed Public Health Authorities that provide expertise and services to tribes on epidemiological concepts:



Tribal data

Facts, knowledge, or information about a tribe and its citizens, lands, resources, programs, and communities. Remember: AI/AN is not just a racial category, it's a political designation!

Tribal Data Sovereignty

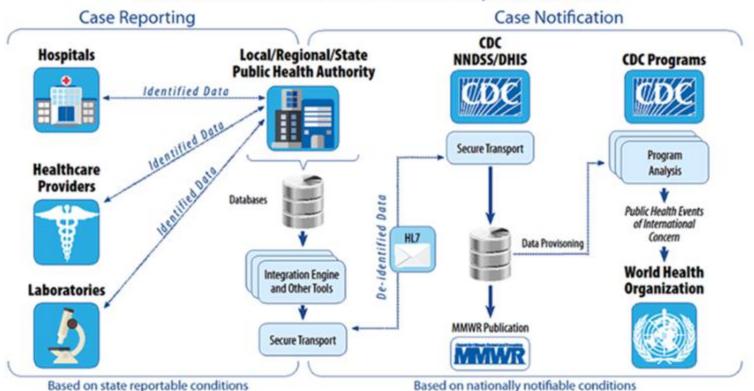
The right of Tribes to govern the collection, ownership, and application of their own data.

Data governance

Tribes exercising their right to control tribal data.

National Notifiable Diseases Surveillance System Data Flow

Tribes and TECs are systematically left out of the public health data flow.



Data Dependency

Much of the data on tribal persons are collected by local, state, and federal agencies.

Data Dependency

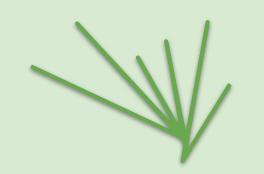
Indigenizing Data Governance

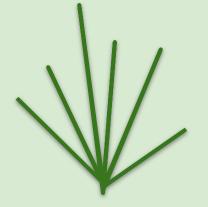
Tribal Health Departments
Tribal Programs
TECs

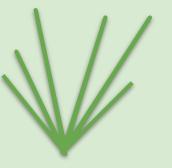
Data Sovereignty

The Public Health Authority of Tribes and Tribal Epidemiology Centers:

The legal bases







POLL QUESTION:

Does your jurisdiction disclose (share) public health data to a Tribal Public Health Authority or Tribal Epidemiology Center?

What is public health authority / power?

The legal ability to further public health by using tools such as

- data collection
- scientific research
- laws and regulations
- enforcement
- community-engaged processes, and
- the many methods of sharing information and guidance with those who need it.

Who or what has public health authority? And on what legal basis?

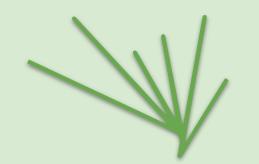
Tribes	CDC	States, counties, municipalities	Tribal Epidemiology Centers
Inherent sovereign authority	Public Health Service Act, Section 361, 42 USC 264(a)	State/municipal laws	42 USC 1621m

Tribal Epidemiology Center Powers

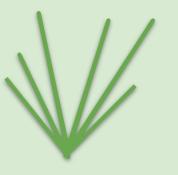
"In consultation with and on the request of Indian tribes, tribal organizations, and urban Indian organizations, each Service area epidemiology center ... shall -

- (1) *collect data* relating to, and monitor progress made toward meeting, each of the health status objectives of the Service, the Indian tribes, tribal organizations, and urban Indian organizations in the Service area; ...
- (3) assist Indian tribes, tribal organizations, and urban Indian organizations in identifying highest-priority health status objectives and the services needed to achieve those objectives, *based on epidemiological data*;...
- (6) provide requested technical assistance to Indian tribes, tribal organizations, and urban Indian organizations in the development of local health service priorities and incidence and prevalence *rates of disease and other illness in the community*; and
- (7) *provide disease surveillance* and assist Indian tribes, tribal organizations, and urban Indian communities to *promote public health*."

 42 USC 1621m







Health privacy laws are designed to balance



the sharing of health information

with

of the person whose health information it is

Health Information Portability and Accountability Act (HIPAA)*

Sets national standards for privacy and security for health information. Gives us certain rights regarding our health information.

HIPAA Privacy Rule**

regulates how and when our PHI (protected health information) can be shared - with and without our express authorization - by HIPAA "covered entities".

^{*} Pub. L. 104-191

^{** 45} CFR Part 160 Subparts A and E of Part 164

HIPAA Privacy Rule

General requirement: Patient's consent needed before his/her/their PHI can be used or shared by HIPAA covered entities.

BIG exceptions:

- For treatment, payment, or operations, 45 CFR 164.506(c)
- For public health activities, 45 CFR 164.512(b)

Remember: If the agency disclosing data is <u>not</u> a covered entity, HIPAA doesn't apply.

Permitted Uses and Disclosures for Public Health Activities*

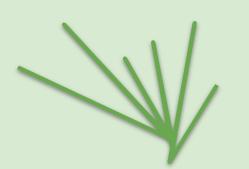
- (1) A covered entity may use or disclose *protected health information* for the *public health activities and purposes* described in this paragraph to:
 - (i) A *public health authority that is authorized by law* to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions; or, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority;...



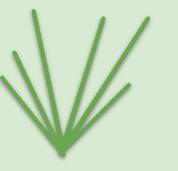


Recognized as public health authorities under HIPAA:

- Tribes 45 CFR 164.501 Definitions: public health authority
- TECs 25 U.S.C. 1621m(e)(1)







Law-Related Barriers:

- Tribe/TEC legal authority not understood / recognized
- applicable laws misapplied (HIPAA)
- inapplicable laws applied (Freedom of Information Act)

State laws may limit disclosure of data, even if for public health activities.

Key barriers to data access of Tribes and TECs (con't) Lack of acknowledgment/respect of Tribal/TEC public health professionals.

Q: The state is already doing epidemiological work that includes tribal persons; why would a TEC or tribe need to?

A: Sovereignty!

Key barriers to data access of Tribes and TECs (con't)

Limiting data access to only AI/AN data.

Q: If your service population is Al/AN, then why do you need data on non-Al/ANs?

A: Per the CDC:

"Basic epidemiologic methods tend to rely on careful observation and use of valid comparison groups to assess whether what was observed, such as the number of cases of disease in a particular area during a particular time period or the frequency of an exposure among persons with disease, differs from what might be expected."

Additionally, as the COVID-19 pandemic demonstrated most recently, diseases do not respect geographic or political boundaries.

Key barriers to data access of Tribes and TECs (con't)

Historical and continuing discrimination.

Any number of questions or actions outside what is asked of any other Public Health Authority asking for data.

- Having to provide excessive detail on data infrastructure.
- Additional legal agreements.

MI

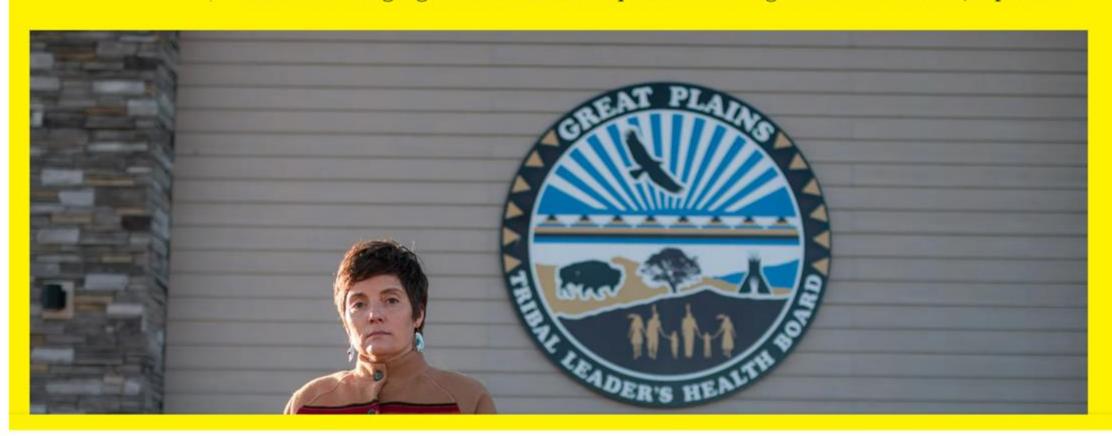
Dec 19, 2023, 4:00 AM MST





How a fight over data made South Dakota's bad syphilis outbreak worse

A decades-long digital turf war's consequences for Indigenous communities, explained.

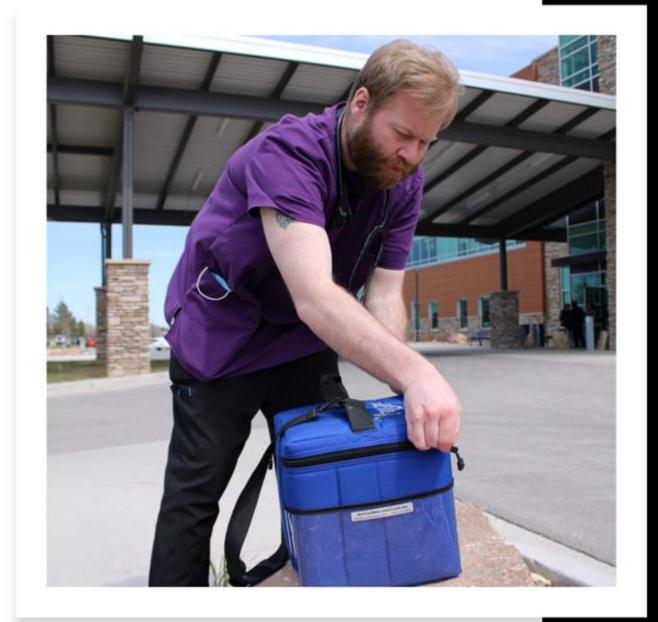


April 2024

GPTEC now able to provide data extracts on syphilis cases previously closed by SDDOH to CDC DIS and field teams with all relevant information for contact tracing.

In two weeks:

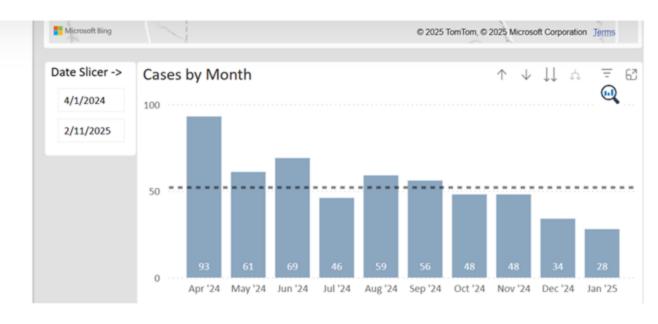
- 249 field visits
- 29 partner service interviews
- 32 contacts initiated
- 102 people were treated including five pregnant mothers



Result

Since April 2024
– syphilis cases
in South Dakota
have fallen by
almost **70**%

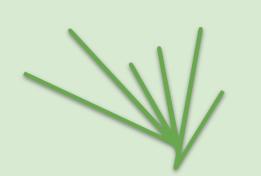


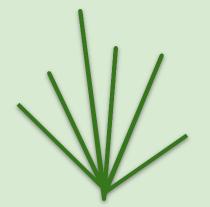


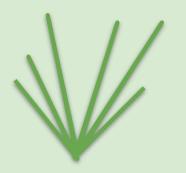
Thank you.

Sarah.Shewbrooks@gptchb.org Chris@caoc.consulting

Time for some Q & A











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