



NATION BUILDING FOR WELLNESS:

TRIBAL DATA SOVEREIGNTY FOR HEALTHY
INDIGENOUS COMMUNITIES

US INDIGENOUS DATA SOVEREIGNTY NETWORK

PRESENTERS



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Partnerships for Native Health

INDIAN COUNTRY

Tribes, Native Nations, Indigenous Nations in the US are:

567

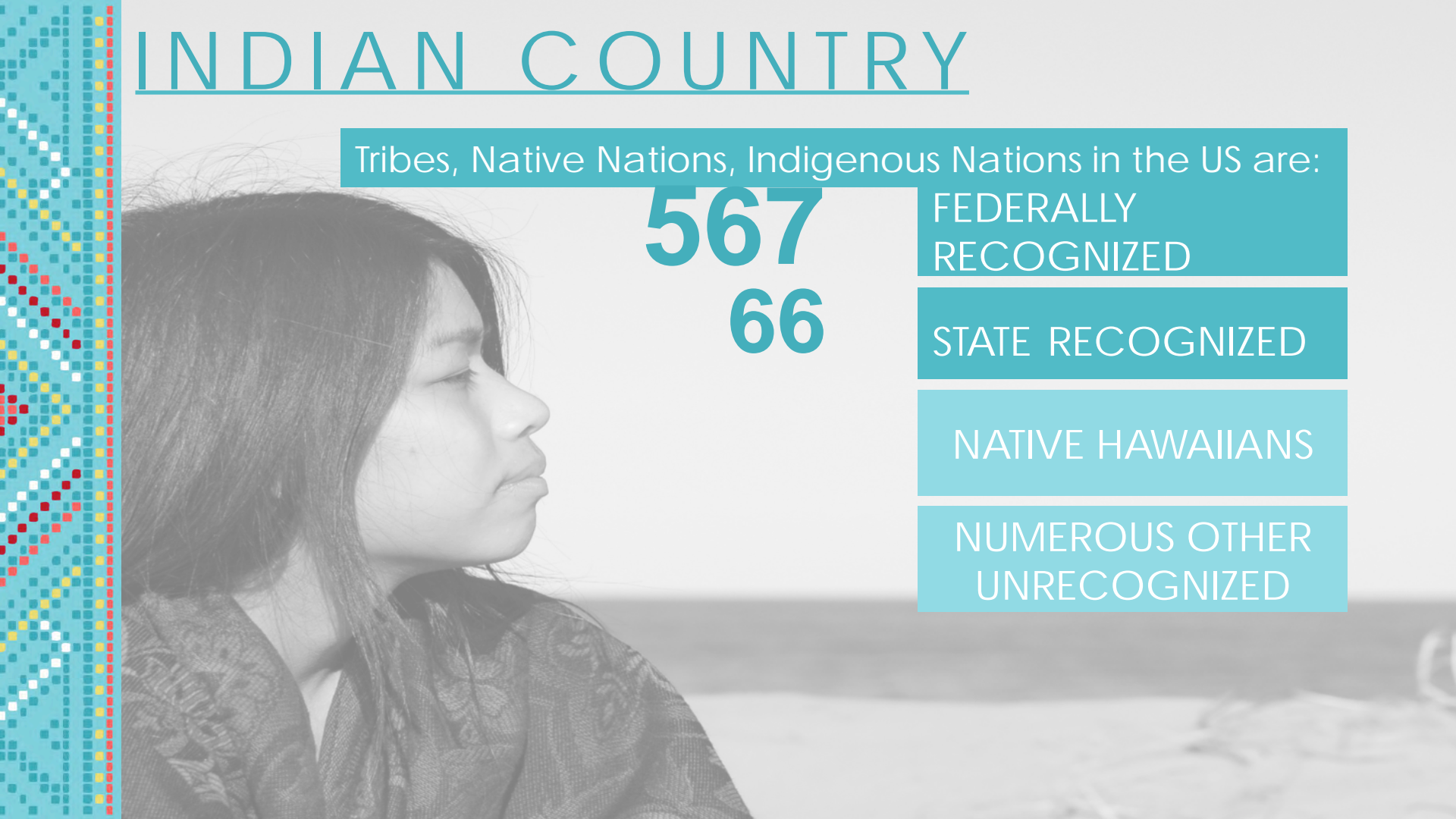
66

FEDERALLY
RECOGNIZED

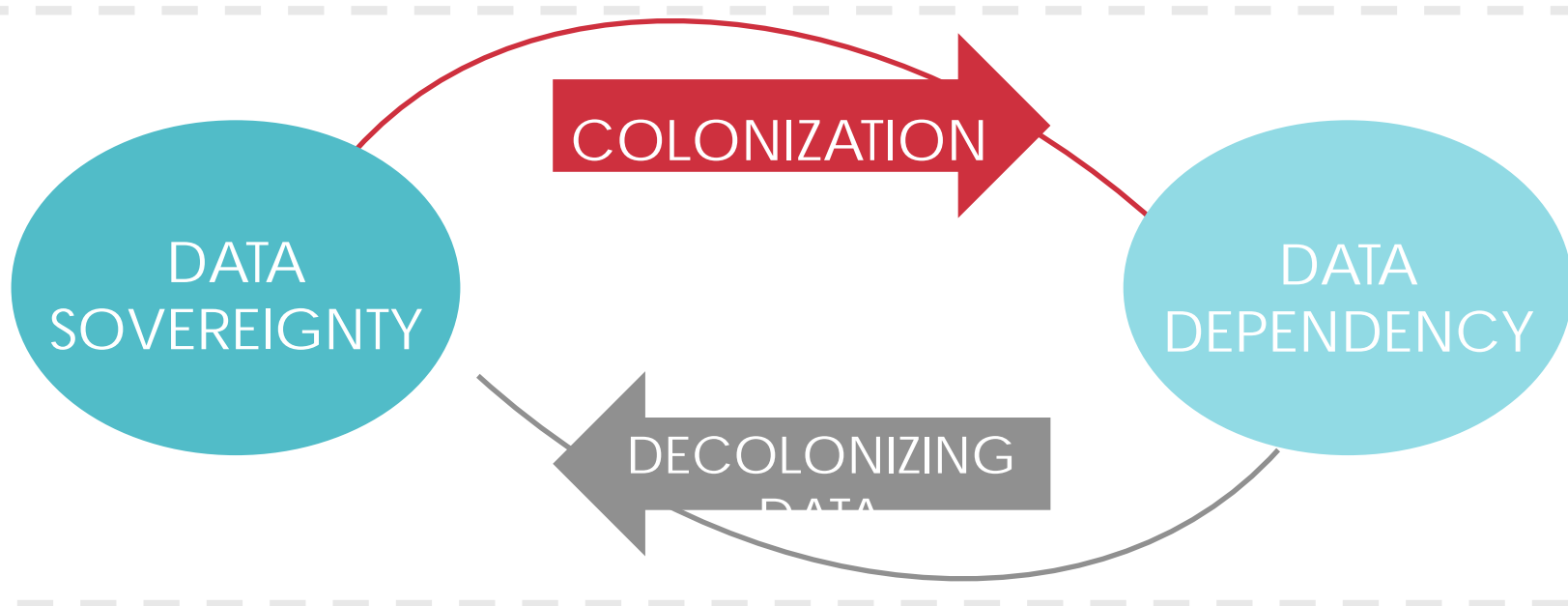
STATE RECOGNIZED

NATIVE HAWAIIANS

NUMEROUS OTHER
UNRECOGNIZED

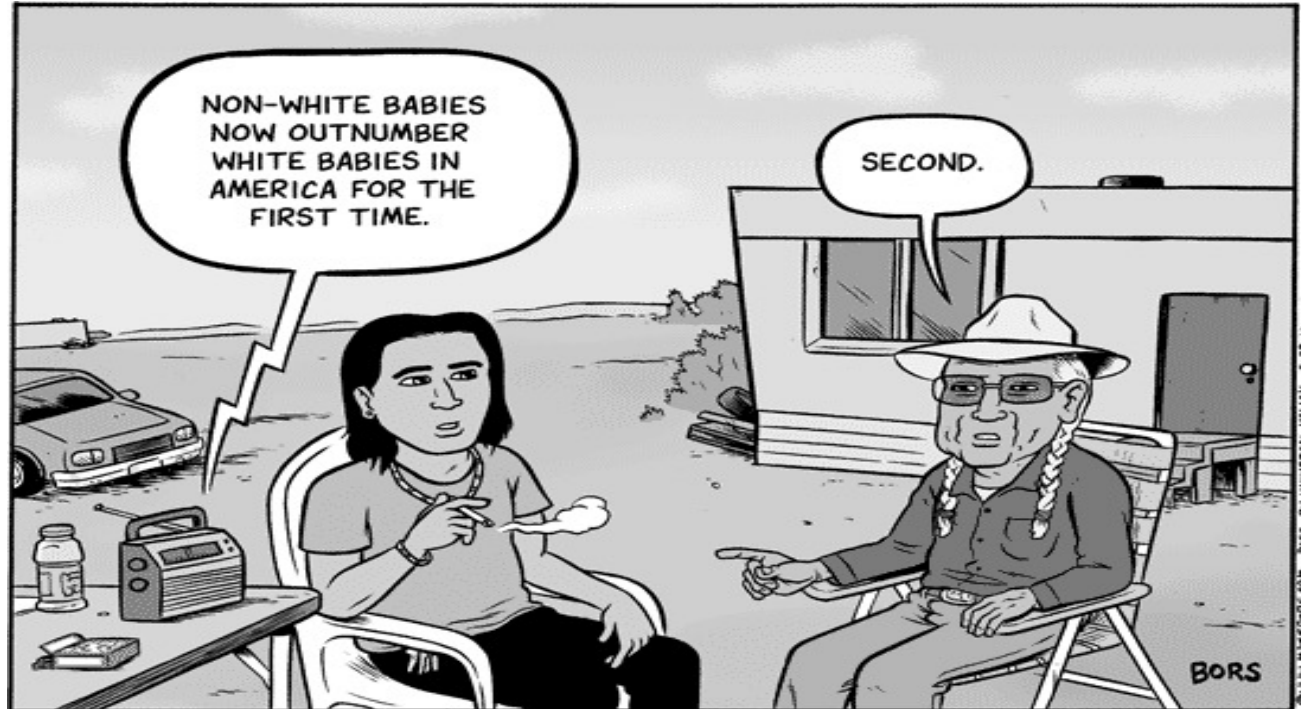


OUR PEOPLES HAVE ALWAYS BEEN DATA EXPERTS



Rodriguez-Lonebear, D., (2016), Doctoral Research.

FROM SOVEREIGNTY TO DEPENDENCY



Bors, M. (2012), Indian Country Today Media Network.

DATA DEPENDENCY IN INDIAN COUNTRY



The paradox of scarcity & abundance

Inconsistency and irrelevance

Mistrust

External control – not by us, for us

Lack of data infrastructure and capability

Rainie, S.C., Schultz, J.L., Palmanteer-Holder, N.L., Briggs, E., and Riggs, P. Data as strategic resource: Self-determination and the data challenge for Unites States Native nations. Under Review.

Rodriguez-Lonebear, D., and Rainie, S.C., (2016), Data Building is Nation Building: US Indigenous Data Sovereignty, presented at the In Pursuit of Indigenous Data Sovereignty: Directions and Challenges panel, Native American and Indigenous Studies Associated meeting, Honolulu, HI, May 19, 2016.

Rodriguez-Lonebear, D (2016), Building a Data Revolution in Indian Country. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty*. Canberra: Australia University Press.

INDIAN COUNTRY'S DATA STAKEHOLDERS

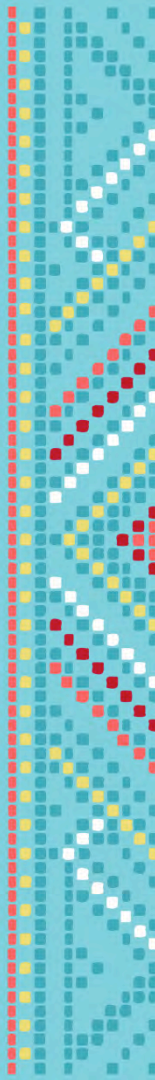
Tribes: federally recognized, state recognized, non-recognized

Urban communities and urban entities

Alaska Native villages, tribes, corporations, NGO's

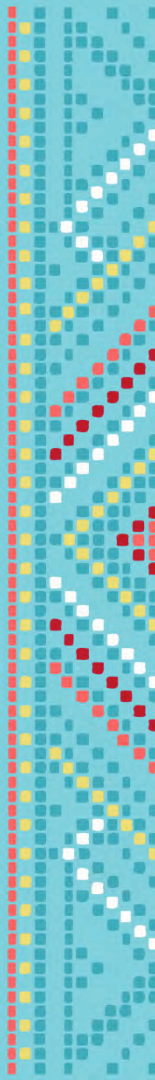
Intertribal relationships and entities

NGO's and advocacy organizations



INDIAN COUNTRY'S DATA MAZE

Data Source	Tribal Identifier
U.S. Census	Self-identification
American Community Survey	Self-identification
Tribal Enrolment Data	Minimum blood quantum, lineal descent, and residency are the most common measures enforced by tribes.
Department of Housing and Urban Development	Census counts
Department of Education Scholarships	Tribal enrolment verification; Certificate Degree of Indian Blood from the Bureau of Indian Affairs
Bureau of Indian Affairs	A tribal service population is defined as all AIANs, citizens and non-citizens, living "on-or-near" a tribe's reservation during the calendar year and who were eligible for BIA funded services.
Indian Health Service	Federally recognised tribal member living within the service area.
State and County Agencies	Census counts
Official Vital Statistics	Lack of data at the tribal level inhibits the ability to calculate vital statistics for enrolled tribal populations.
U.S. Armed Forces	Certificate Degree of Indian Blood from the Bureau of Indian Affairs



GOVERNANCE & SELF-DETERMINATION

Governance:

The system of values, policies and institutions by which a society manages its economic, political and social affairs through interactions within and among the state, civil society and private sector. *It is the way a society organizes itself to make and implement decisions.*

Government:

An organization to do these things.

Self-governance

Self-government

Self-determination:

The extent that a nation is able to make and enforce its own rules, resolve disputes, problem-solve when the rules don't work as well as people might like, and establish its own governing institutions.



SOVEREIGNTY IS SELF RULE

As applied to Indigenous nations, sovereignty boils down to:
Who is going to decide...

- What constitution will the nation operate under?
- What environmental rules will govern?
- Should a natural resource get developed?
- Should a gaming casino be opened?
- What is taught in the reservation high school?
- What taxes are collected and from whom?
- Who can regulate and enforce contracts, provide remedies for negligent conduct, and adjudicate disputes over property?
- What data should be collected, where should it be stored, and how should it be used?
- Questions such as these?

Kalt, Joseph P., Joseph William Singer. "Myths and Realities of Tribal Sovereignty: The Law and Economics of Indian Self-Rule". Joint Occasional Papers on Native Affairs No. 2004-03, The Harvard Project on American Indian Economic Development, Native Nations Institute for Leadership, Management, and Policy, The University of Arizona. Tucson, Arizona. 2004. JOPNA.

DATA SOVEREIGNTY & GOVERNANCE

Data sovereignty

is the right of a nation to collect and manage its own data.

- Geographically bound; cloud

(Rouse, 2013; <http://whatis.techtarget.com/definition/data-sovereignty>)

Data governance

refers to the ownership, collection, control, analysis, and use of data.

(The Data Governance Institute, 2015; http://www.datagovernance.com/adg_data_governance_definition/)

INDIGENIZING DATA: DEPENDENCY → SOVEREIGNTY

INDIGENOUS DATA SOVEREIGNTY

is the right of a nation to govern the collection, ownership, and application of its own data.

1

Derives from tribes' inherent right to govern their peoples, lands, and resources.

2

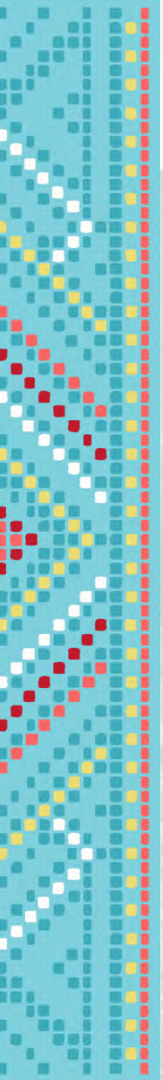
Positioned within an Indigenous rights framework.

3

Collective and individual rights.

Definition from Rodriguez-Lonebear, D., and Rainie, S.C.. (2016). US Indigenous Data Sovereignty founding documents.

Much of the language regarding rights and framing comes from the charter of Te Mana Raraunga, the Maori Data Sovereignty Network in Aotearoa/New Zealand founded in July 2015.



INDIGENOUS DATA SOVEREIGNTY

IS SUPPORTED BY INTERNATIONAL
POLICY

2007

UN DECLARATION ON THE RIGHTS OF INDIGENOUS PEOPLES – ARTICLE 15

“Indigenous peoples have the right to the dignity and diversity of their cultures, traditions, histories and aspirations which shall be appropriately reflected in education and public information”

A call for disaggregated, meaningful data in follow up reports.

2008

WHO'S COMMISSION ON THE SOCIAL DETERMINANTS OF HEALTH A 'MINIMUM HEALTH EQUITY SURVEILLANCE SYSTEM'.

As part of the system, 'good-quality data on the health of Indigenous Peoples should be available, where applicable'.

A call for disaggregated, community-relevant data during an Indigenous-focused social determinants meeting in Adelaide in 2009.

INTERNATIONAL INDIGENOUS DATA SOVEREIGNTY

▶ TE MANA RARAUNGA MAORI DATA SOVEREIGNTY NETWORK

Advocating for the development of capacity and capability across the Māori data ecosystem including:

Data rights and interests

Data governance

Data access and control

Data storage and security

▶ OWNERSHIP, CONTROL, ACCESS, AND POSSESSION

OCAP in Canada, governing research and data

▶ FIRST NATIONS DATA GOVERNANCE INITIATIVE

Nation-based, community-driven data governance

▶ INTERNATIONAL INDIGENOUS DATA SOVEREIGNTY NETWORK

Linking efforts across the globe, including Australia, Canada, New Zealand, Peru, Sweden, and others.



TRIBAL DATA SOVEREIGNTY IN ACTION

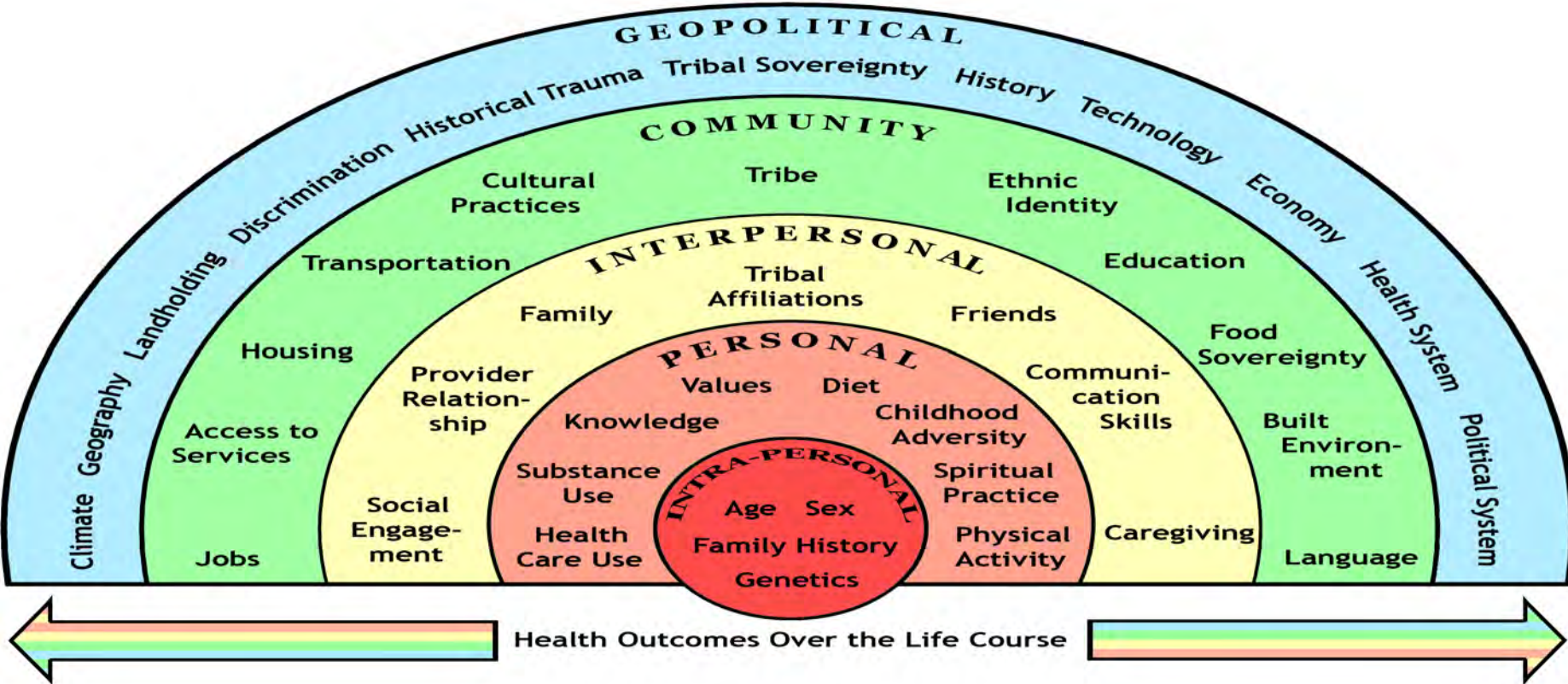
- ▶ **TRIBAL LEADER VIEWS:** Rodriguez- Lonebear, D., doctoral research interviews with 15 tribal leaders in July 2015
- ▶ **TRIBAL CENSUSES:** Ho-Chunk Nation (WI) Laguna Pueblo (NM)
- ▶ **NCAI SURVEY OF TRIBAL LEADERS AND STAFF:** 567 federally recognized tribes Types of data Data governance
- ▶ **TRIBAL EFFORTS CAPACITY AND CAPABILITY**
- ▶ **SECTOR OR POPULATION SPECIFIC EFFORTS**
- ▶ **US CENSUS**
- ▶ **US INDIGENOUS DATA SOVEREIGNTY NETWORK**



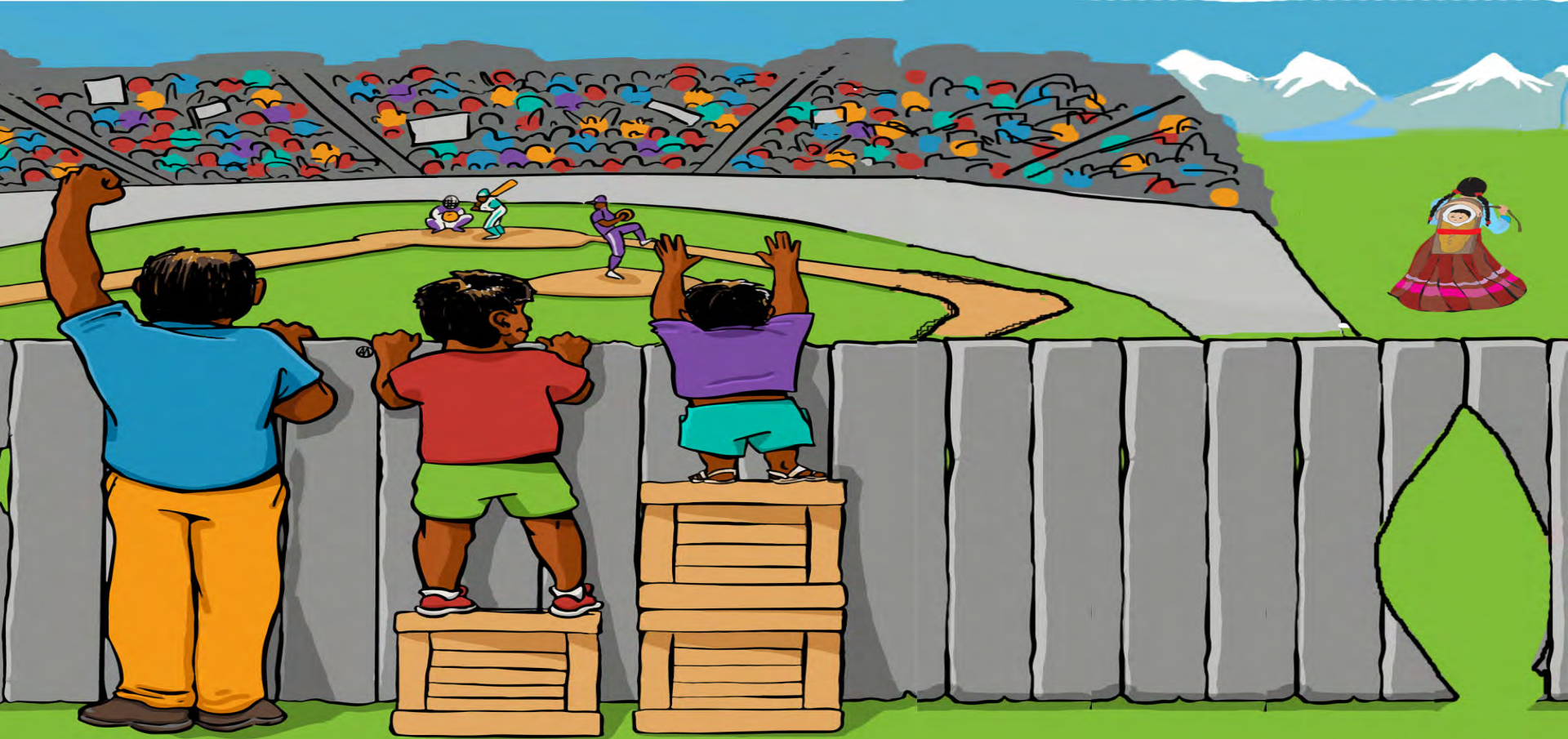


what may be
possible?

SOCIAL DETERMINANTS OF HEALTH



Source: R. Harris 2013. Developed from Dahlgren G, Whitehead M. 1991. Policies and strategies to promote social equity in health. Stockholm: Institute for Future Studies.



EQUITY

SELF-DETERMINATION



US INDIGENOUS DATA SOVEREIGNTY NETWORK



The USIDSN seeks to link its members to share stories about data initiatives, successes, challenges, and resources

HOST ORGANIZATION: [NNI](#)

ADMINISTRATIVE AND RESEARCH SUPPORT

COORDINATION OF ADVISORY BOARD ACTIVITIES

WEB HOSTING

LISTSERV MAINTENANCE

USIDSN ADVISORY COUNCIL

TRIBAL LEADERS & STAFF

*Joe Garcia (Ohkay Owingeh)
Head Councilman, Ohkay Owingeh Pueblo

Travis Jansen (Sicangu Oyate Lakota)
Legislative Director, Rosebud Sioux Tribe

ACADEMIA

Dr. Randall Akee (Native Hawaiian)
Department of Public Policy
UCLA

Dr. Matthew Snipp (Cherokee)
School of Humanities and Sciences
Stanford University

Dr. Nanibaa' Garrison (Navajo)
The Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital

Dr. Stephanie Carroll Rainie** (Ahtna Athabascan)
Native Nations Institute and College of Public Health
University of Arizona

Desi Rodriguez-Lonebear** (Northern Cheyenne)
University of Arizona and University of Waikato

TRIBAL COMMUNITY DATA EXPERTS

*Eileen Briggs (Cheyenne River Sioux)
Executive Director, Cheyenne River Tribal Ventures

Pat Riggs (Tigua)
Consultant, Red Vision Strategies

POLICY ADVOCATES

Dr. David Sanders (Oglala Lakota)
Research Director
American Indian College Fund

Liz Medicine Crow (Haida, Tlingit)
President/CEO
First Alaskans Institute

Dr. Malia Villegas (Sugpiaq/Alutiiq)
Director, Policy Research Center
National Congress of American Indians

Abigail Echohawk (Pawnee)
Co-Director & Tribal Liaison, Partnerships for Native Health
Washington State University

Gaps: IT, Legal, Business Entrepreneurs
Mentoring: Andrew Martinez,
University of Arizona

*Denotes Co-Chairs **Denotes Co-Founders

NETWORK MEMBERSHIP

Data users
Tribal leaders
Researchers
Policymakers and planners
Businesses
Service providers
Community advocates
Information & communication technology providers

APPROX.

60

MEMBERS

Need not be Indigenous so long as interested in furthering the aims
of Indigenous data sovereignty in the US

CHARTING THE COURSE

1

Building support and resources for data governance

2

Mentoring and building capacity and capability

3

Connecting domestically & internationally for strategies, resources, and ideas



CHALLENGES & OPPORTUNITIES

Number and diversity
of tribes and contexts

Moving beyond silos

Meeting the demand

Bridging tribal leaders
and data warriors

Funding

Many voices and
contributors, intertribal data
agenda, regional hubs

Collaborating, teaching,
technical assistance,
mentoring

Forums, op eds, policy
briefs

Foundations, feds, tribes



"Sovereignty as tribal nations was given to us by the Creator. It is sacred. Data to exercise our sovereignty is also sacred."

-Tribal Leader at 2015 NCAI Mid-Year Conference

THANK YOU TO OUR FUNDERS



Strengthening Indigenous Governance



