



Trails and Traps: The Path to Research in Indian Country

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Presented by
Jacque Gray, Choctaw & Cherokee Descendant, Ph.D., LPC
University of North Dakota
Grand Forks, ND



Objectives

- ♦ Describe Indian Country
- ♦ Define who is Indian
- ♦ Describe basis for AI/AN historical mistrust
- ♦ Describe basis for AI/AN research mistrust
- ♦ Describe the process for rebuilding trust with AI/AN communities



Definitions



- **American Indian Tribe**

- Any Indian tribe, band, nation, pueblo or other organized group or community, including any Alaska Native entity, that is recognized as eligible for the special programs and services provided by the United States to Indian tribes because of their status as Indians
- A list is published annually in the *Federal Register* indicating the federally recognized tribal entities
- 564 federally recognized tribes
- Other state-recognized tribes



American Indian

Conceptually: Has an ancestor who lived in North America before the arrival of the first Europeans and is regarded as an Indian by his or her tribe or community (e.g., through enrollment).

Note: The Bureau of the Census relies on self-reporting; people who identify themselves as American Indian/Native Alaskan are counted as such, regardless of whether they are enrolled as a member in a federally recognized Indian tribe.

For most federal agencies, a person who is an enrolled member of any federally recognized Indian tribe or a descendant of an enrolled tribal member



Who is a “real” Indian?

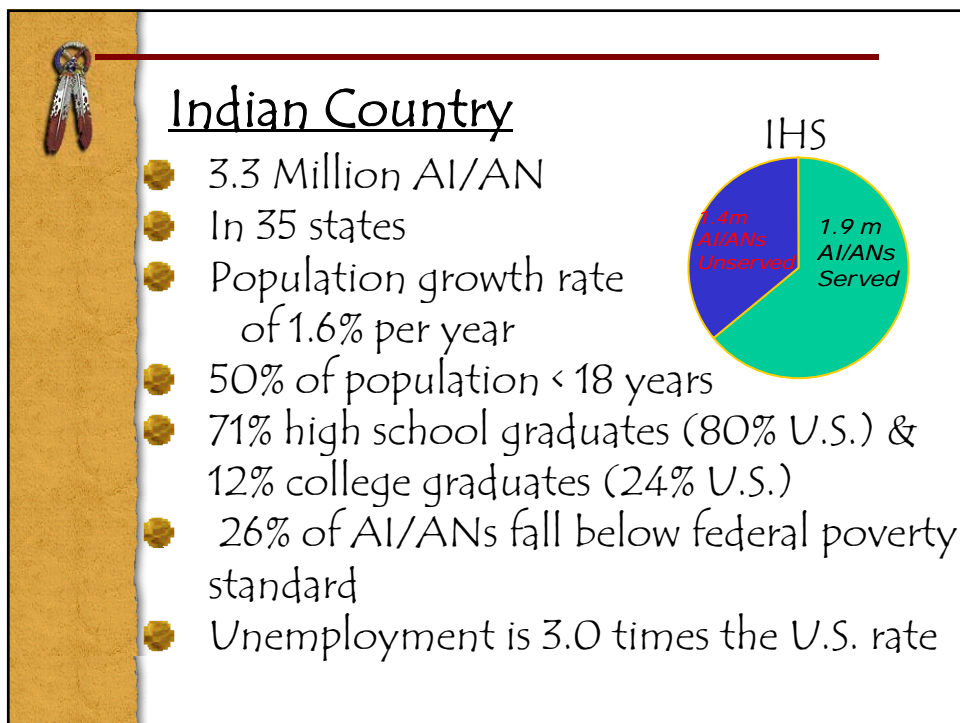
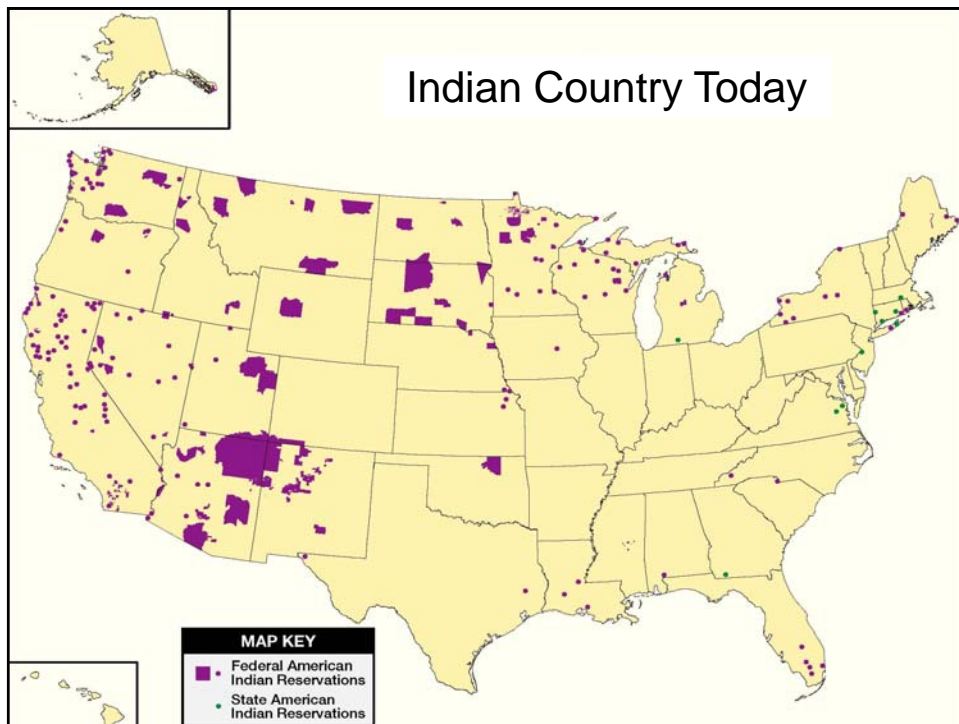
- Tribes establish criteria for membership
 - One-quarter tribal blood is the Bureau of Indian Affairs (BIA) standard
 - A descendant of a tribal member
 - A person recognized by the tribal members as a member
- Alaska Native: The term collectively refers to Eskimos, Aleuts, and American Indians who are indigenous to Alaska.
- Blood quantum is a federal designation based upon the “certified degree of Indian blood” or what is entered on the CDIB card.

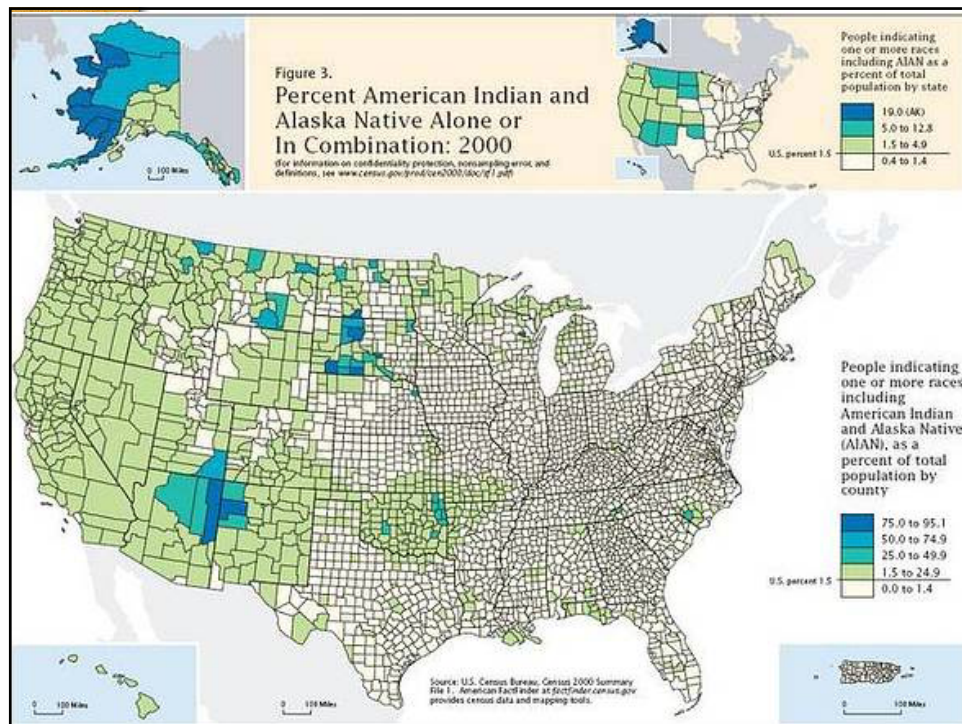


Common questions about Indian Country?

- ◇ American Indian or Native American?
- ◇ My grandmother was a Cherokee Princess!
- ◇ What is Indian Country
- ◇ Where is Indian Country?
- ◇ What state is it in?
- ◇ How do I find it?

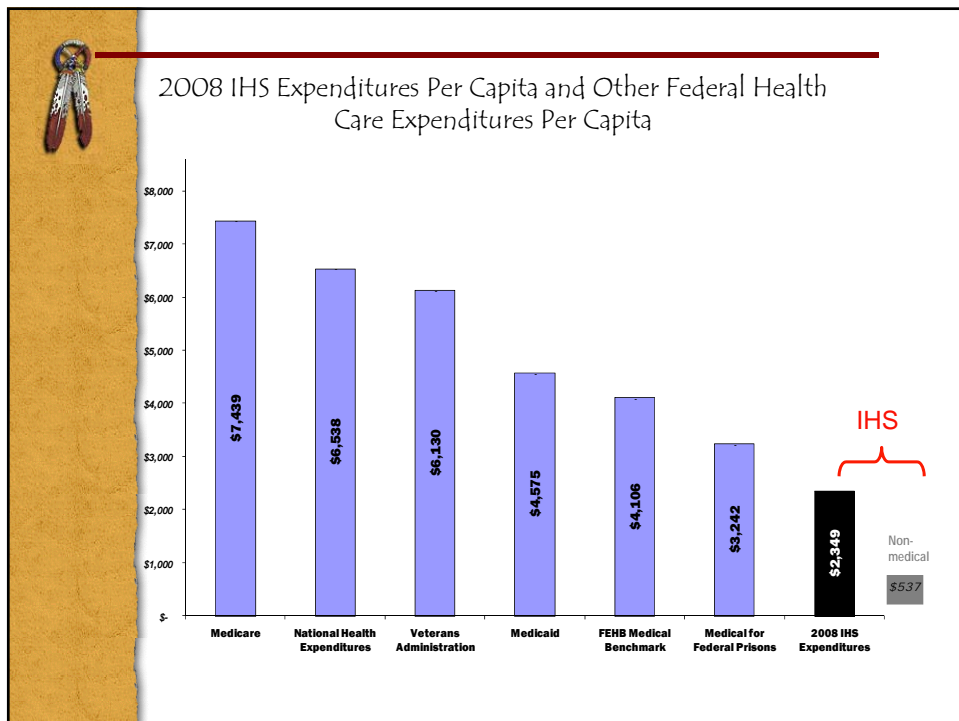
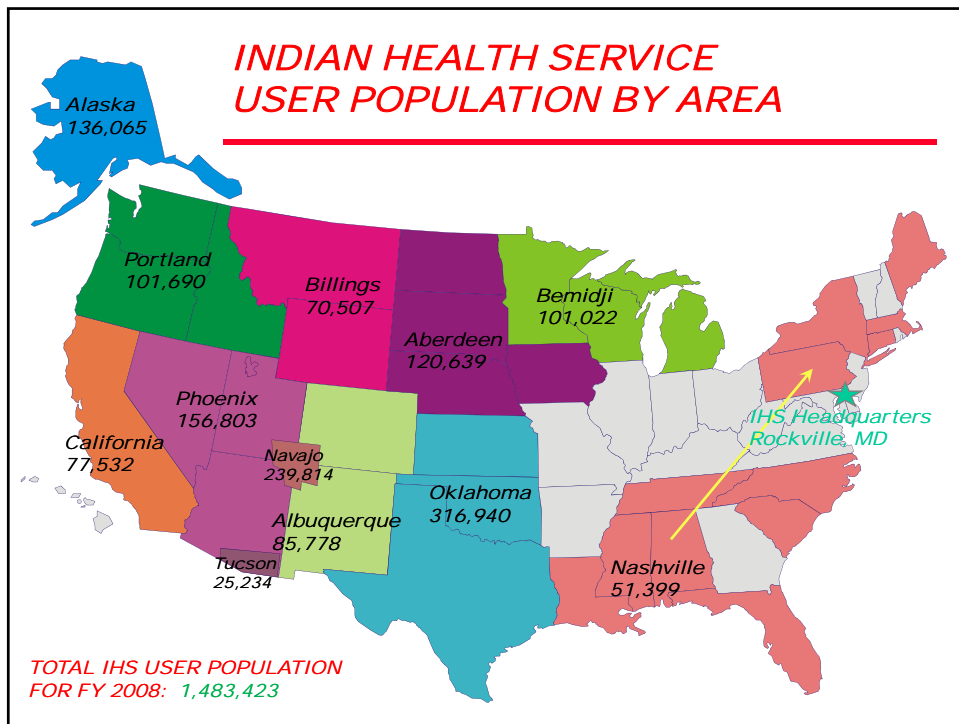






BASIS FOR FEDERAL HEALTH BENEFITS TO INDIANS

- *Treaties exchanged aboriginal lands for federal trust responsibilities and benefits.*
- *Snyder Act authorized funds "for the relief of distress and conservation of health ... [and] for the employment of ... physicians ... for Indian tribes throughout the United States." (1921)*
- *Transfer Act placed Indian health programs in the PHS. (1955)*
- *Indian Sanitation Facilities Act (P.L. 86-121) (1959)*
- *Indian Self-Determination and Education Assistance Act (P.L. 93-638) (1975)*
- *Indian Health Care Improvement Act (P.L. 94-437) (1976)*
- *Political relationship ... domestic sovereign ... not race based*



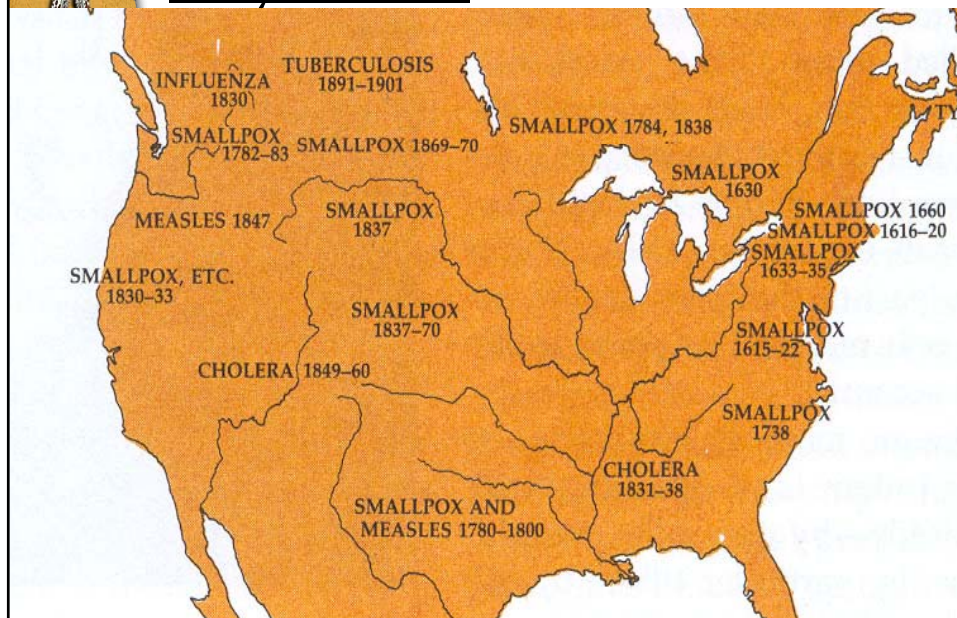


Historic Distrust

- Infectious Diseases from Europeans
 - Measles
 - Small Pox
 - Tuberculosis



Early Diseases





First They Took Our Land ...Then They Took Our Children



Tom Torlino (Navajo) as he appeared upon arrival to the Carlisle Indian School, October 21, 1882.



Three years later



Boarding Schools

- Existed between 1870 and present
- Mission: to educate Indian children and assimilate them into the European language & culture



PHOTOGRAPH BY U.S. ARMY SIGNAL CORPS.
COURTESY OF THE ARIZONA HISTORICAL FOUNDATION



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Boarding Schools



- Forced separation of children from communities
- Physical, sexual, and emotional abuse by caretakers
- Exposure to infectious diseases, resulting in illness and death



Boarding Schools



- Extreme diet changes
- Children who did not go home took on the characteristics of the caretakers.



Historic Distrust

- Termination of government-to-government relationship with many tribes. (1950 & 1960s)
- Relocation to urban areas (1950s & 1960s)
- Sterilization without knowledge or permission (through 1970s)



Research Distrust

- U.S. Army Research
- Indian Health Service
- Helicopter Research
- Samples used in unapproved ways
- Results reported to public before tribal community was informed causing harm to the community
- Community-identifying information revealed in publications causing harm to community.



Great Eskimo Snow Words Hoax

- ❖ Laura Martin (1986) – *Eskimo Words for Snow: A Case Study in the Genesis and Decay of an Anthropological Example*
- ❖ counts range from 3, 9, 20, 40, 50, 100, and even 400
- ❖ no complete inventory seems possible
 - ❖ lack or inaccuracy of citations
 - ❖ application of the example to diverse theories
 - ❖ wholesale reanalysis of the example and its history
- ❖ proof for the Sapir-Whorf hypothesis (worldview problem)

Great Eskimo Snow Words Hoax

- ❖ Franz Boas (1911) – brief citation of 4 lexicons for snow in Eskimo (Inuit)
- ❖ Benjamin Lee Whorf (1940) – *Science and Linguistics* – vague usage of example – suggest 5 words but not the same set used by Boas
- ❖ Edward Hall (1959) – *The Silent Language* – uses snow example 3 times and considered it already part of general knowledge
- ❖ Why?
 - ❖ Exoticism
 - ❖ prepared to believe almost anything about the unfamiliar reflection of admiration for adaptive quality of societies
 - ❖ grants the lecturer as one in possession of specialized knowledge



What were the good, the bad, & the ugly in AI/AN research—and how to avoid the bad & ugly?

- *Research with AI/AN people/communities/tribes is not listed in the catalog of problematic research*
- *A common feeling among many tribal people: research has harmed AI/AN people*
- *What is behind that feeling?*



Older & current good history/research

Tuberculosis was a killer, major cause of AI/AN death

◊ last half of 19th & first half of 20th centuries

- **Clinical trial of INH** [isoniazid] in the Navajo Rez in early 1950s proved INH was an effective treatment, saved many AI/AN lives

Diabetes is a killer

- **Diabetes Prevention Program** ["DPP"] proved that intense counseling for lifestyle change could prevent type 2 diabetes (reduce calories, especially fats; moderate exercise 30 minutes a day, 5 times a week; reduce weight by 7%)

Community-Based Participatory Research

- **Kahnawake Schools Diabetes Prevention Project**
- **People Awakening Project** with Alaska Native groups, about resiliency and strengths in dealing with alcoholism



Current bad research – 1

Nuu-chah-nulth First Nations [western Vancouver Island, BC, Canada], severe unusual arthritis

- Early 1980s, UBC rheumatology & genetic researchers studied their problem, took blood specimens
- Geneticist kept specimens with him (UBC → U Utah → Oxford U), report migration genetic research results

● *Community found out 5 years ago*

- Major adverse publicity across Canada

● *Community wanted the specimens back to finish the arthritis research*

- Geneticist died early 2004, specimens were returned



Older bad history

Research with radioactive iodine (I131)

- Early 1950s, USAF
- "Do ANs survive the cold by having higher metabolism?"

● *Gave I131 to Alaska Native people*

- Same amount as then used for thyroid scan
- Almost all ANs did not speak English
- Three AN women in research were breast-feeding children

● *Long-term effects of thyroid scan not then known*

● *(ANs: not higher metabolism; know how to dress and eat)*

● *Involved radiation—a feared modern hazard*



Implications of older bad history

- *I131 and a few other older problematic studies had complex issues*
- Children who were breast-feeding may not have been followed up
- *The problem was basic protocol design*



Examples Community Harms of Research

- Results of a study on alcoholism in an Alaskan community were revealed at a news conference in Pennsylvania.
- Epidemiological study on syphilis in a Southwestern Indian tribe.
- Research on the genetics of diabetes among the Havasupai Tribe.
- Research on severe atypical arthritis among the Nuu-chah-nulth First Nations people in Canada.



Recent bad history-1

- *Barrow, Alaska study on alcoholism*
- *1970s, researchers from northeastern U.S.*
- *Announced findings in press conference*
 - *held at their northeastern university*
- *Internal stigmatization by people from Barrow & nearby communities*
- *Bonds on Wall Street adversely affected*
- *Impact of research results?*
- *No positive change in/by Barrow*



Recent bad history - 2

- *Congenital syphilis epidemic, 1980s*
 - *Rez not named in publication*
 - *gave precise 1980 US Census pop.*
- *Rez children taunted ("Your mama's ...")*
- *Gas stations refused to let Rez people use restrooms*



Recent good & bad history – 3

Hantavirus, summer 1993

50% of infected people died

- First recognized on the Navajo Rez
- CDC found cause < 10 days—a virus from deer mice

Good: *helped NNDOH develop prevention programs*

NNDOH asked CDC not to give Navajo place names in scientific articles

Bad: *First two articles CDC named the Navajo Chapters*

- Where the people lived who were infected first
- Where the deer mice and other animals were trapped

Navajo approved no research for > 13 months



Implications of recent bad history

- *Major community harm was disruption*
- *Major individual harm was “internal” self-stigmatization*
- *All subsequent research in many of those communities was adversely affected*
- *The problem was publication-dissemination*



Current bad research – 2

Havasupai

Early 1990, tribe approved a diabetes study including genetic analysis by ASU researchers

No NLM-listed journal articles on genetic analysis of T2DM among Havasupai, one article on nutrition

HLA, inbreeding, & migration genetic research also done using the specimens

Sources:

Rubin P. Indian givers. *Phoenix New Times* 2004; May 27

Dalton R. When two tribes go to war. *Nature* 2004; 430:500-2

Editorial. Tribal culture versus genetics. *Nature* 2004; 430:489

Pubmed: Havasupai OR Markow T[Author] OR Martin JF[Author] OR Benyshek D[Author] OR Zuerlein K[Author]

Paul Rubin [personal communication]



Implications of current bad history

The old NIH policy and researcher practice of sharing genetic specimens [usually anonymized for identity of the individual] is no longer appropriate

“Tribal approval of research” extends to future uses

- of genetic & biological specimens and
- of data

Tribes vary about their degree of favorable or unfavorable attitude toward research in general

- Extent to which they see research as an enemy, or a friend, of the tribe’s future physical and cultural survival

The values and relationships of the tribes and researchers are changing



Current ugly research

Havasupai [there is more]

- concurrently with T2DM study was *schizophrenia* study
- apparently researchers told neither tribe nor individuals
- apparently research team obtained information from clinic charts surreptitiously, after hours, with no approval
- apparently the ASU IRB did not comply with own procedures & requirements

Was this “amateur night”?

Now prime example of ugly research in Indian Country

- major adverse publicity in Arizona, major law suit by Havasupai

More self-discipline by researcher and institution could have prevented this!



Current good research and *practices*

“Kennewick Man” is an example of bad practice

- skeleton found 08/96, 1st scientist said was “caucasoid”

Kwaday Dan Ts’inchi - “Long Ago Man Found”

- Champagne-Aishihik First Nations [FN], d. 1415–1445

- Glacier in Tatshenshini-Alsek Park, British Columbia [BC]

- Body found 08/99, plan developed, studied to 12/2000

- Returned to the Champagne-Aishihik

- Cremated, potlatch, ashes scattered where found 07/2001

- Head found 08/2003, studied, laid to rest 10/2004

- Final ceremonies were planned and carried out 2005

FN community + BC government set up a joint group to oversee the research within cultural limits

“People Awakening” Project



Rebuilding the Trust

- Personal Relationships
- Mutual Respect
- Permission from Tribal leadership
- Benefits to Tribe & Researcher
- Use of local research support
- Interpretation/results in collaboration with tribal entity.
- Community-Based Participatory Research
- Tribes as FULL partners in research



How can we protect our Tribal communities from harm?

- Build respectful relationships.
- Build the skills of the community and the researcher.
- Promote interdependence.
- Engender commitment and reciprocity.



Building Relationships

- Belonging
 - Honors infancy and childhood
 - Outcome:
 - Builds foundation for community consultation.
-



Building Skills

- Mastery
- Acknowledges adolescence
- Outcome:
- Individual and community empowerment — Confidence to set limits for research



Promoting Interdependence

- Interdependence (working together)
- Honors adulthood
- Outcome:
- Mutually beneficial partnerships between, and among, Tribal communities and researchers.



Engendering Commitment and Reciprocity

- Generosity (giving back)
- Honors elders
- Outcome:
- True community-based participatory research that elevates the health status of Native people.

Native values not explicit in regulations



- *Protection of communities*
 - Except obliquely
- *Respect for elders & knowledge of community*
 - Ethnographic interviews published or archived by outsiders
- *Respect Native communities, strengths, and survival*
 - Much research focuses on how bad things are not on how/why people survived and do well
- *Promote resiliency, help activate the community*
- *Respect and promote tribal sovereignty*



"Protect communities," "respect elders," and "respect communities"

- *Typical research on alcoholism or domestic violence: document how bad things are*
 - Attacks the value of community
- *Rather, research how/why people stopped domestic violence, or became and stayed sober – and thus promote resiliency, help activate the community*
- *"People Awakening Project"*



With Thanks
to all of my
Elders & Teachers
and the Wisdom
They have passed on to
All of us



Jacque Gray, Ph.D.
Center for Rural Health
School of Medicine & Health Sciences
University of North Dakota

jgray@medicine.nodak.edu
(701)777-0582

