

Tribal Data Sovereignty

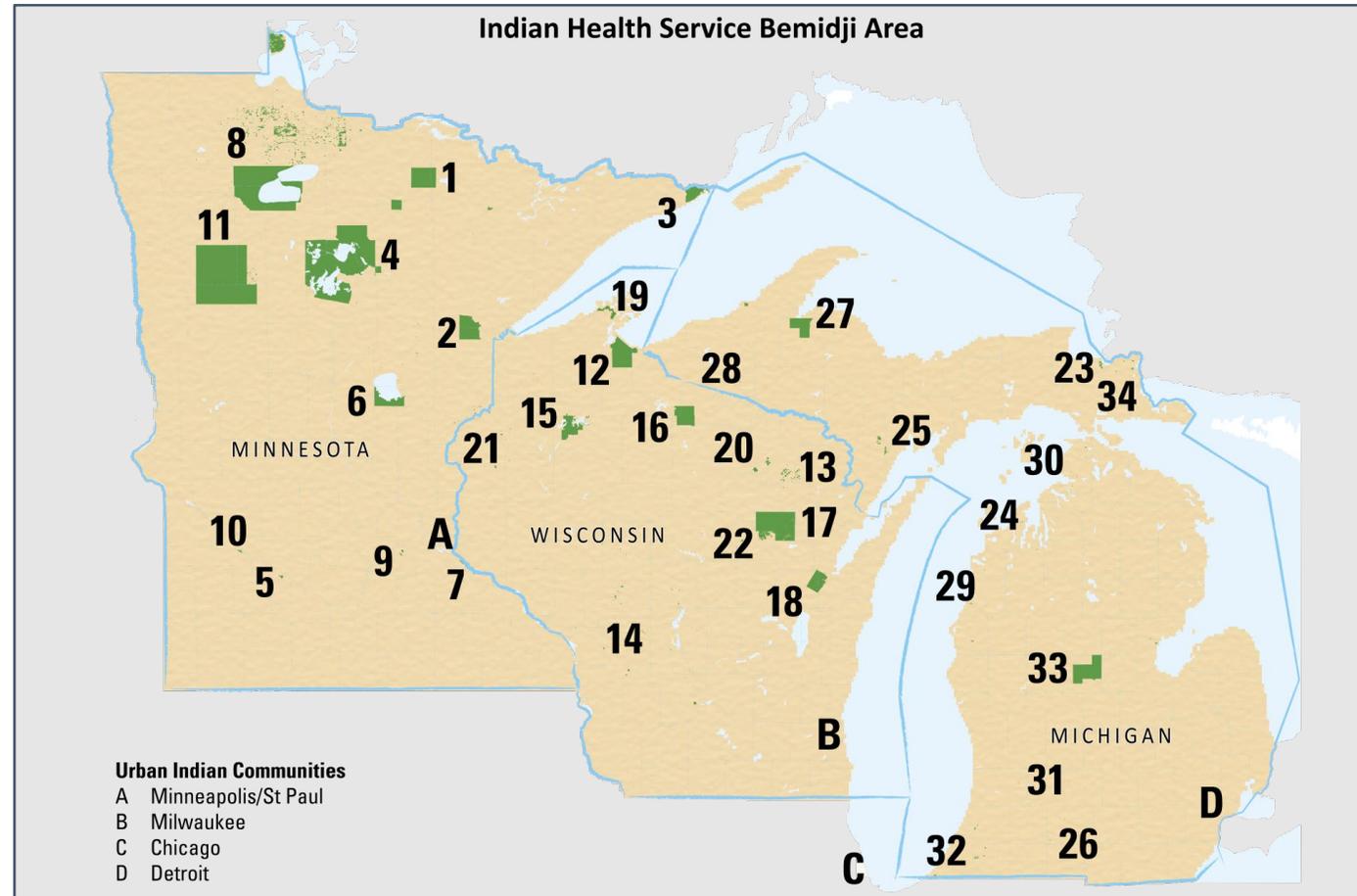
August 6, 2025



Great Lakes Inter-Tribal Epidemiology Center (GLITEC)
Great Lakes Inter-Tribal Council, Inc. (GLITC)

Great Lakes Inter-Tribal Epidemiology Center Service (GLITEC)

“To support Tribal communities in their efforts to improve health by assisting with data needs through partnership development, community-based research, education and technical assistance.”



Learn more: <https://www.glitec.org/programs/epidemiology-and-education/>

Great Lakes Inter-Tribal Epidemiology Center Central and Satellite Offices

Minnesota

A Indian Health Board of Minneapolis
2020 Minnehaha Ave.
Minneapolis, MN 55404

B University of Minnesota
1300 S. Second St., Suite 300
Minneapolis, MN 55454

Wisconsin

C Great Lakes Inter-Tribal Council (GLITC)
2932 Hwy 47 N., PO Box 9
Lac du Flambeau, WI 54538

D Green Bay Office
1566 W. Mason St.
Green Bay, WI 54303

E University of Wisconsin-Madison
610 Walnut St.
Madison, WI 53726

Michigan

F Grand Rapids Office
250 Monroe Ave NW, Suite 400
Grand Rapids, MI 49503

G University of Michigan
1415 Washington Heights
Ann Arbor, MI 48109



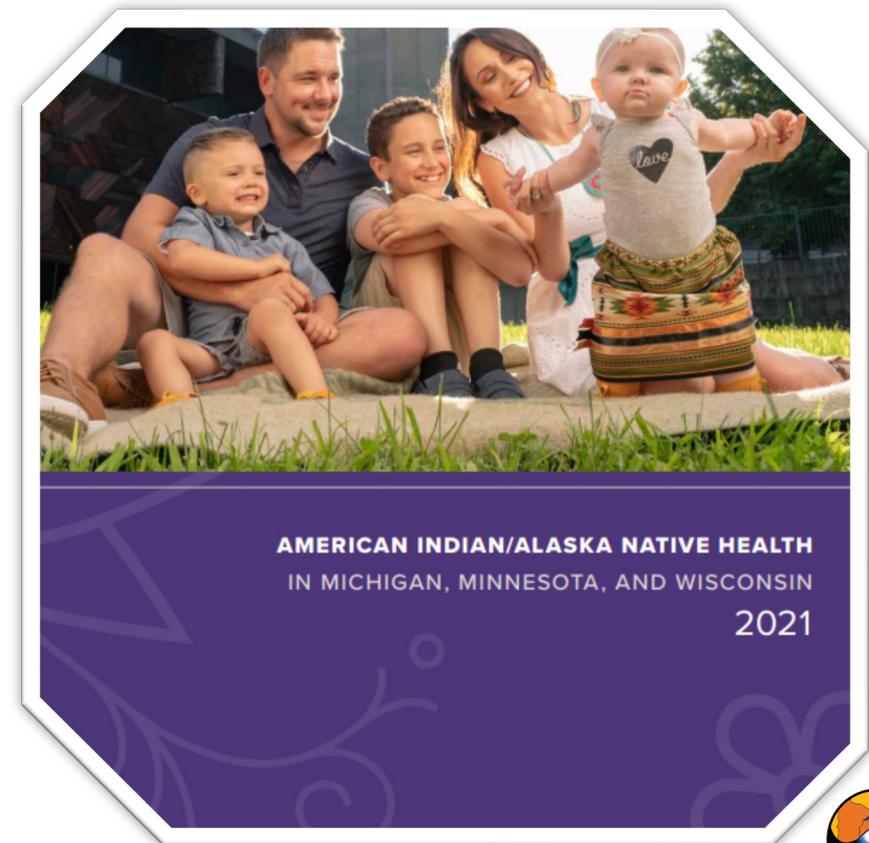
Providing Assistance to Tribes and Urban Indian Organizations

- Community health surveys
 - Survey development
 - Data entry
 - Data analysis
 - Report writing
- Community readiness assessments
- Health promotion/disease prevention materials & presentations
- *All individuals should consult with their health care providers to understand their options regarding vaccinations*



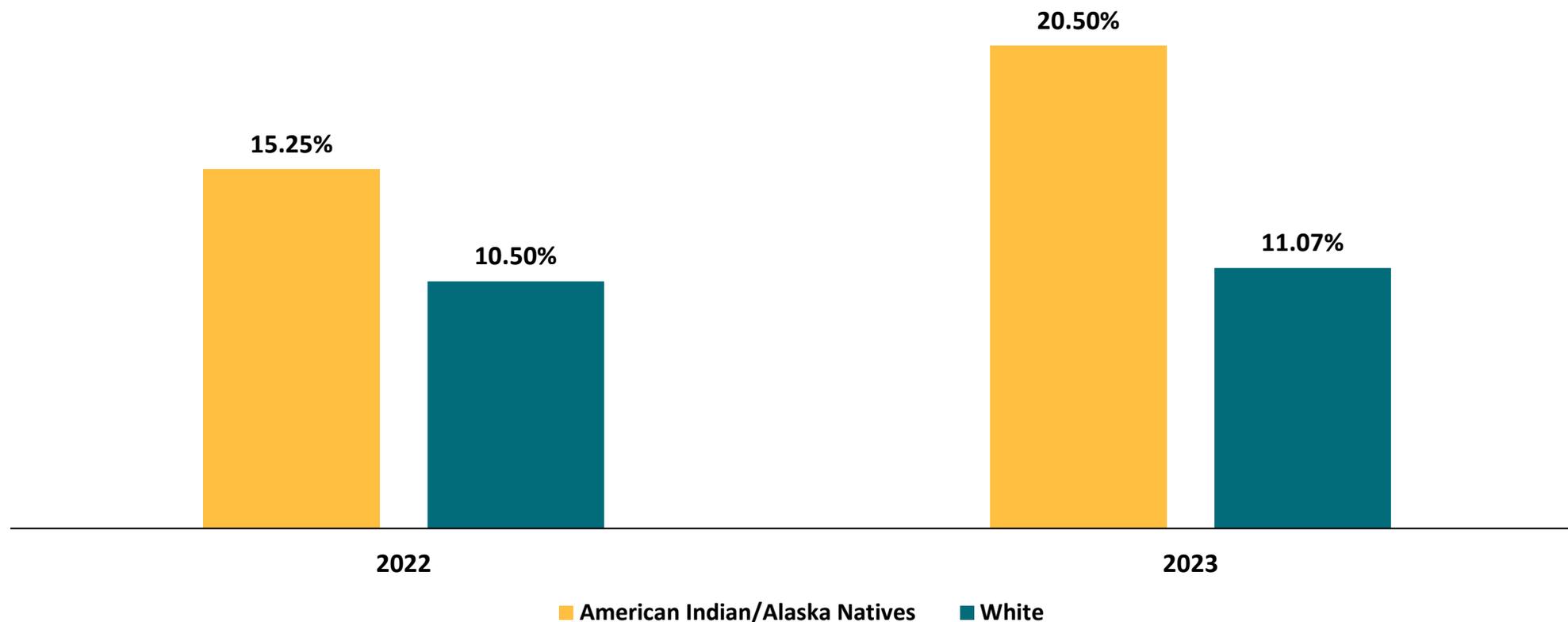
Providing Assistance to Tribes and Urban Indian Organizations

- Area and Tribal-specific health status reports
- Disease/health condition special reports
- Public Health Accreditation assistance
- Policy, Systems, and Environmental (PSE) strategies and activities support
- Public health law & policy development

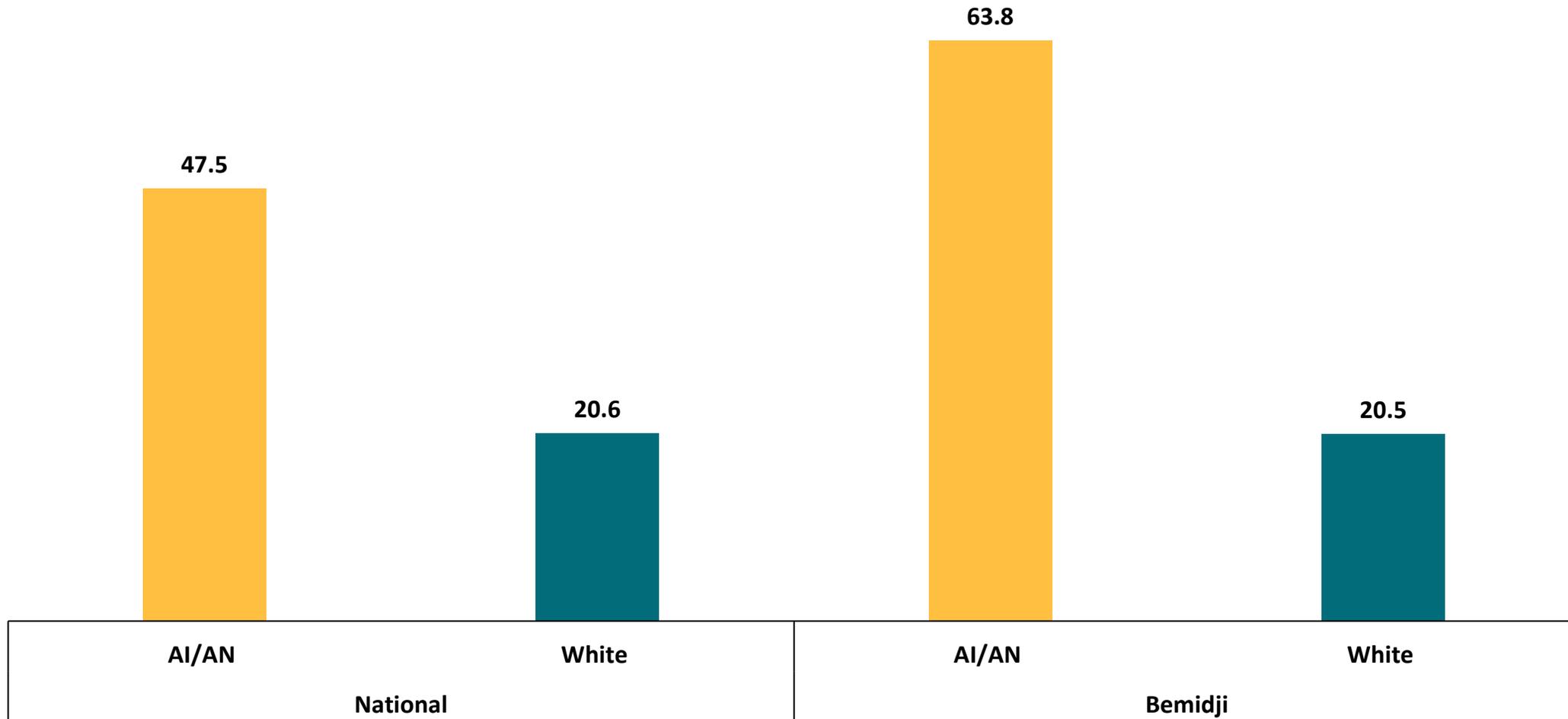


Crude prevalence of Diabetes for Bemidji Area (Wisconsin, Minnesota and Michigan) by race, 2022-2023 ²

Have you ever been told by a doctor that you have diabetes?



Age-adjusted Diabetes mellitus Mortality rate for AI/AN Bemidji Area (Wisconsin, Minnesota and Michigan) compared to national, 2018-2022³



Tribal Data Sovereignty

- **Tribal sovereignty** is the inherent right of Native people to self-government, self-determination and self-education; governance of activities within Native lands
- **Tribal sovereignty** maintains the authority of Native nations to regulate research within their jurisdiction; most often, their jurisdiction is reservation lands, resources, and residents

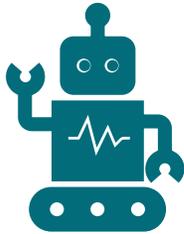
History

Initially Indian health care was under the US Department of War in concern for non-Native soldiers who had contact with Natives

In 1849, oversight was transferred to the US Department of the Interior that had little experience in health care management

In 1955, Indian Health Service was established within the US Public Health Service

Continued



Indian Health Care Improvement Act (IHCA) – Amended 2010



Reaffirms the federal government's responsibility to support Tribal public health.



Allows for Tribal involvement in data collection and analysis related to health services.

Indian Self-Determination and Education Assistance Act (ISDEEA)



Indian Self-Determination and Education Assistance Act (ISDEEA) – 1975



Federal Laws & Policies That Support Tribal Data Sovereignty



Allows Tribes to take over the administration of federal programs and services.



Supports Tribal control of data generated under those programs.

How Tribes Can Uphold Data Sovereignty: Legal & Policy Tools



Develop and adopt Tribal data governance laws or resolutions.



Create Data Use Agreements (DUAs) that define rights and responsibilities.



Establish Tribal Institutional Review Boards (IRBs) to oversee research.



Exercise legal authority over data collected on Tribal lands or citizens.



Assert sovereignty in contracts, grants, and research proposals.

How Tribes Can Uphold Data Sovereignty: Capacity & Practice

1

Build internal data systems and infrastructure (e.g., data platforms, staff).

2

Train Tribal staff in data literacy, privacy, and security.

3

Partner with organizations like GLITEC to access tools and technical support.

4

Promote awareness among leadership and community members.

5

Engage in national and regional Indigenous data sovereignty movements.

Challenges in Data

- Lack of Recognized Public Health Authority
- Policy Gaps and Inconsistent Procedures
- Inconsistent, Confusing, and Lengthy Request Processes
- Poor Quality, Incomplete, or Limited Data from States and Federal Sources
- Sources of Data Unsure What Data They Have

Contact us

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Thank You