

Prevention science and methodology: Considerations for working with Indigenous populations

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Provost Fellow, Indigenous Health Policy
Johns Hopkins University



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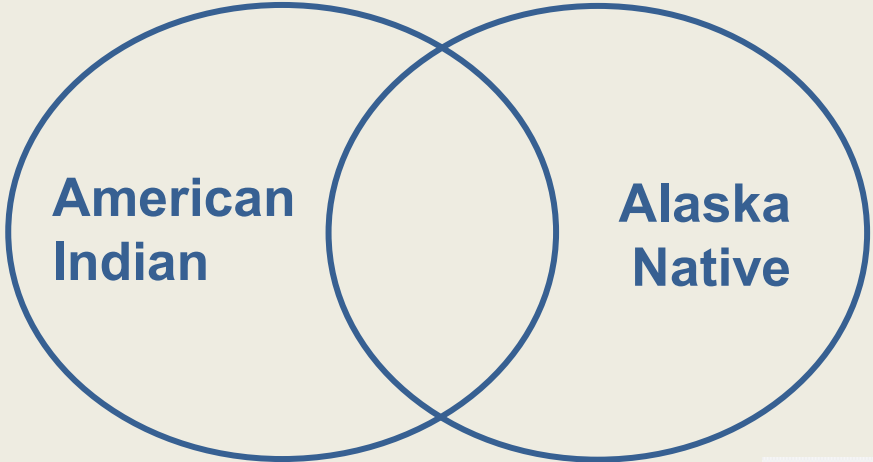
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UNIVERSITY

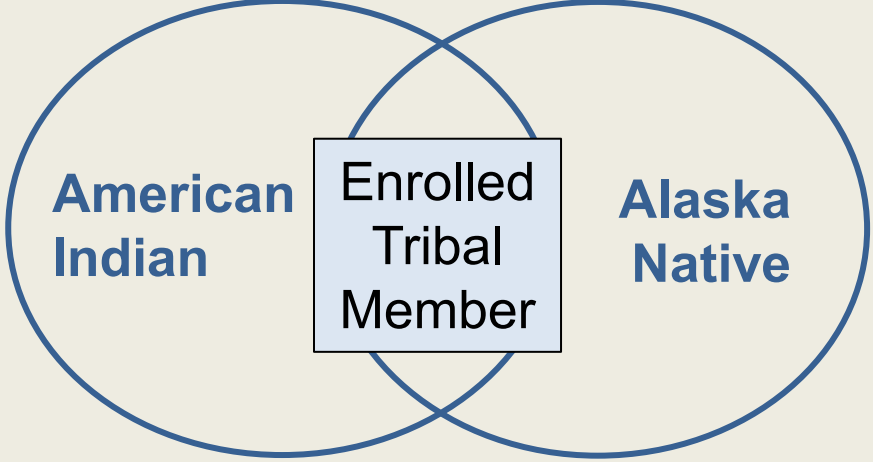
Overview

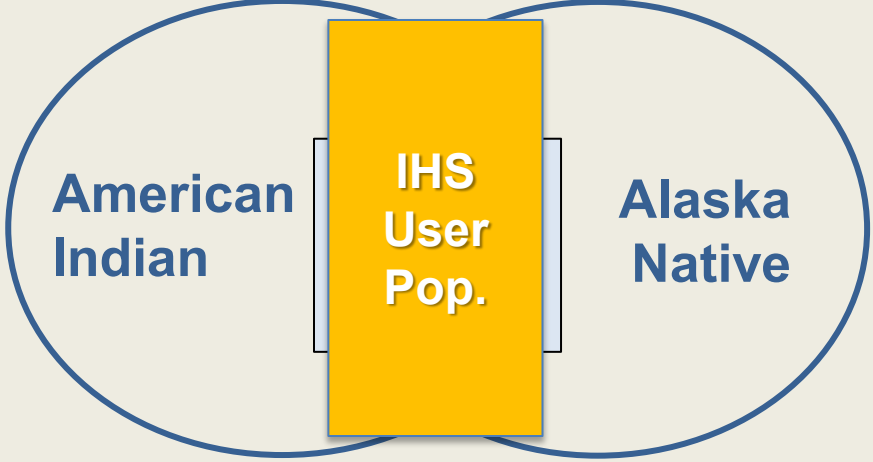


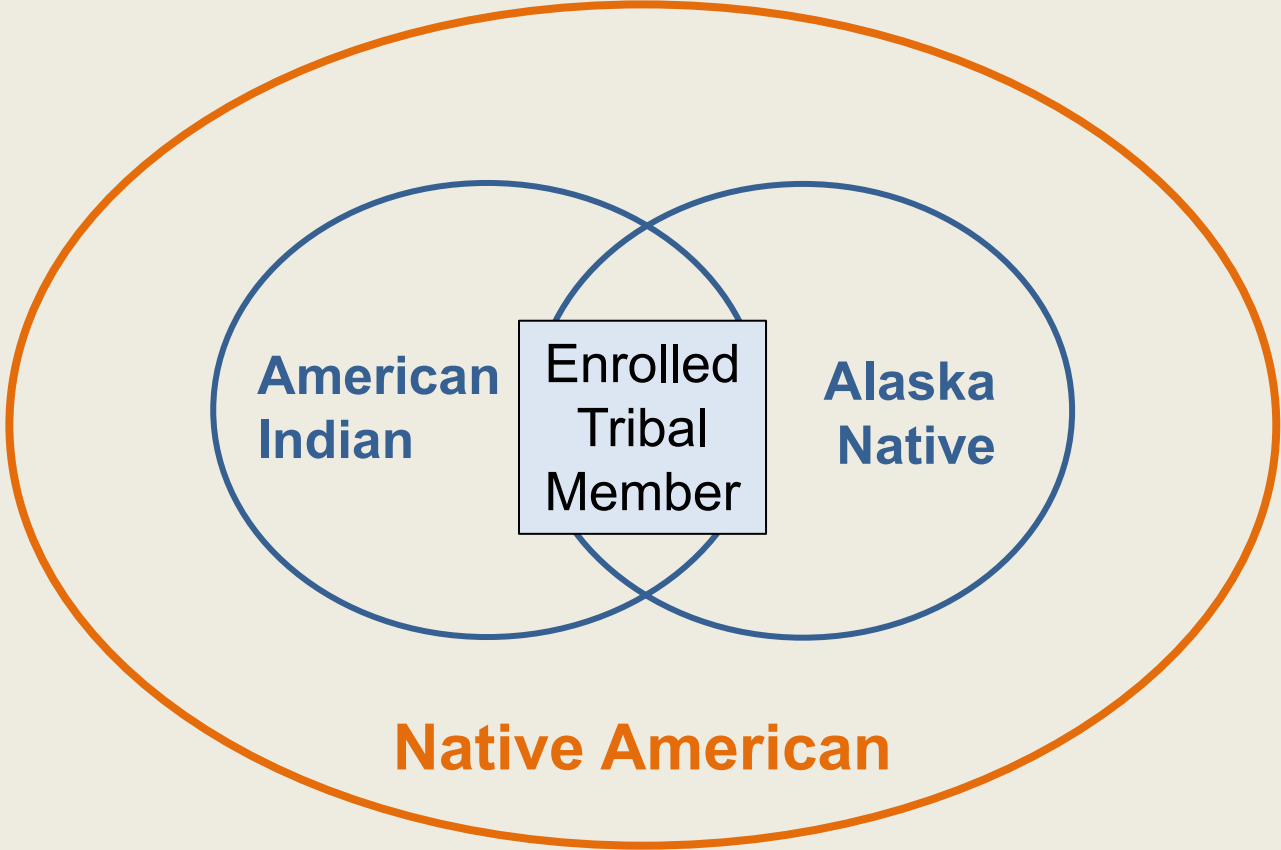
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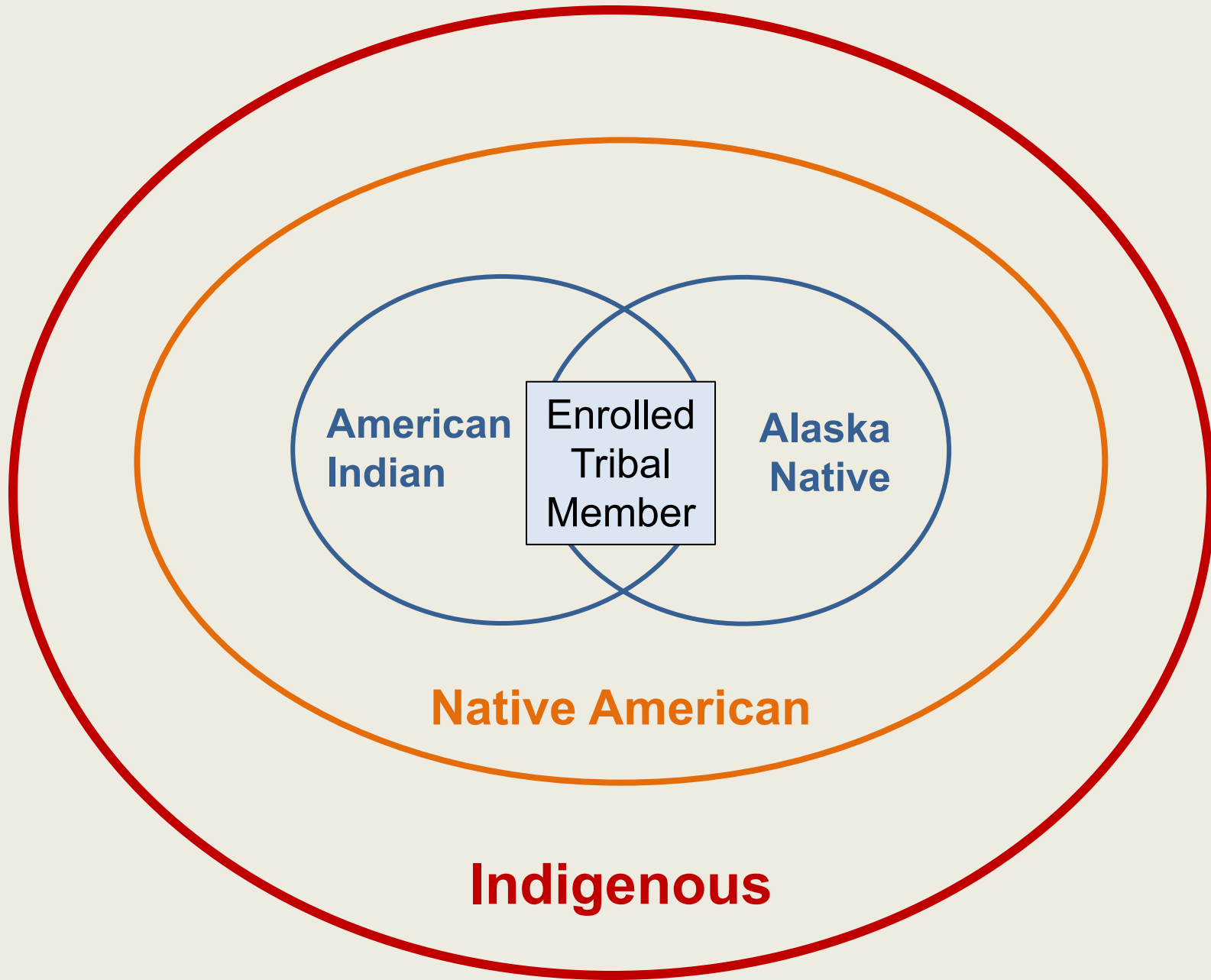
- Terminology—AI/AN, NA, etc.
- Policy History & Marginalization
- Impact of Historical & Unresolved Trauma
- Contemporary Challenges
- Potential Solutions & Roles for Prevention Science and Indigenous methodologies











**American
Indian**

**Enrolled
Tribal
Member**

**Alaska
Native**

Native American

Indigenous

1776



NORTH AMERICA

A MAP FOR THE ILLUSTRATION OF COLONIAL
THE GEOGRAPHICAL DISTRIBUTION OF LIFE

PREPARED BY THE BUREAU OF GEOGRAPHICAL NAMES
OF THE UNITED STATES DEPARTMENT OF THE INTERIOR



WASHINGTON

U.S. GEO. SURV. 3111105502

Types of Trauma



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Emotional & Psychological Trauma

- One-time events
 - Accident/injury, death of someone close, loss of a relationship or job, humiliating experience, etc.
- Ongoing, relentless stress (toxic stress)
 - Individual—Poverty, domestic violence, social isolation, pandemic, chronic illness/pain, etc.
 - Societal—Racism, war, oppression, politics, hate, etc.
- Childhood trauma
 - ACEs and beyond...

Types of Trauma



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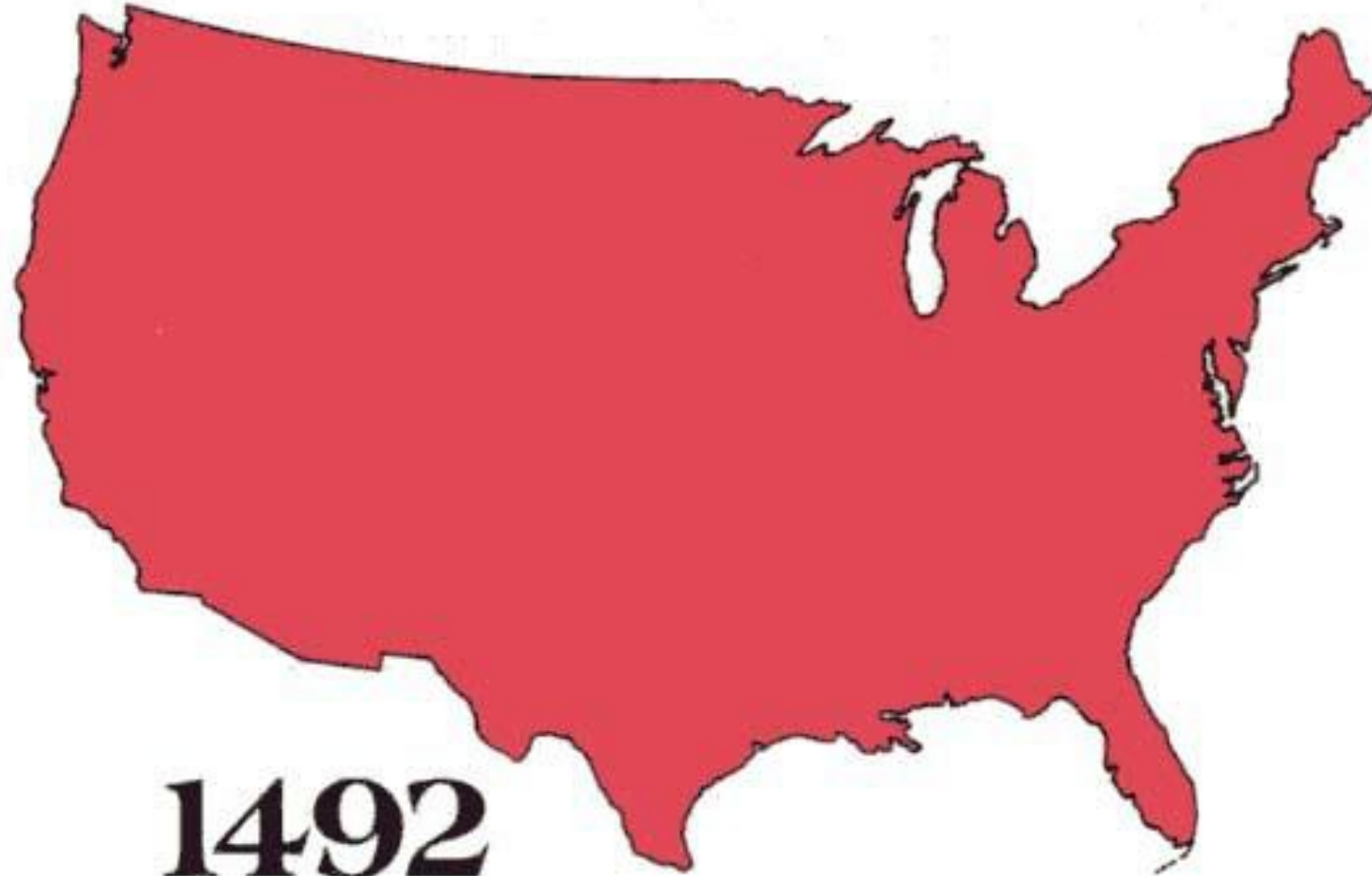
Emotional & Psychological Trauma

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- Childhood trauma
 - ACEs and beyond...
- **Indigenous Communities**
 - Historical Trauma, colonization, loss of land/language/culture, discrimination, marginalization/exclusion, racism, etc.

Holistic Perspective on Trauma and Resilience

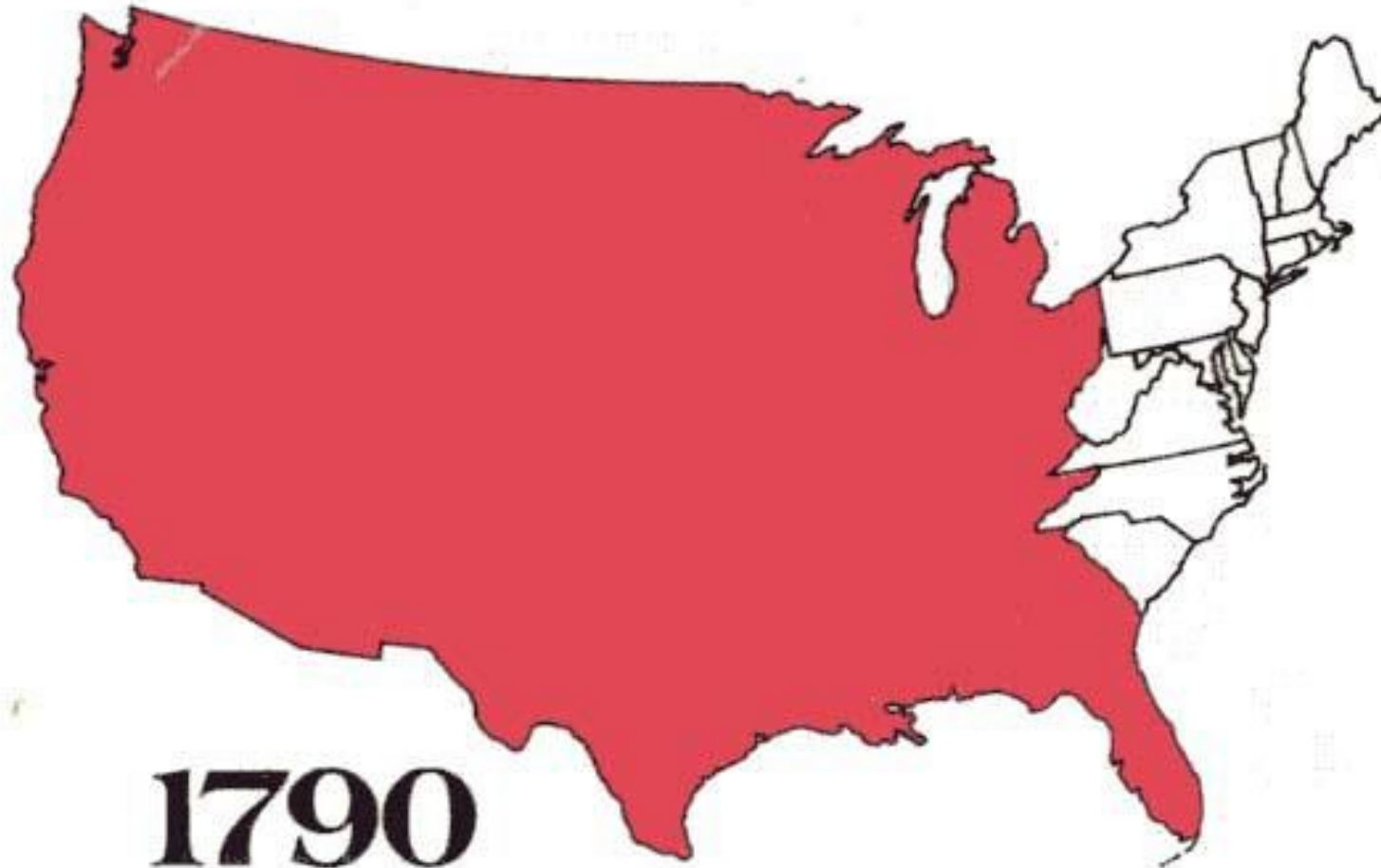


Historical Context



1492

Historical Context



1790



PETERS '01

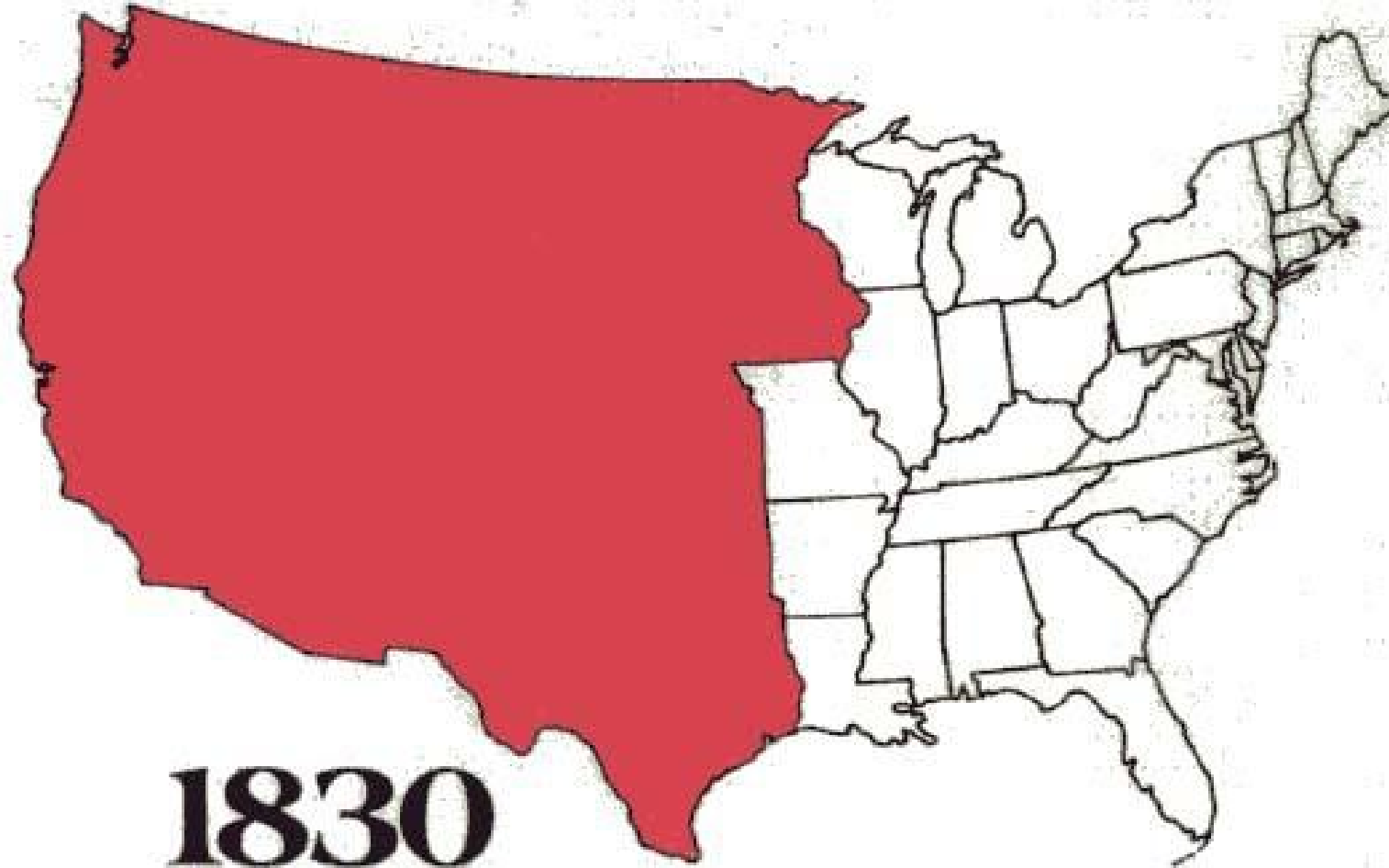
P.S.

You will do well to try to inoculate the
Indians by means of Blanketts, as well as to try
every other method that can serve to extirpate
this execrable Race. I should be very glad your
Scheme for hunting them Down by Dogs could take
Effect

Effect, but I find it is at too great a Distance
to think of that at present

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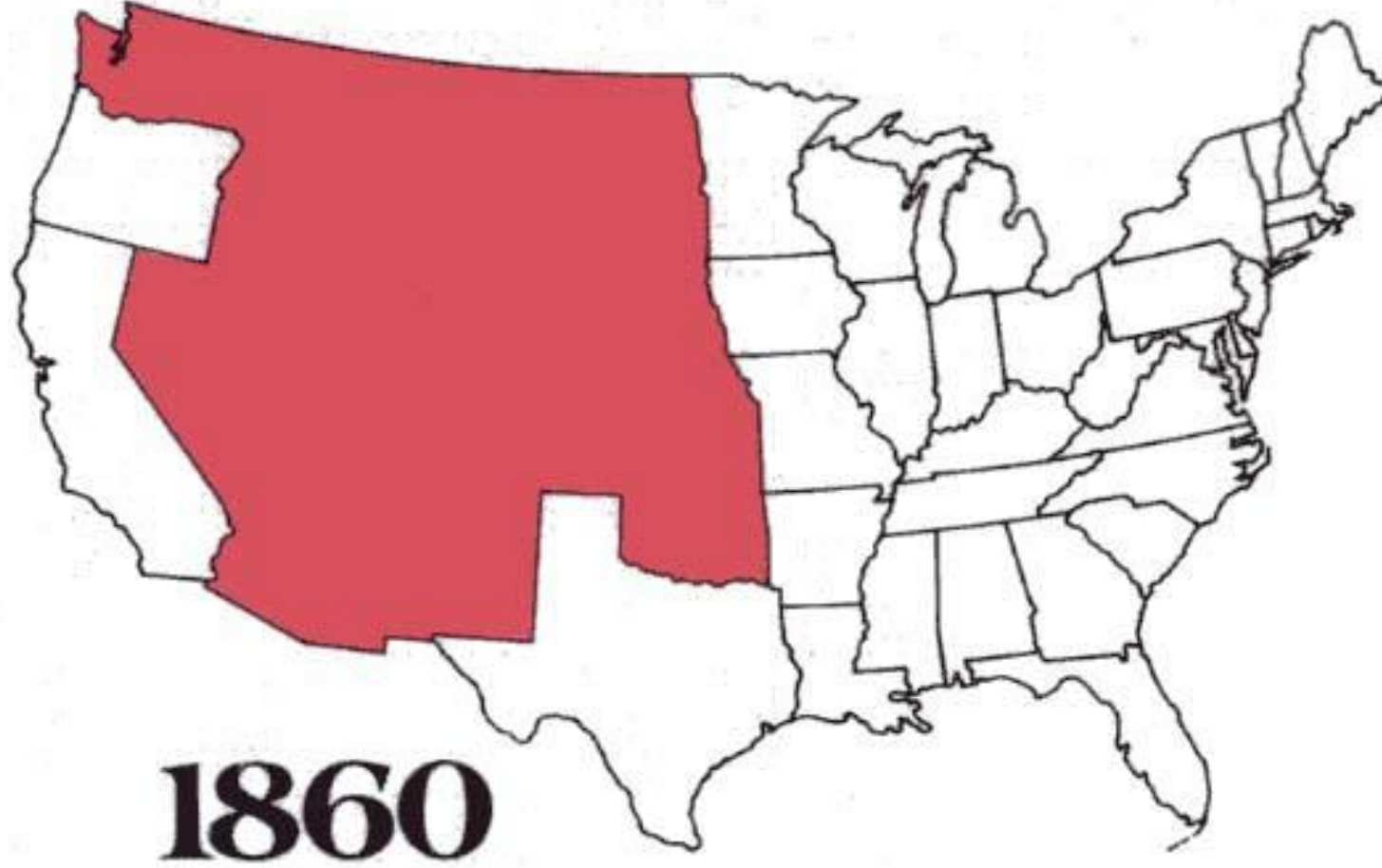
Historical Context



1830



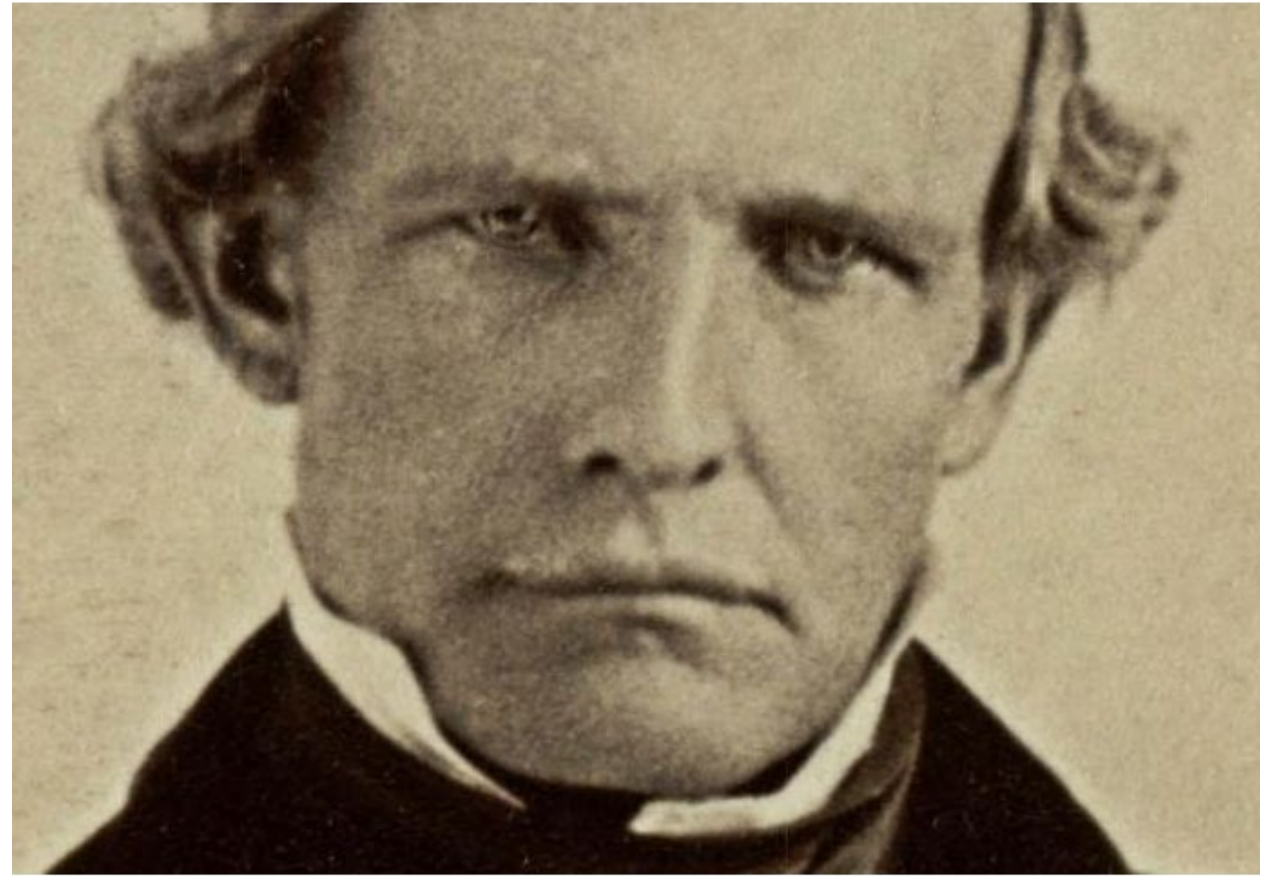
Historical Context



Peter Hardeman Burnett, CA's first governor, acknowledged that white settlers were taking territory and bringing disease, but he felt that it was an inevitable outcome.

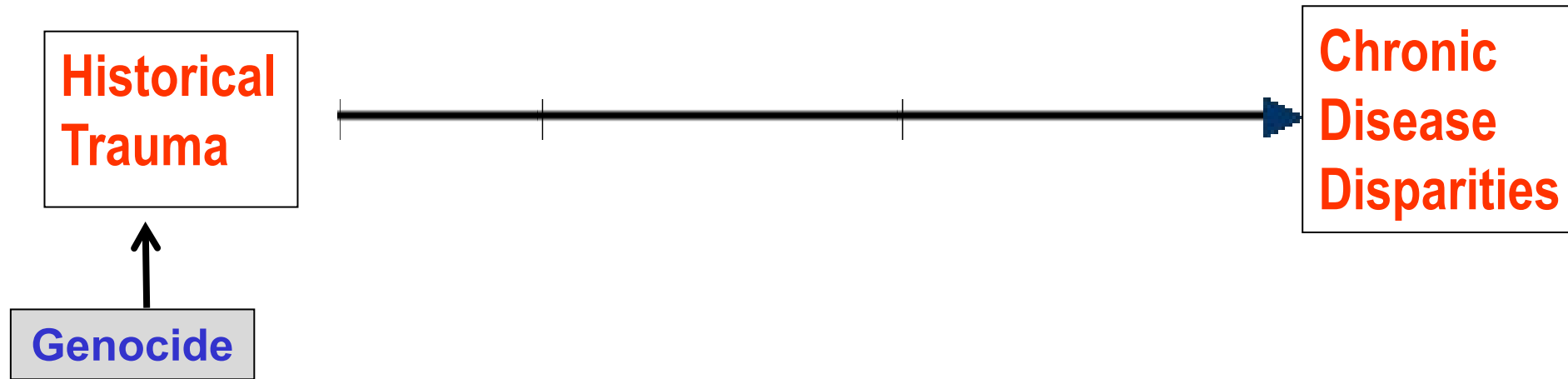
"That a war of extermination will continue to be waged between the races until the Indian race becomes extinct must be expected. While we cannot anticipate this result but with painful regret, the inevitable destiny of the race is beyond the power or wisdom of man to avert."

State of the state address, 1851

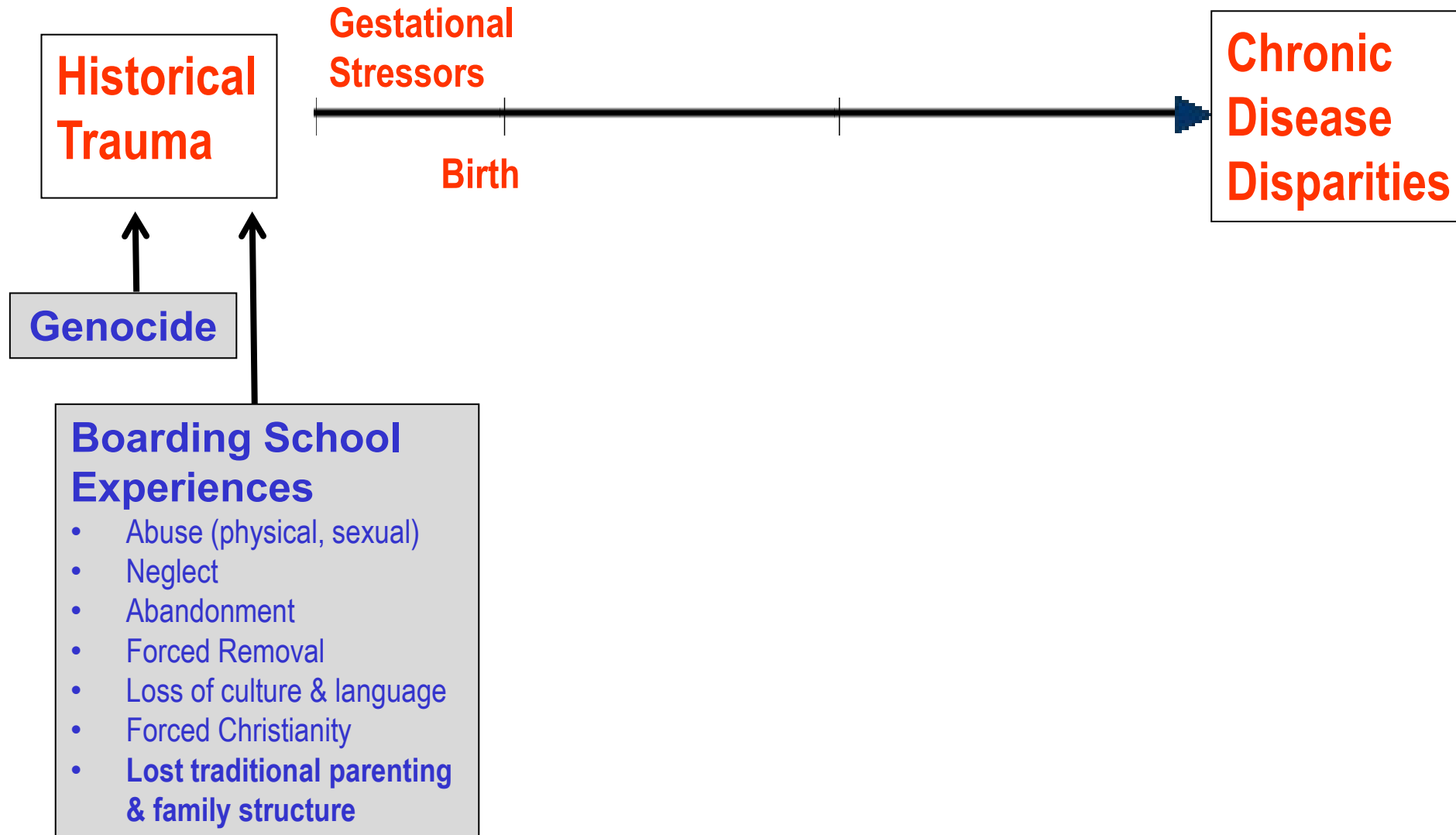


~100,000 AIs died during the first two years of the Gold Rush alone;
By 1873, only 30,000 Indigenous people remained of around 150,000.

Inter-Generational Basis for Chronic Disease Disparities Among American Indians and Alaska Natives



Inter-Generational Basis for Chronic Disease Disparities Among American Indians and Alaska Natives





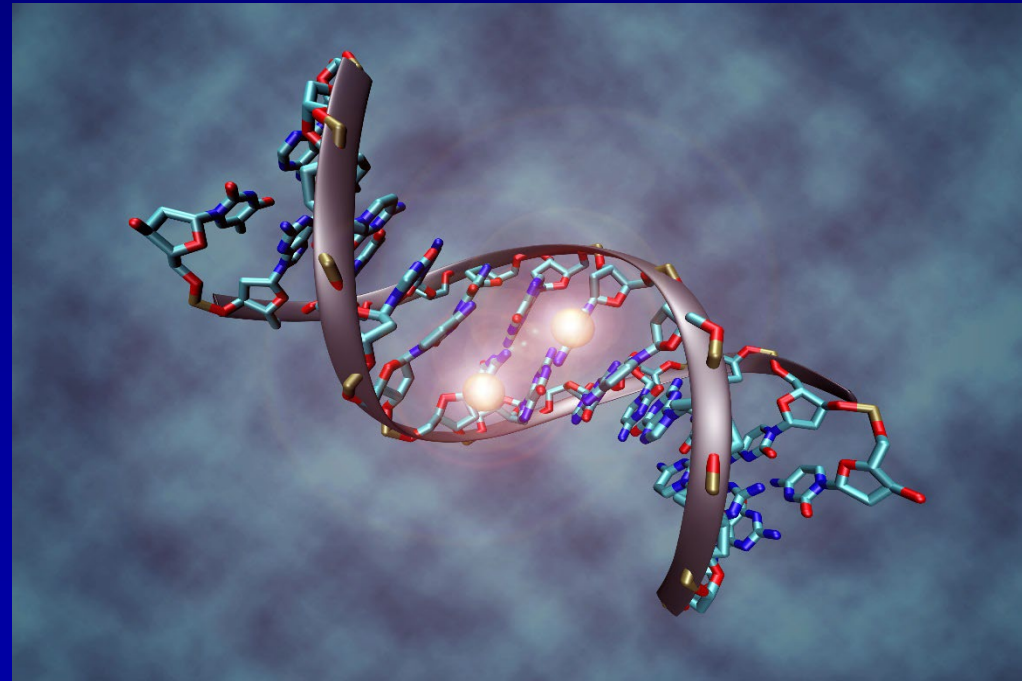
Historical trauma is the collective emotional wounding across generations that results from massive cataclysmic events – Historically Traumatic Events (HTE)*



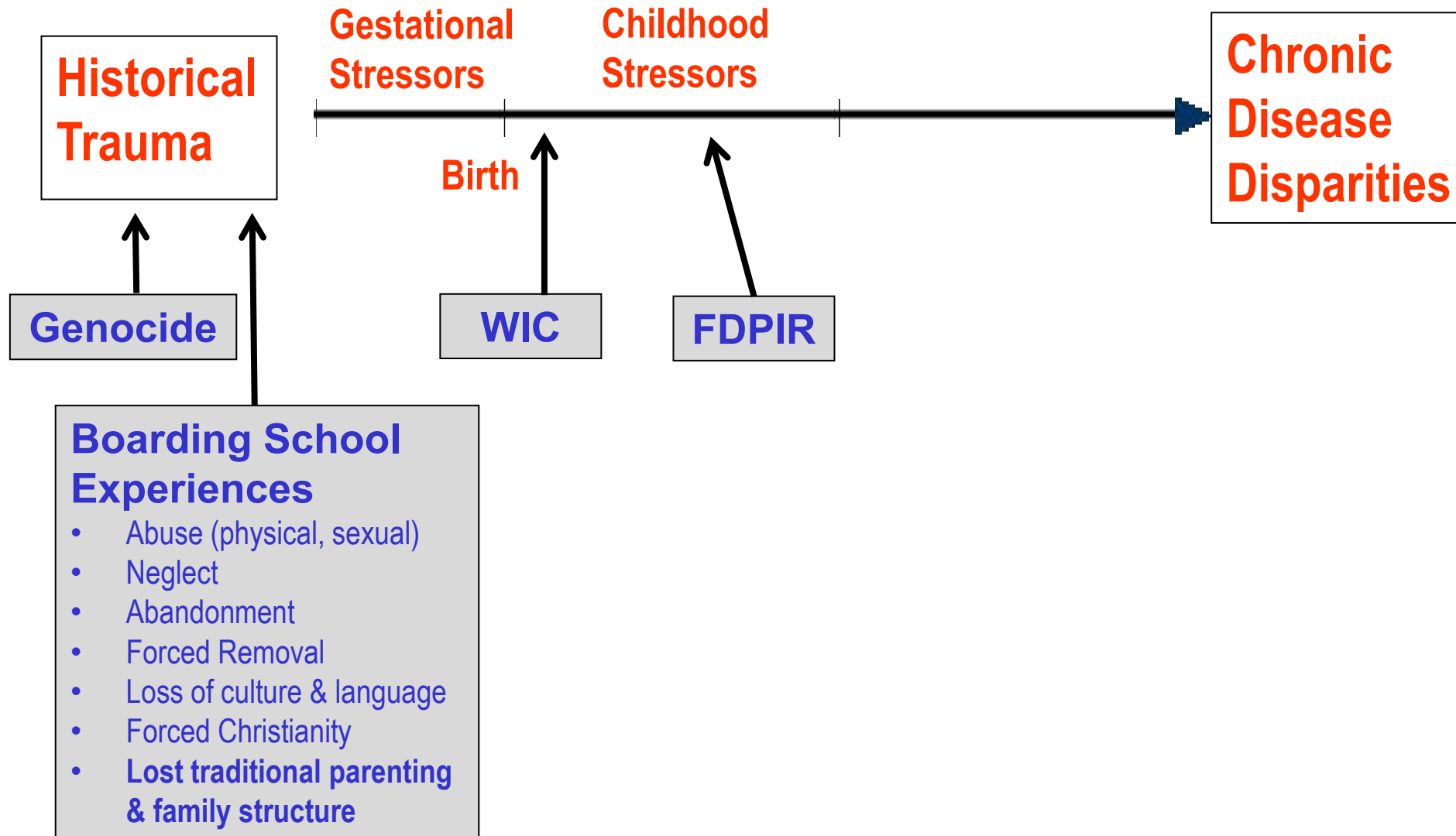
- The trauma is held personally and transmitted over generations. Thus, even family members who have not directly experienced the trauma can feel the effects of the event generations later

Epigenetics

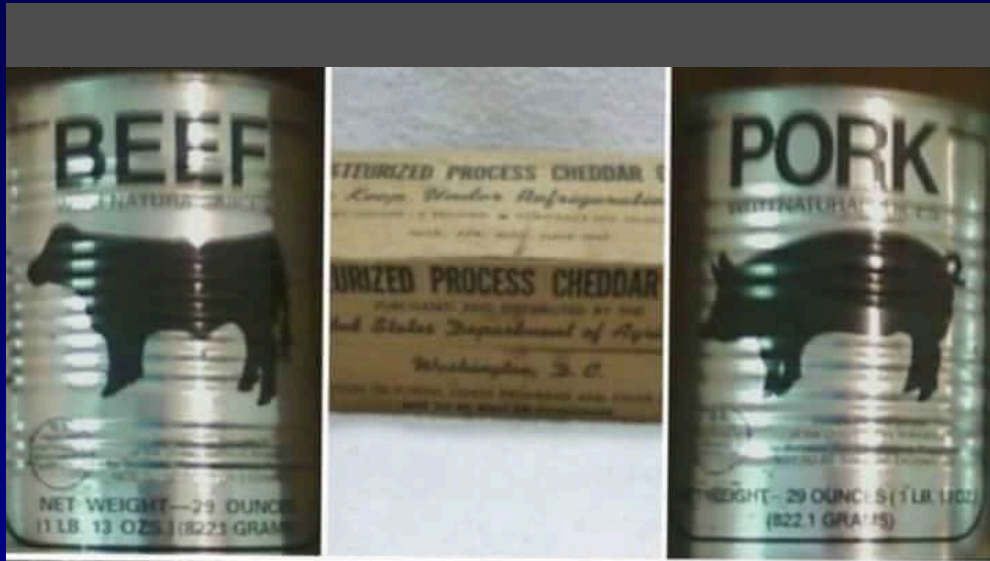
- Epigenetics refers to the study of changes in the regulation of gene activity and expression that are not dependent on DNA sequence.



Inter-Generational Basis for Chronic Disease Disparities Among American Indians and Alaska Natives



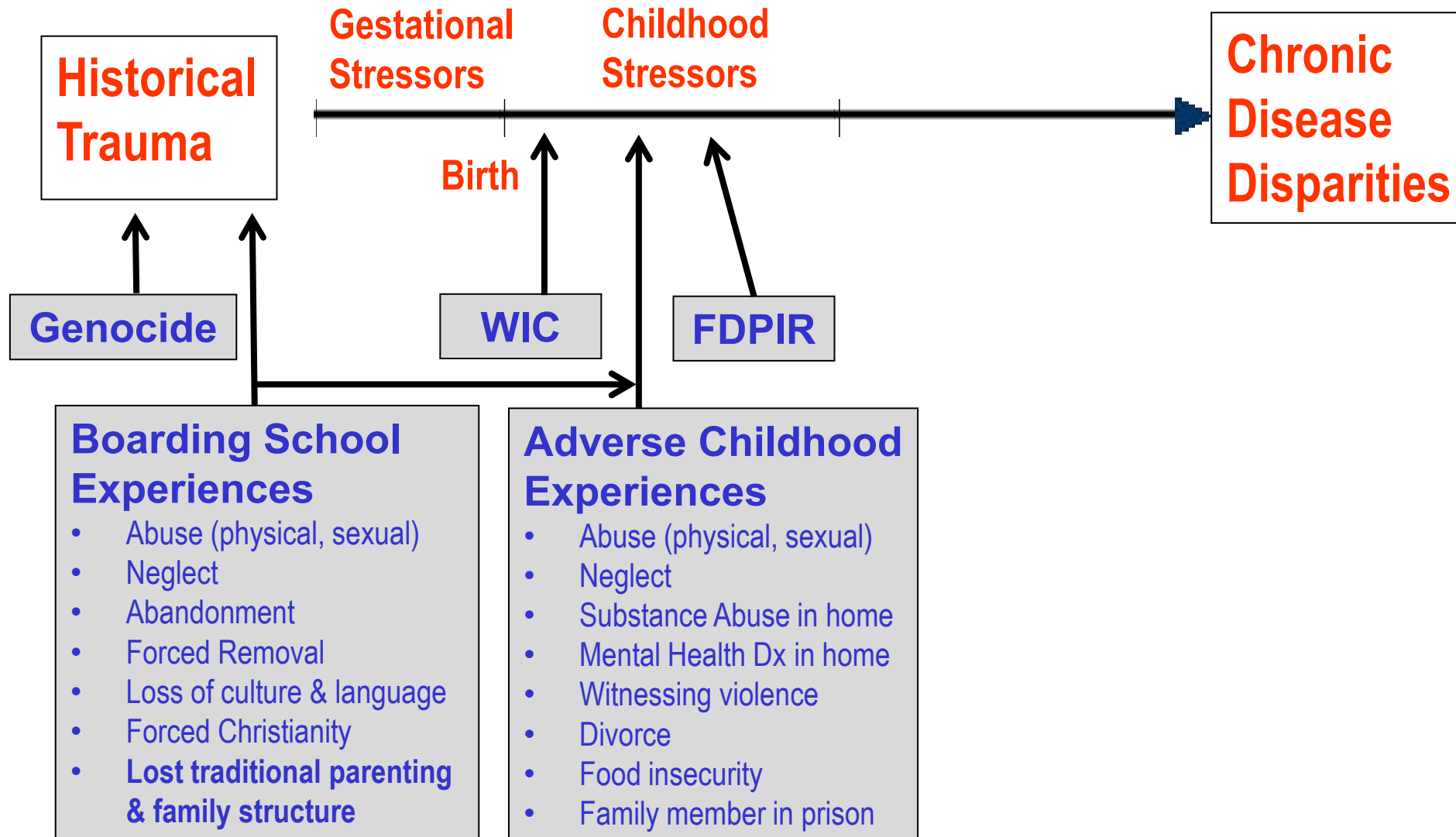




@MacarioAeugus



Inter-Generational Basis for Chronic Disease Disparities Among American Indians and Alaska Natives



Impact of ACEs on Health

ACES can have lasting effects on....



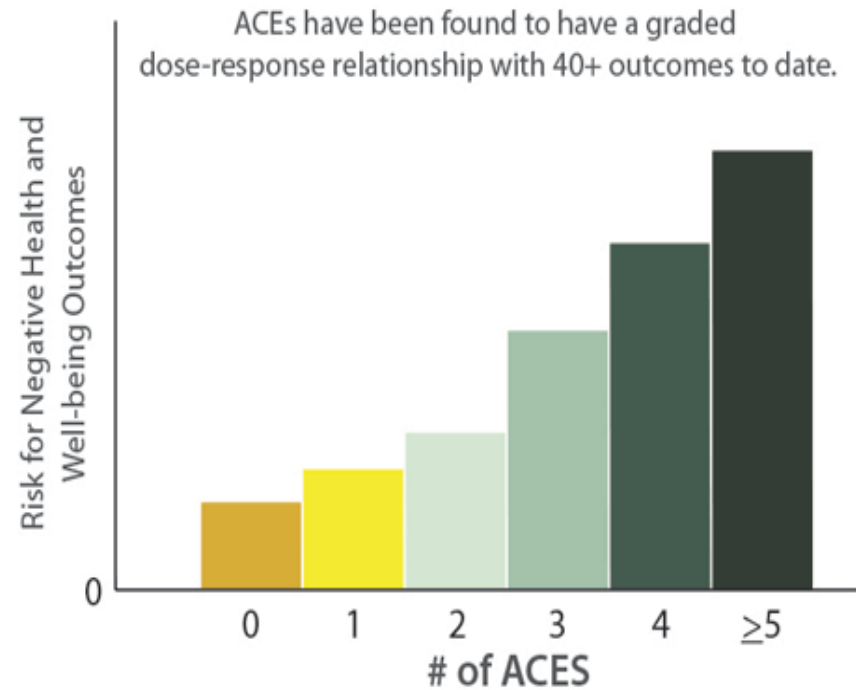
Health (obesity, diabetes, depression, suicide attempts, STDs, heart disease, cancer, stroke, COPD, broken bones)



Behaviors (smoking, alcoholism, drug use)



Life Potential (graduation rates, academic achievement, lost time from work)



*This pattern holds for the 40+ outcomes, but the exact risk values vary depending on the outcome.

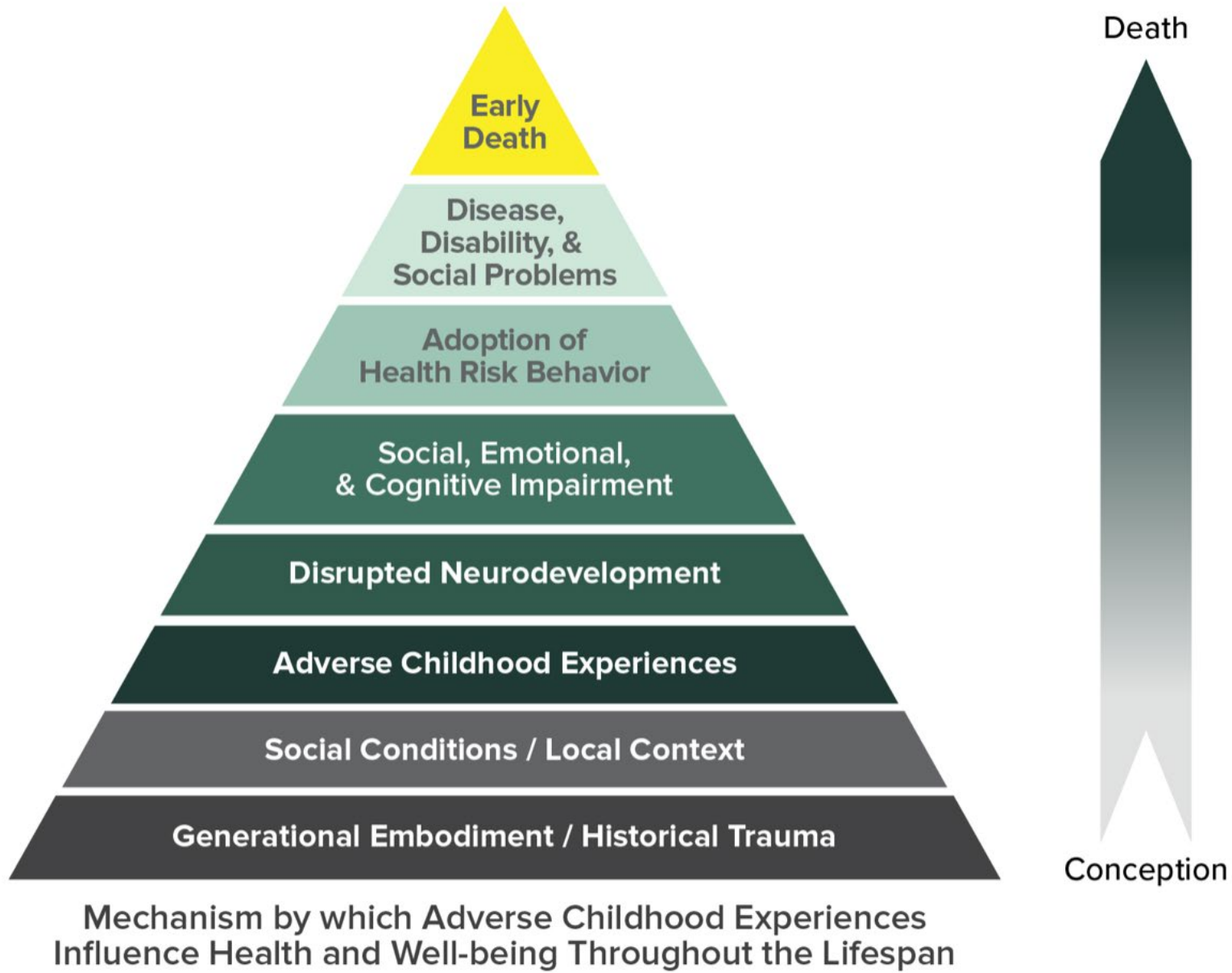
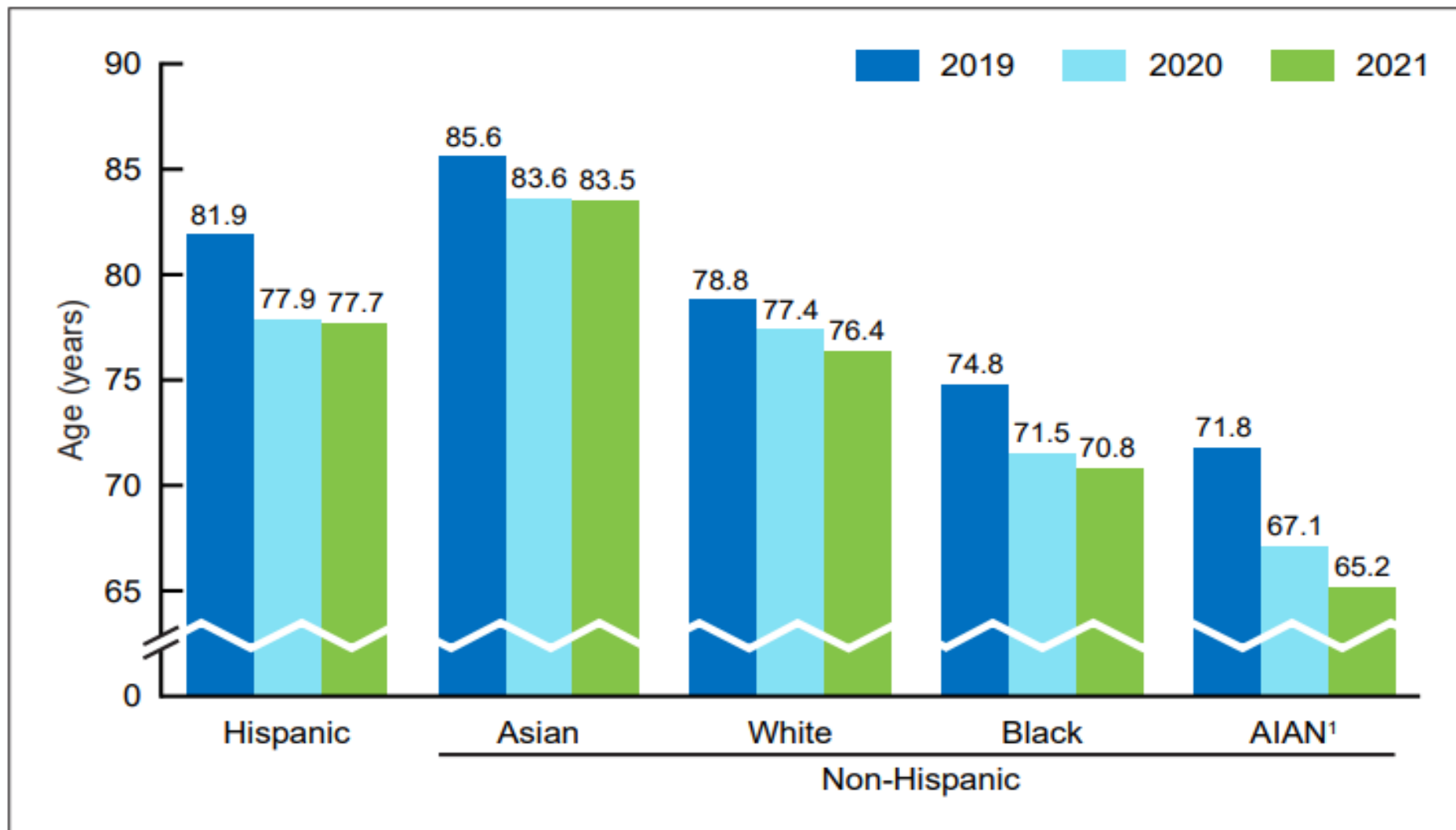


Figure 2. Life expectancy at birth, by Hispanic origin and race: United States, 2019–2021



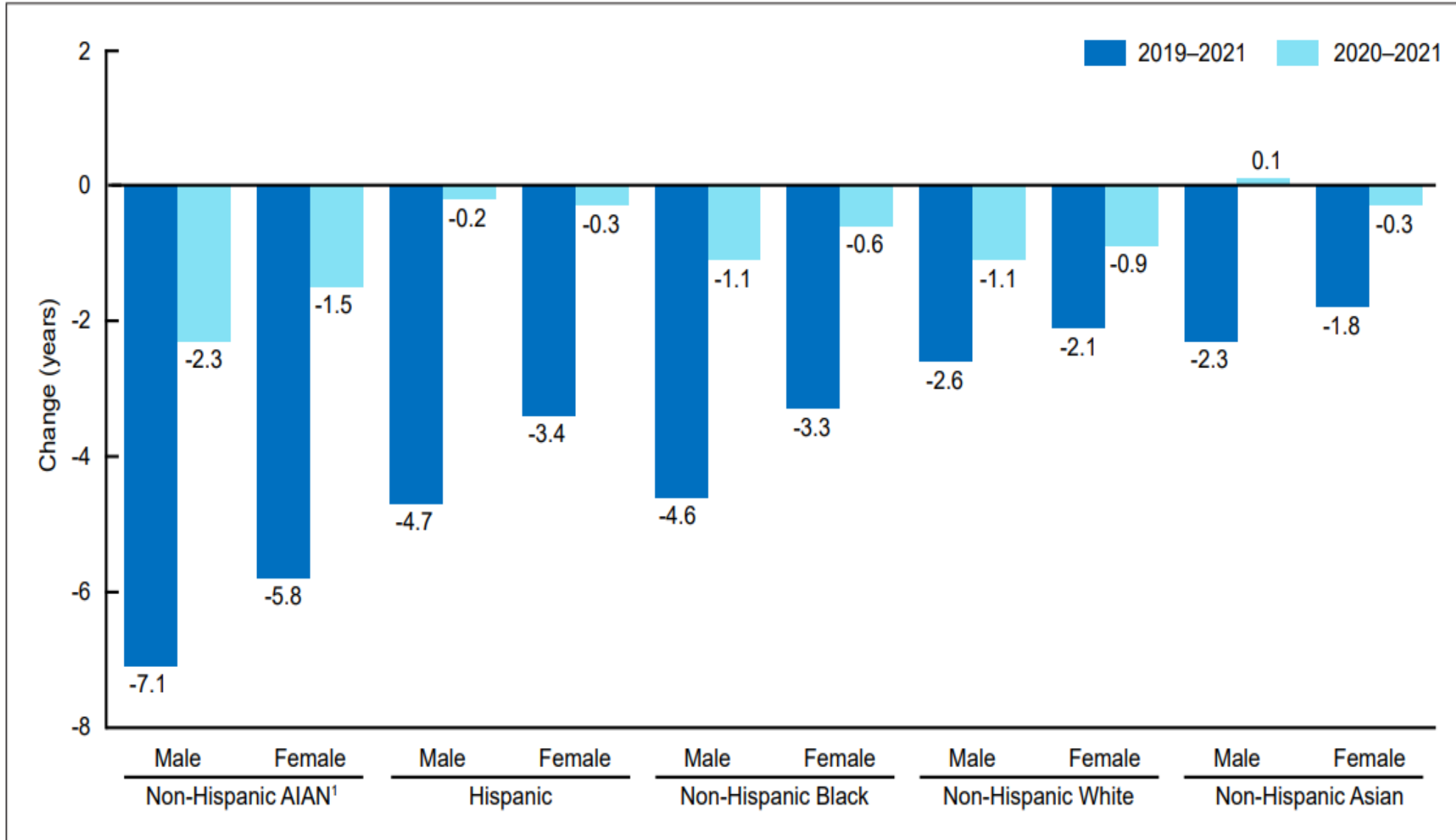
¹American Indian or Alaska Native.

NOTES: Estimates are based on provisional data for 2021. Provisional data are subject to change as additional data are received. Estimates for 2019 and 2020 are based on final data. Life tables by race and Hispanic origin are based on death rates that have been adjusted for race and Hispanic-origin misclassification on death certificates; see Technical Notes in this report.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

Arias E, Tejada-Vera B, Kochanek KD, Ahmad FB. Provisional life expectancy estimates for 2021. Vital Statistics Rapid Release; no 23. Hyattsville, MD: National Center for Health Statistics. August 2022. DOI: <https://dx.doi.org/10.15620/cdc:118999>

Figure 3. Change in life expectancy at birth, by Hispanic origin and race: United States, 2019–2021 and 2020–2021



Arias E, Tejada-Vera B, Kochanek KD, Ahmad FB. Provisional life expectancy estimates for 2021. Vital Statistics Rapid Release; no 23. Hyattsville, MD: National Center for Health Statistics. August 2022. DOI: <https://dx.doi.org/10.15620/cdc:118999>

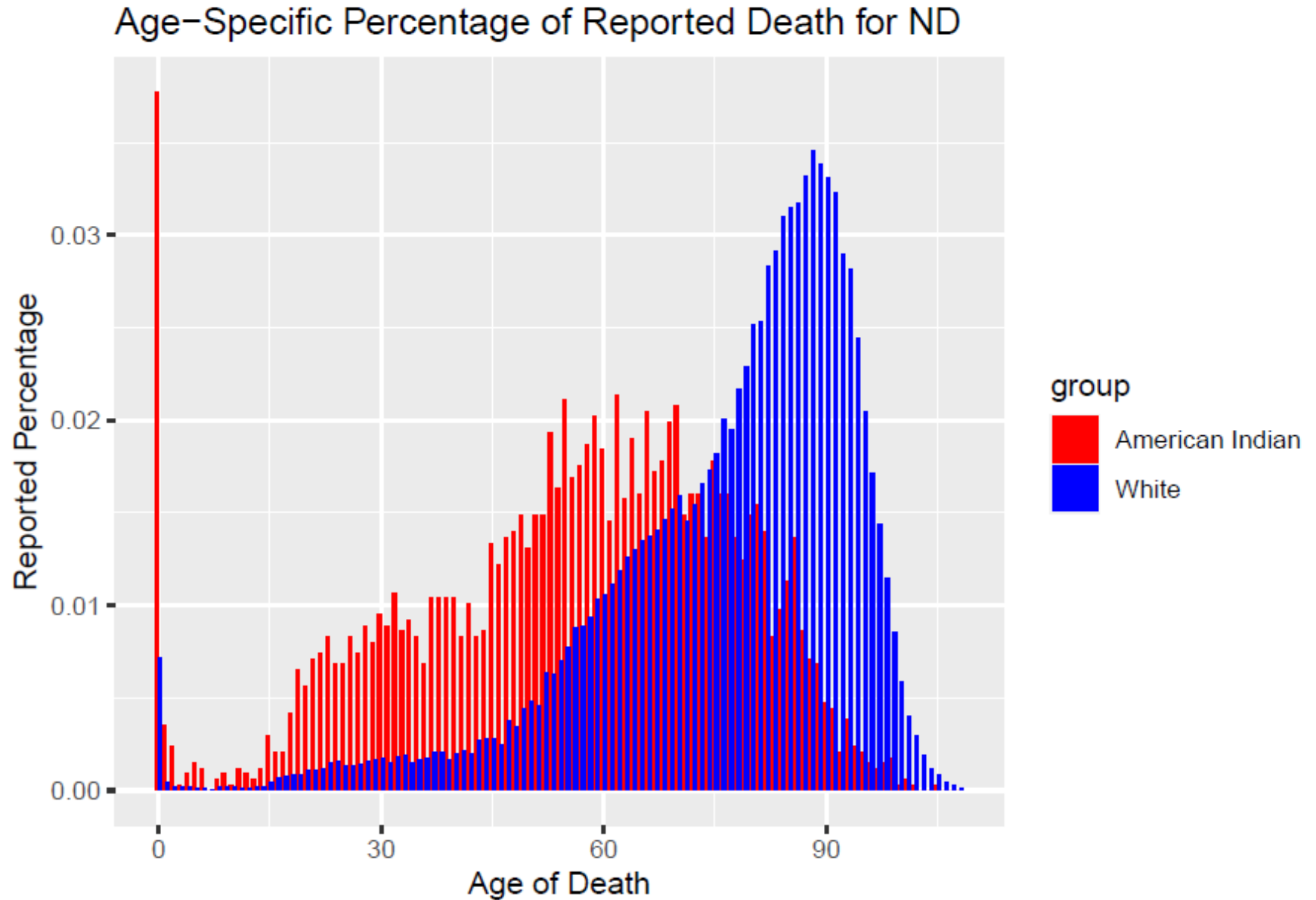
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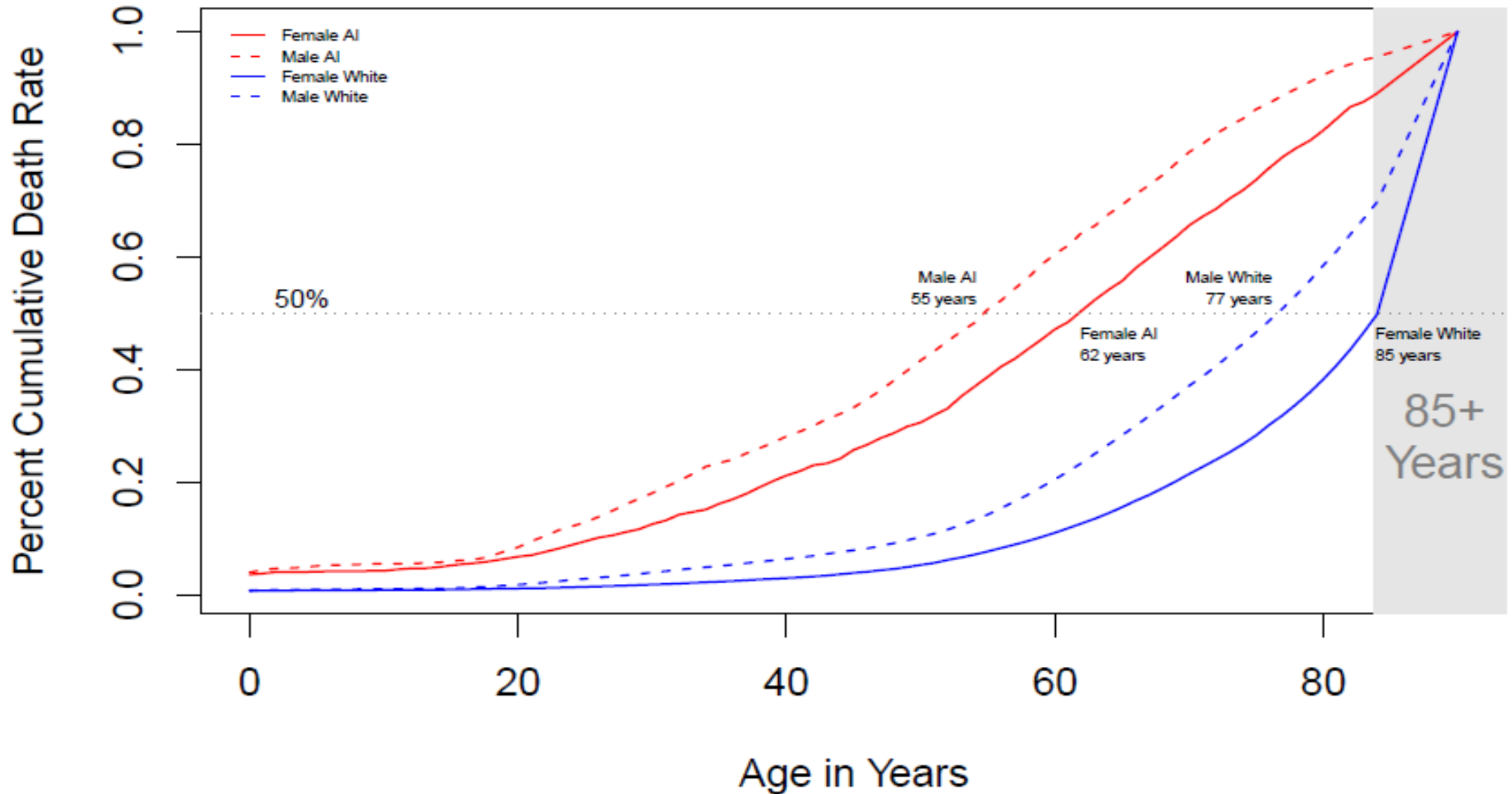
Age at Death in North Dakota

2009-2019

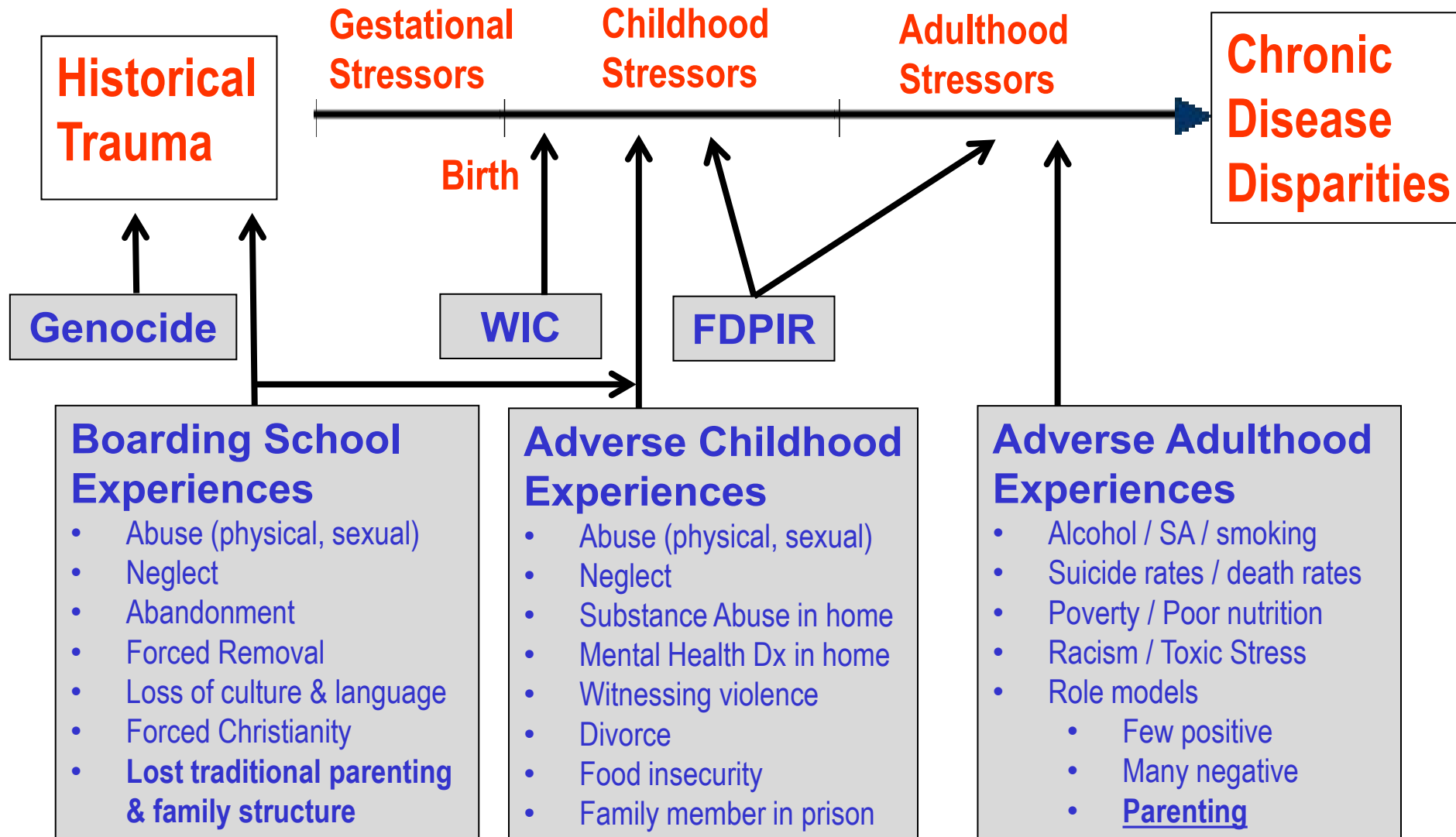


Age at Death in North Dakota

2009-2019



Inter-Generational Basis for Chronic Disease Disparities Among American Indians and Alaska Natives



South Dakota Health Survey

The survey included questions on:

- Basic information, including age, sex, race;
- Self-reported health status, including chronic diseases, depression, and other health issues;
- Mental Health Screening;
- Access to services, including cost, distance, and other access issues; and
- Adverse Childhood Experiences.

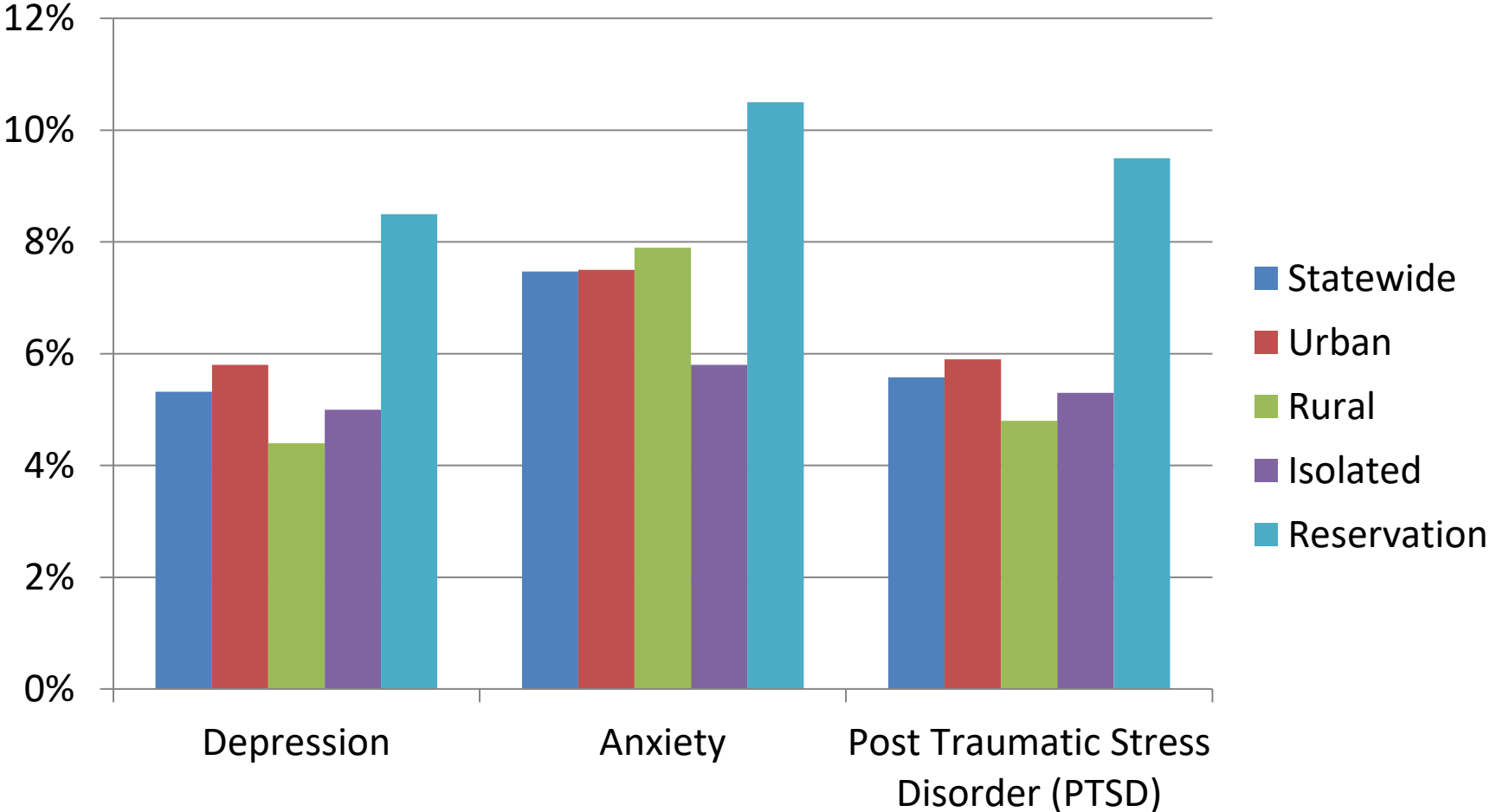
DEMOGRAPHIC CHARACTERISTICS FOR AI AND NON-AI RESPONDENTS

	American Indian (n = 516)	Non-American Indian (n = 7078)	Total (n = 7593)	p value
Age				.0002
18–34	36.63%	29.69%	30.34%	
35–64	57.62%	49.94%	50.65%	
65 and older	5.75%	20.37%	19.01%	
Gender				.21
Male	37.16%	43.08%	42.53%	
Female	62.84%	56.92%	57.47%	

	AI	Non-AI	Total	p-value
Employment status				<u><.0001</u>
Not employed	31.60%	7.58%	9.64%	
Employed part time	11.91%	19.63%	18.97%	
Employed full time	49.59%	54.47%	54.05%	
Retired	6.89%	18.31%	17.34%	
Income (%FPL)				<u><.0001</u>
<50% FPL	38.90%	12.73%	15.17%	
50–138% FPL	22.48%	10.18%	11.33%	
138–250% FPL	17.29%	22.46%	21.98%	
250–400% FPL	11.13%	28.75%	27.11%	
>400% FPL	10.20%	25.88%	24.42%	
Education				<u><.0001</u>
Less than high school	9.95%	3.23%	3.85%	
High school diploma or GED	39.29%	32.40%	33.05%	
Vocational or 2-yr. degree	24.86%	23.87%	23.96%	
4-year college degree	22.47%	25.69%	25.39%	
Advanced or graduate degree	3.44%	14.81%	13.75%	

Prevalence: Mental Health Screens

Participants who screened positive for a condition using standardized mental health screening tools



Adverse Childhood Experiences <i>Domains</i>	American Indian (n = 516)	Non-American Indian (n = 7078)	Significance
Abuse			
Emotional Abuse	30.10%	17.41%	.0008*
Physical Abuse	24.51%	12.31%	.0002*
Sexual Abuse	15.53%	9.60%	.0263*
Neglect			
Emotional Neglect	25.87%	14.00%	.0005*
Physical Neglect	15.89%	2.78%	<.0001*
Household Dysfunction			
Mother Treated Violently	23.76%	5.31%	<.0001*
Household Substance Abuse	50.04%	21.49%	<.0001*
Household Mental Illness	24.36%	13.89%	.0032*
Parental Separation or Divorce	39.34%	20.17%	<.0001*
Incarcerated Household Member	22.57%	3.73%	<.0001*

AI ACE Disparities in South Dakota

	<u>AI</u>	<u>Non-AI</u>	<u>p-value</u>
Number of ACEs (Score)			<u><.0001*</u>
0	16.84%	50.02%	
1	21.59%	23.02%	
2	16.20%	9.60%	
3	12.99%	6.09%	
4-5	13.10%	7.38%	
≥6	19.28%	3.89%	

Note

*statistically significant

Trauma Informed Care Elements

Understanding the **prevalence** of trauma

Recognizing how trauma **impacts** individuals

Putting this knowledge into **practice**

to **actively resist re-traumatization**

Indigenous Perspective on Trauma



Holistic Healing from Trauma



NEWS & UPDATES

White House Commits to Elevating Indigenous Knowledge in Federal Policy Decisions

NOVEMBER 15, 2021 • PRESS RELEASES

*White House Office of Science & Technology Policy and Council on
Environmental Quality release first-of-its kind memorandum to initiate new
federal guidance on Indigenous Traditional Ecological Knowledge*

<https://www.whitehouse.gov/ceq/news-updates/2021/11/15/white-house-commits-to-elevating-indigenous-knowledge-in-federal-policy-decisions/>

USDA announces a new focus on Indigenous food and agriculture

Dan Gunderson Moorhead, Minn. November 16, 2021 12:45 p.m.



Bear Island corn comes from an island on the Red Lake Reservation in northern Minnesota. ■ Dan Gunderson | MPR News 2011

Respect for Indigenous Knowledge

- Indigenous STEM



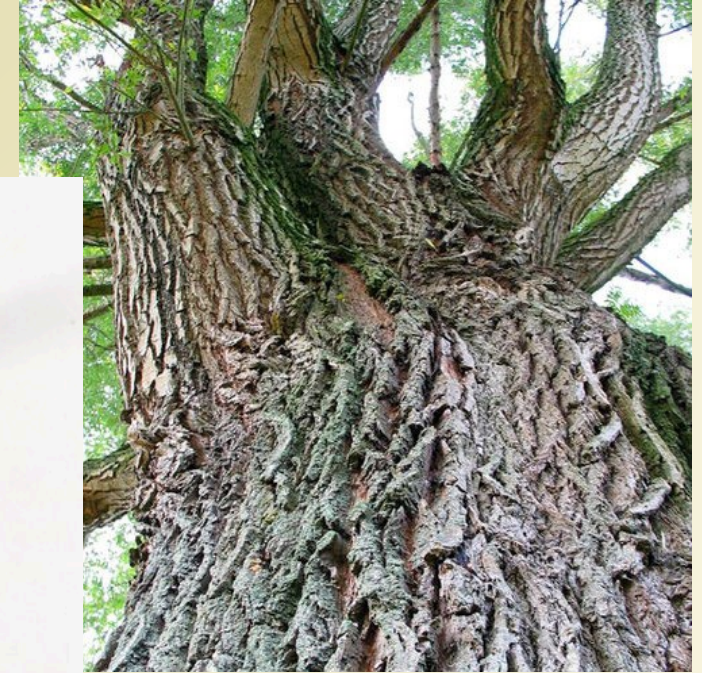
Respect for Indigenous Knowledge

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Respect for Indigenous Knowledge

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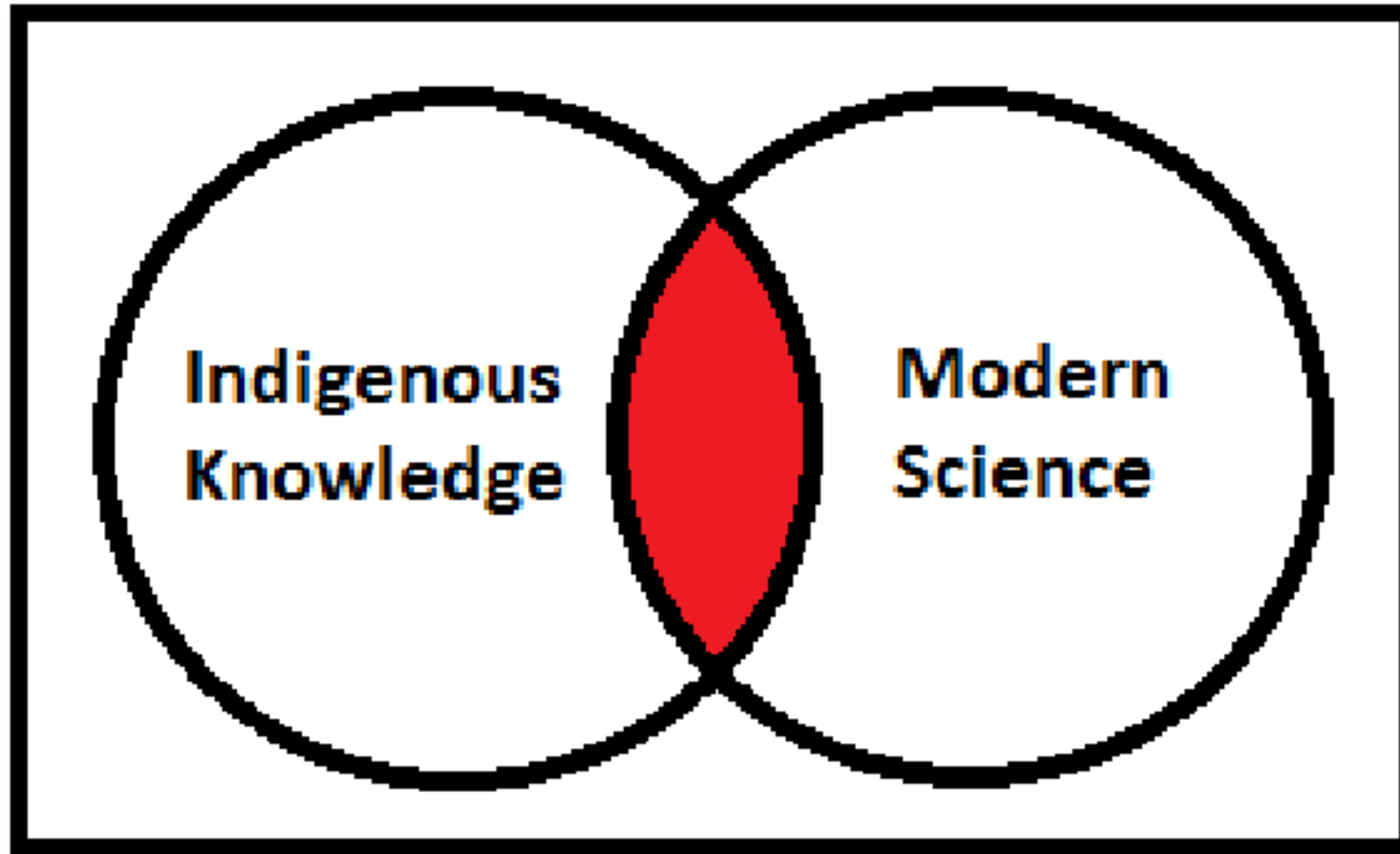


Respect for Indigenous Knowledge

- Indigenous STEM



Research in Balance



Building Relationships

First Steps and Collaboration

- Community Engagement
 - Tribal Leaders
 - Elders
 - Tribal Health Programs
 - Tribal Colleges
 - Traditional Healers
 - Informal Community Leaders
 - Local Health Professionals / IHS?
 - Others



Building Relationships

Institutional Review Boards

- IHS IRB Process
 - 12 Areas, most with IRBs
 - National IHS IRB
- Tribal IRBs?
 - OST RRB
 - SRST IRB (Sitting Bull College)
 - TM—Tribal Nations Research Group
 - Others?
- University IRBs



Research Regulation in American Indian/ Alaska Native (AI/AN) Communities

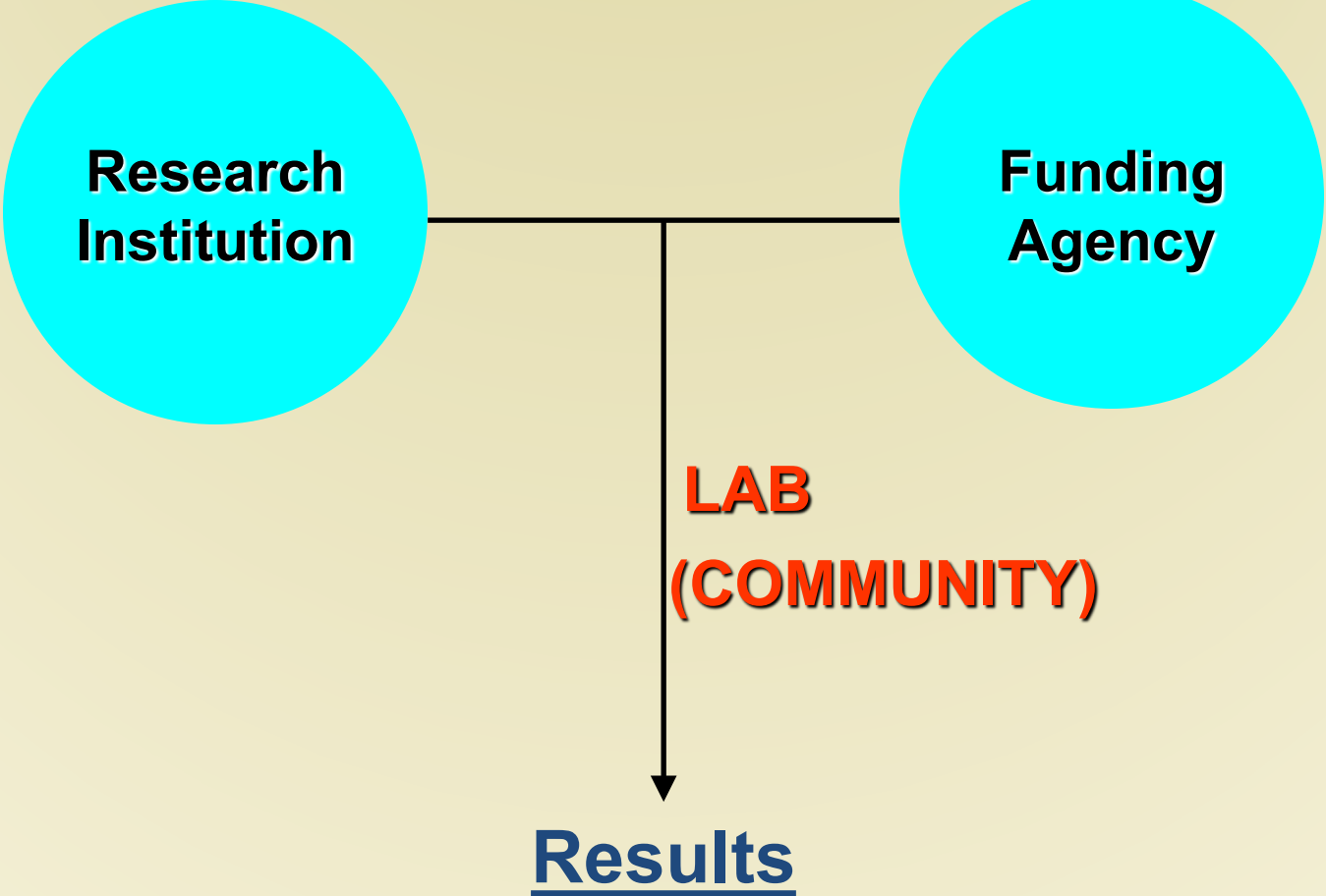
- Researchers working in AI/AN communities experience a complex set of IRB review processes
- Tribal sovereignty a unique consideration
 - Tribal government relationship with university



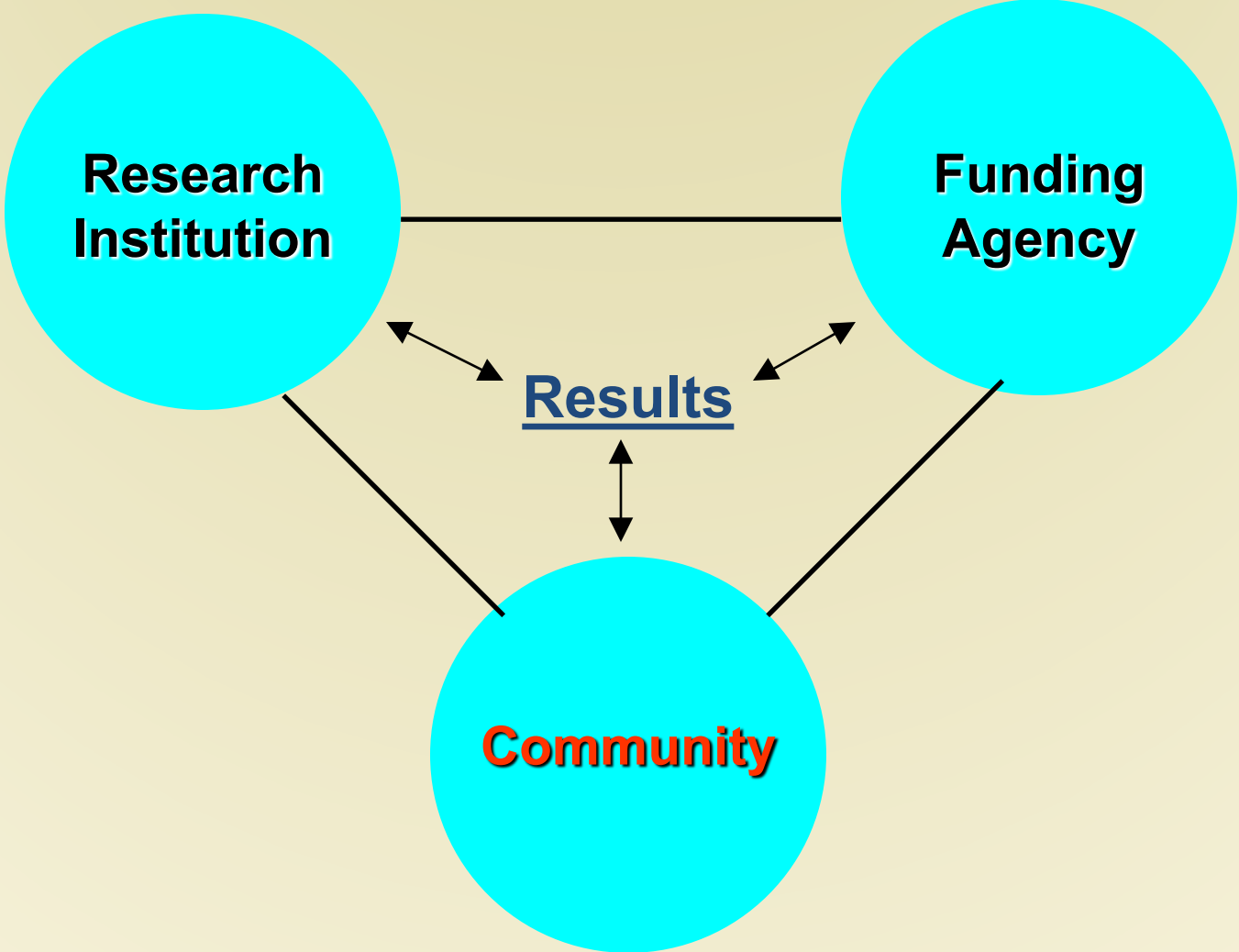
CBPR and AI/AN Communities

- CBPR has become ethical *gold standard* for conducting research with AI/AN communities
- History of research abuses and mistrust (also for other disadvantaged communities)
- Many AI/AN communities will not approve projects without *full partnership*
- Data ownership a major issue (NIH v Tribe?)
- Publication review common
- Whose responsibility is it to protect community?

HISTORICAL RESEARCH PARADIGM



COMMUNITY PARTICIPATORY RESEARCH PARADIGM



Challenges for University IRBs

- Protection of individual vs. community
 - Group risks and harms
 - Anonymity of individuals and communities
- Jurisdictional issues with tribal IRBs
 - Which IRB should review project first?
 - Changes requested by tribal vs. university IRBs?
 - When to review a project – when does the research truly begin?
 - Role of community member-researchers?



AI/AN Data Sovereignty

- Data sovereignty is the idea that data are subject to the laws and governance structures within the nation it is collected. The concept of data sovereignty is closely linked with data security, cloud computing, network sovereignty and technological sovereignty.
- Tribal Data sovereignty is the right of a nation to govern the collection, ownership, and application of its own data. It derives from tribes' inherent right to govern their peoples, lands, and resources.

Circle of Trust



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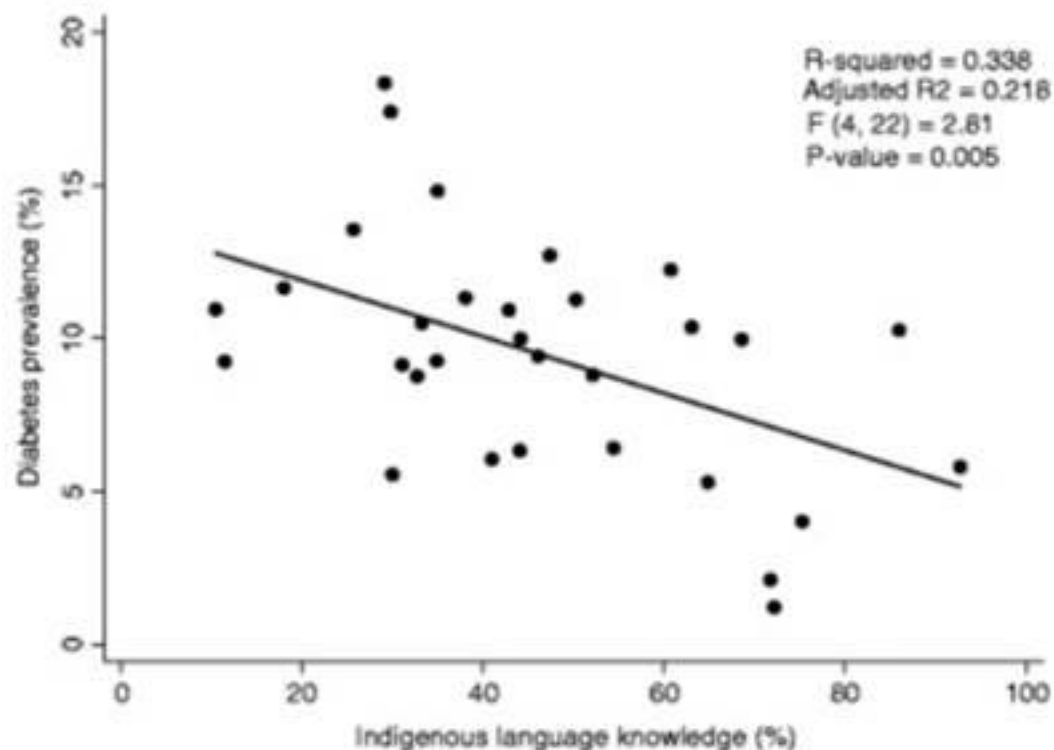
Mainous A, Kelliher A, Warne D. Recruiting Indigenous Patients Into Clinical Trials: A Circle of Trust. *Ann Fam Med*. 2023 Jan-Feb;21(1):54-56. doi: 10.1370/afm.2901. PMID: 36690478; PMCID: PMC9870649.

Culture Protects



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Figure 2



Crude diabetes prevalence by Aboriginal language knowledge for the year 2005. P-value reflects multiple linear regression test result (adjusted for socio-economic factors).

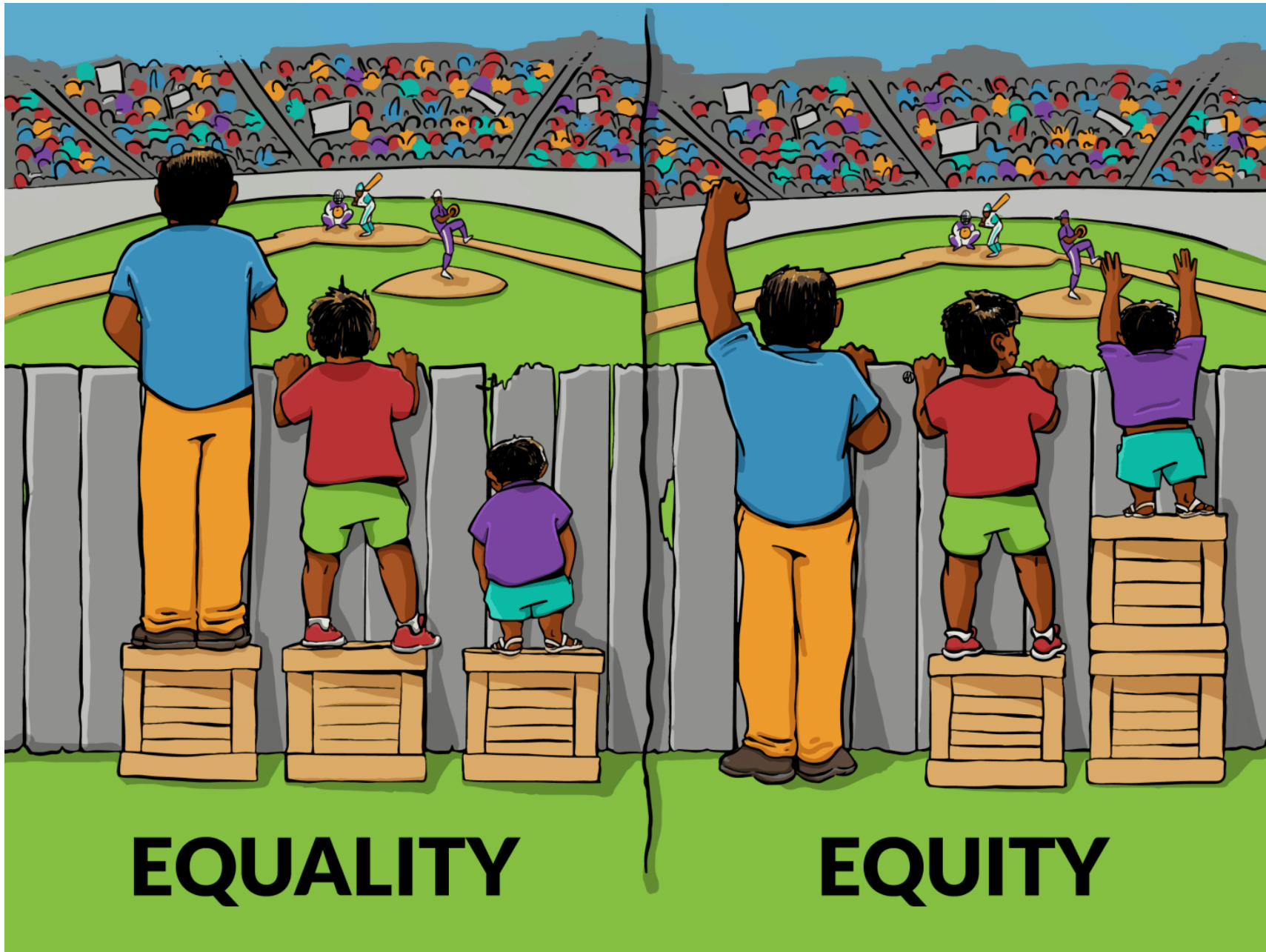
- Oster, Richard T., Angela Grier, Rick Lightning, Maria J. Mayan, and Ellen L. Toth. "Cultural Continuity, Traditional Indigenous Language, and Diabetes in Alberta First Nations: A Mixed Methods Study." *International Journal for Equity in Health* 13, no. 1 (October 19, 2014): 92. <https://doi.org/10.1186/s12939-014-0092-4>.

Considerations/Challenges



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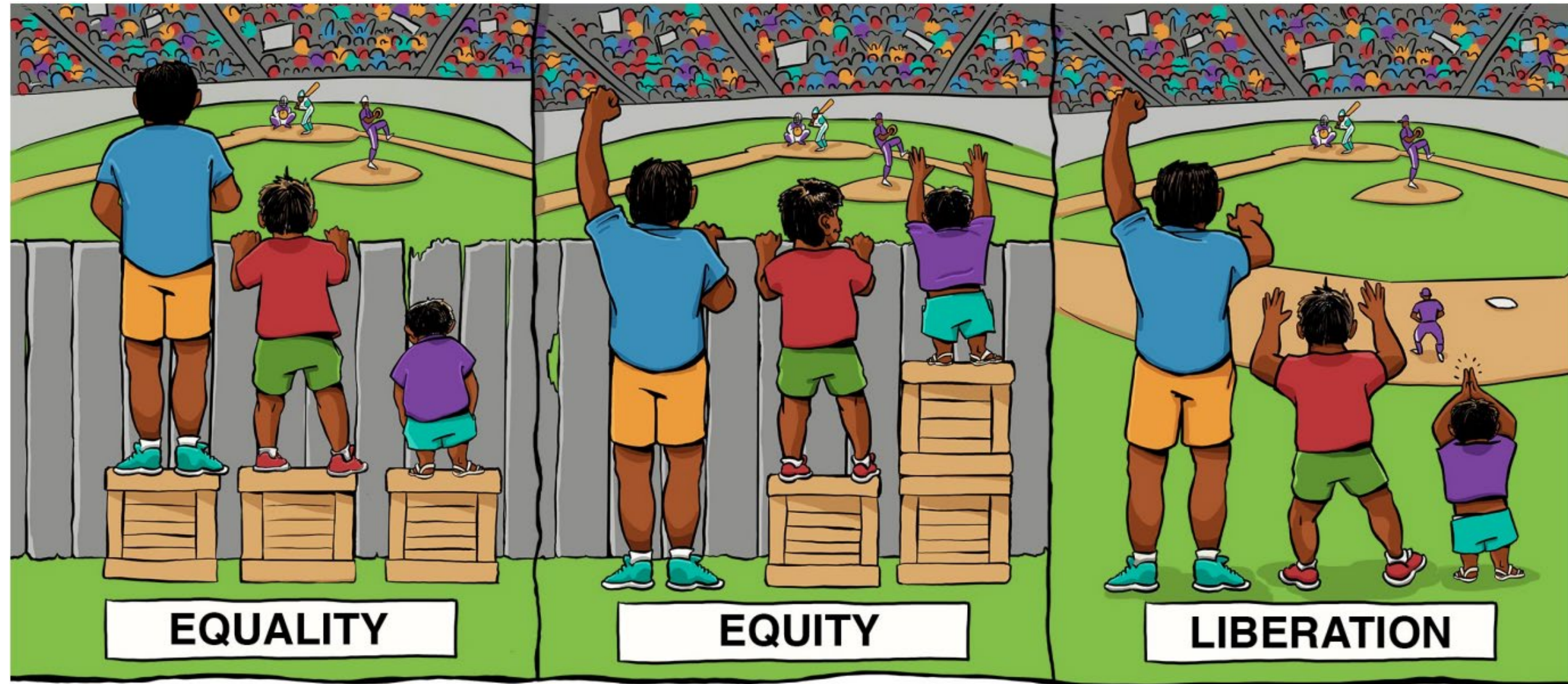
- Contributions of AI/ANs to US PH
 - Efficacy of ORS and of routine vaccines (Hib, PCV, Rotavirus, COVID-19)
 - Diabetes management
- Promote respect for Indigenous healing systems & methodologies
 - Botanical medicines (ASA, digoxin, echinacea, etc.)
 - Osteopathy
 - Indigenous STEM
- Pre-K to Post-Doc disparities
- Few role models in PH leadership, health sciences, & higher education
- Poverty (housing, education, addiction, crime, ACEs...)
- *One size fits all approach...*



EQUALITY

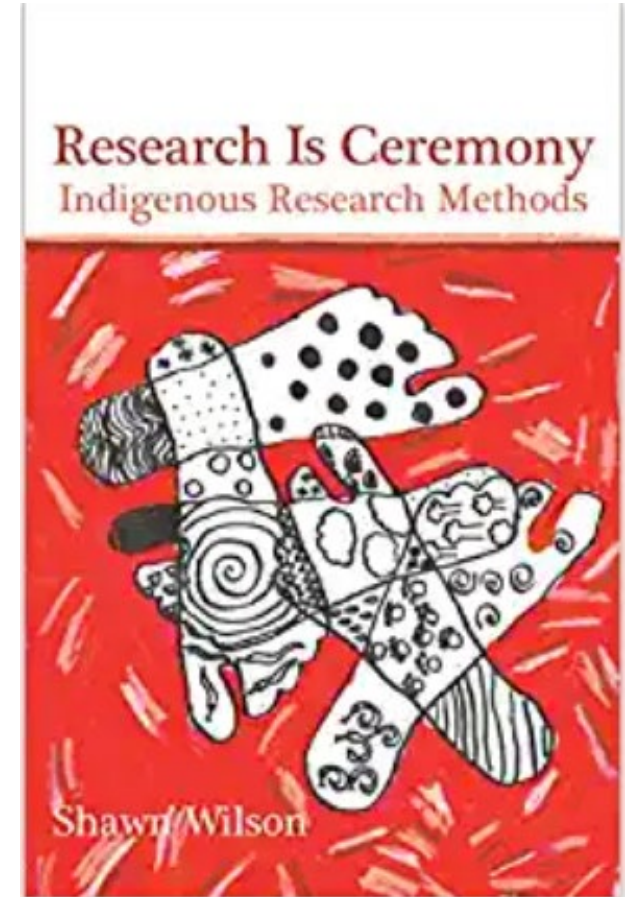
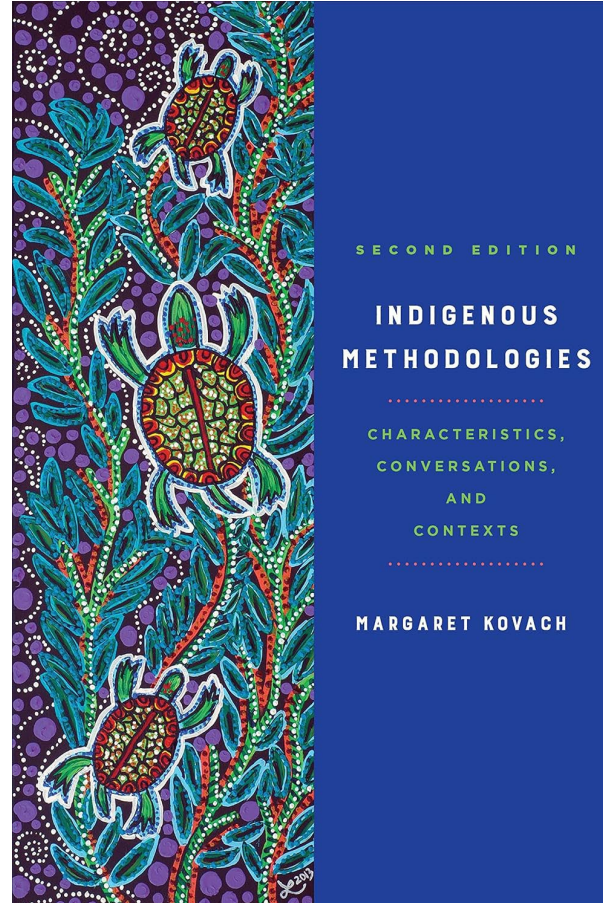
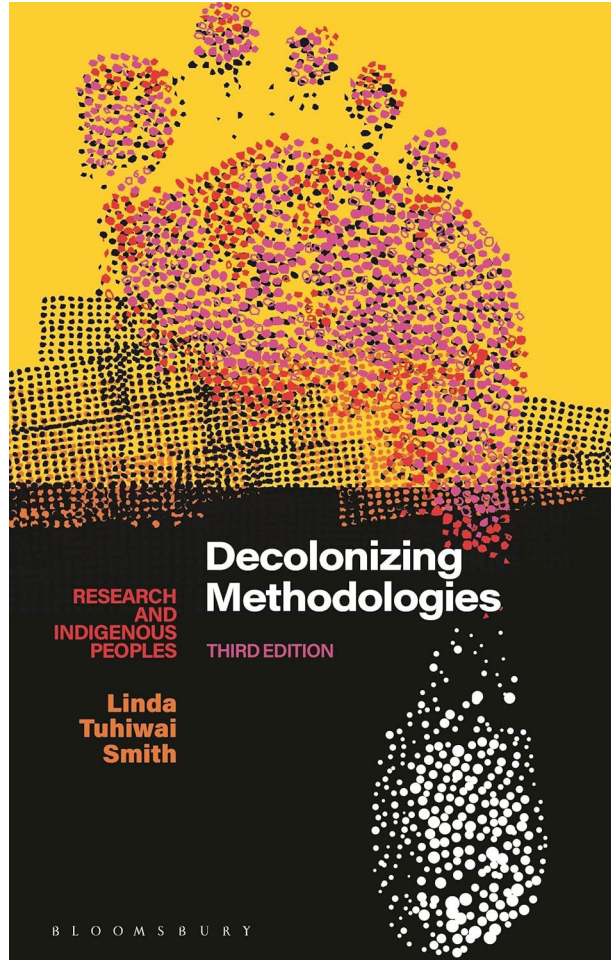
EQUITY

Equality, Equity, Systemic Barriers



Indigenous Methodologies

- **Research by and for Indigenous Peoples, using techniques and methods drawn from the tradition and knowledges of those people**
- Recognition of colonial past and of Indigenous Peoples.
- Resist colonial narratives.
- Resurgence of Indigenous Ways of Knowing and Being
- Preventing research extraction
- Indigenous self-determination
- Combating power dynamics in currently dominant research practices
- ” (Evans, Hole, Berg, Hutchinson & Sookraj 2008)
- Indigenous Research Guide: <https://guides.library.ualberta.ca/>



Indigi-Centered Research

- Community-led
- Incorporates Indigenous World Views
- Purposeful
- Personal
- Based on relationships
- Pushes back against colonial boundaries
- Focused on resiliency and resistance
- Raises up Indigenous voices and peoples

Potential Solutions



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- Respect & integrate Indigenous knowledge and health sciences education
- *Wise Practices* approach to PH and Epidemiology
- Trauma-informed epidemiology & public health
- Develop the Indigenous public health *evidence-base*
- Develop the Indigenous public health workforce
- Respect & integrate principles of Tribal data sovereignty
- Funding for infrastructure support and for data collection
- Respect & integrate Indigenous methodologies
- Engage communities & focus on community-based priorities
- Develop and honor critical allies
- Establish an *Indigenous EIS program* or *Field Epi Training Program*



BLACK ELK

Of course it was not I who cured. It was the power from the outer world, and the visions and ceremonies had only made me like a hole through which the power could come to the two-leggeds. If I thought that I was doing it myself, the hole would close up and no power could come through.



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