

# Discrimination and Health within a Native American Context: building the body of science

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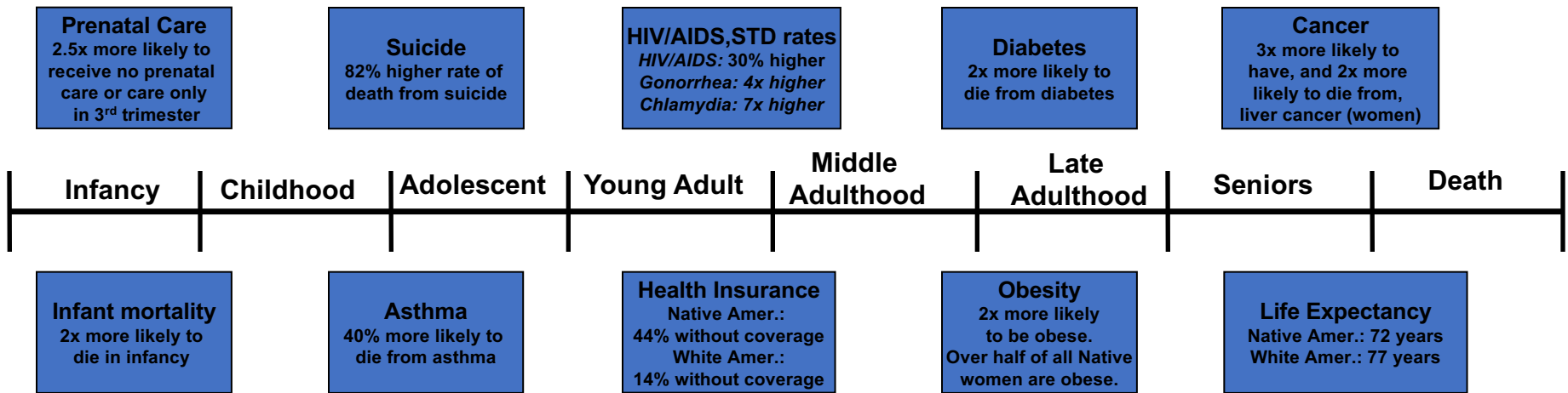


*“Indigenous peoples (including American Indian and Alaska Natives) remain on the margins of society: they are poorer, less educated, die at a younger age, and are generally in worse health than the rest of the population.”*

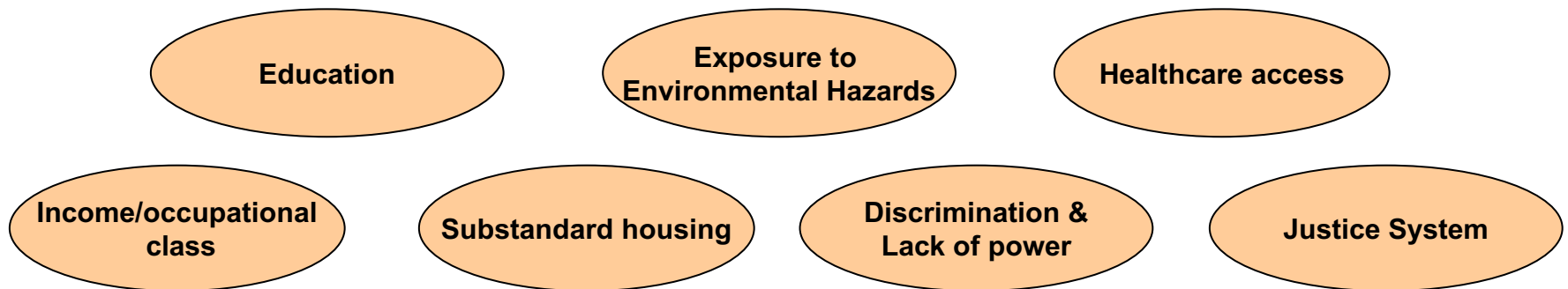
(Source: The Indigenous World 2006, International Working Group on Indigenous Affairs (IWGIA) WHO; slide from One Sky Center-Oregon Health & Science University)

# American Indian Health Inequity Life Continuum

*American Indians compared to general non-Hispanic whites*



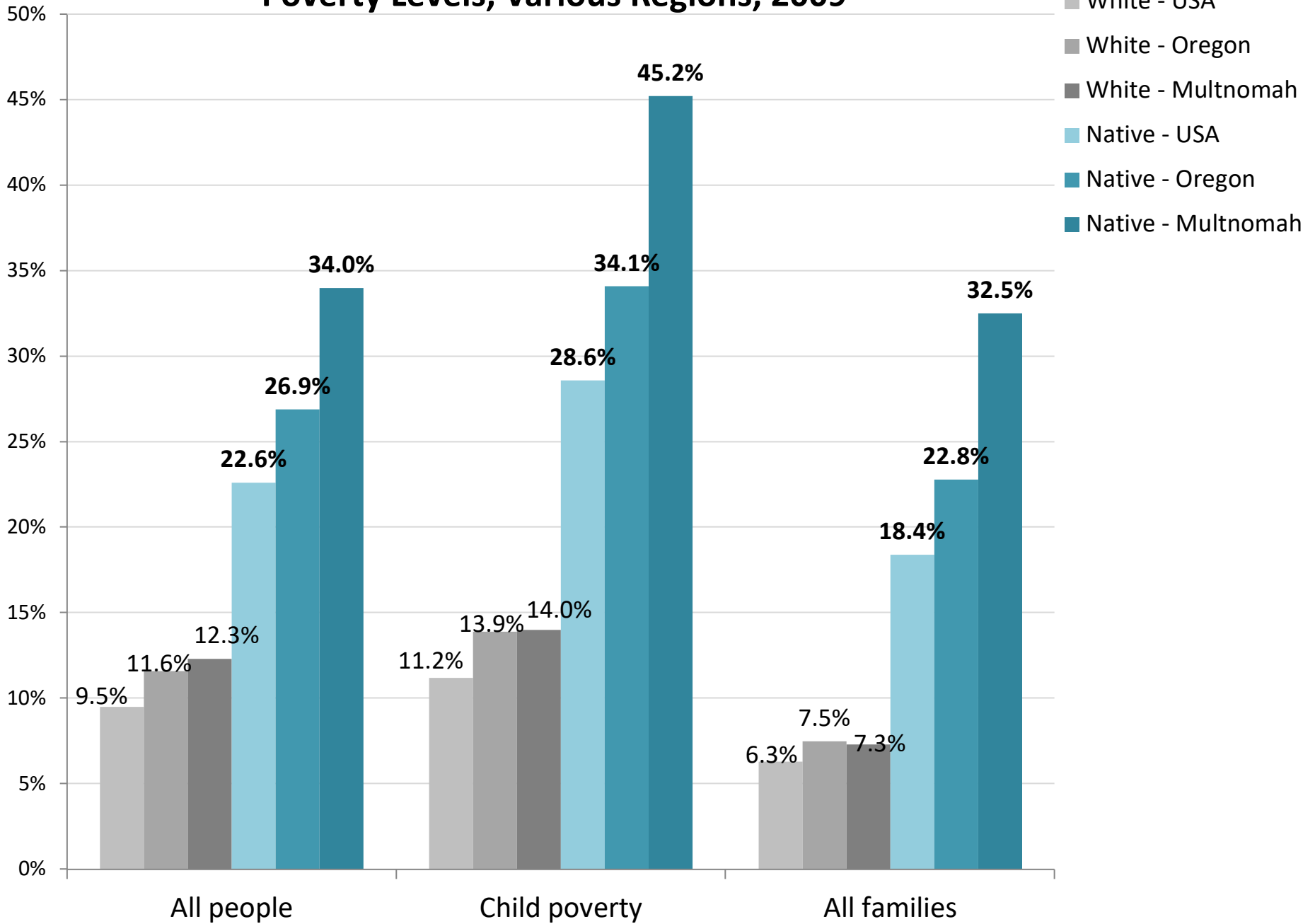
## Socioeconomic factors



### References

- <http://www.ihs.gov/PublicAffairs/IHSBrochure/Disparities.asp> ; <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=9>; <http://www.cdc.gov/nchstp/healthdisparities/AmericanIndians.html>; <http://www.cdc.gov/nchs/fastats/indfacts.htm>
- [http://www.cdc.gov/nchs/fastats/white\\_health.htm](http://www.cdc.gov/nchs/fastats/white_health.htm)

# Poverty Levels, Various Regions, 2009



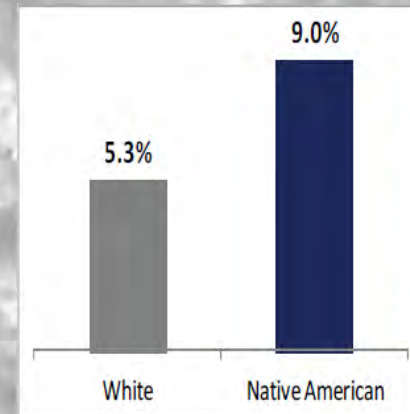
# Native Elders

Today in Multnomah County

- 20% are hungry on a regular basis
- One-in-five live in poverty
- One-in-six go without utilities monthly
- Live on \$11,709/year (half that of Whites)

Source: Curry-Stevens & Coalition of Communities of Color (2011). *The Native American community in Multnomah County: An Unsettling Profile*. Portland, OR: Portland State University. This fact sheet is part of an educational series from the Coalition of Communities of Color and Portland State University, School of Social Work, 2011.

# Unemployment in Multnomah County (2009)



In Multnomah County, Native Americans have almost double the rate of unemployment of Whites.

The community will be slow to recover from this economic crisis.

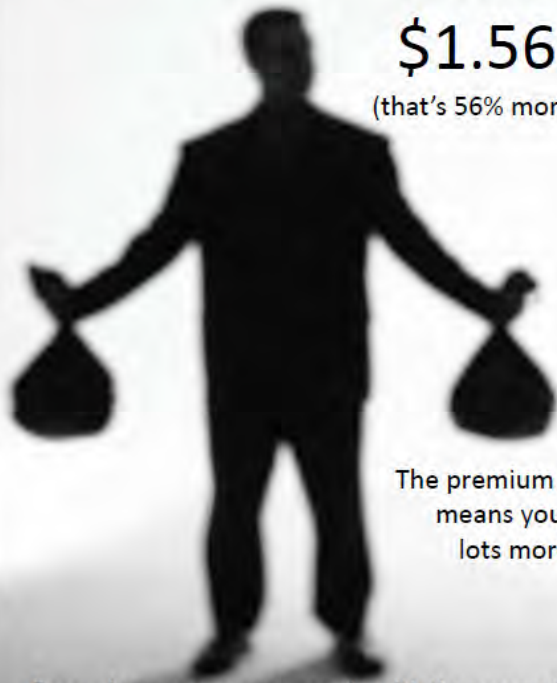
Source: Curry-Stevens, Cross-Hemmer & Coalition of Communities of Color (2011). *Native Americans in Multnomah County: An unsettling profile*. Portland, OR: Portland State University

This fact sheet is part of an educational series from the Coalition of Communities of Color and Portland State University, School of Social Work, 2011.

For every \$1 earned by Native Americans working in full time, year-round jobs, how much do White workers earn?

**\$1.56**

(that's 56% more)



The premium of being White means you take home lots more income.

*Even when we compare people with the same education levels, Whites take home about 25% more income.*

Source: Curry-Stevens & Coalition of Communities of Color (2011). *The Native American community in Multnomah County: An Unsettling Profile*. Portland, OR: Portland State University. This fact sheet is part of an educational series from the Coalition of Communities of Color and Portland State University, School of Social Work, 2011.

*Who graduates from high school today?*



*63% of Whites got through in 2010.*

*Only 40% of Native Americans got through in the same year.*

*Down from 47% in 2009.*

Source: Curry-Stevens & Coalition of Communities of Color (2011). *The Native American community in Multnomah County: An Unsettling Profile*. Portland, OR: Portland State University. This fact sheet is part of an educational series from the Coalition of Communities of Color and Portland State University, School of Social Work, 2011.

# There's more to the story...

- While income and access matters, research shows us that even after accounting for differences in these indicators, American Indians still experience poorer health status
  - One explanation for these differences is racism and experiences perceived as discrimination

# What is Racism, Discrimination, Stereotype Threat?

- 3-levels of **Racism**

- Institutional
- Inter-personal
- Internalized



- Discrimination- the belief that one has experienced unfair treatment, judgement
- Stereotype threat – concern of being reduced to a label, image established by the dominant and embedded within our social systems by the power of the dominate



# Trigger Stress Responses

- When it comes to discrimination –
  - The experience may cause stress that triggers stress coping responses that may adversely affect physical, mental, and behavioral health
- Associated with:
  - Risky health behaviors such as **smoking, alcohol** and **drug** use
  - Higher increase **weight** over-time among those reporting experiences of discrimination
  - Higher levels of **hypertension**– a risk factor associated with cardiovascular disease

(Rodney Clark, Anderson, Clark, & Williams, 1999; Mays, Cochran, & Barnes, 2007).

# Discrimination and AI/AN Health

- Higher levels of perceived experiences of race-based and weight-based discrimination among AI/ANs have been associated with:
  - Poorer measures of diabetes management
  - Disengagement from healthcare & health intervention
    - Unmet need for cancer screening
    - Avoidance of care and certain providers
    - Unmet prenatal care
    - More likely to not be retained and complete intervention

# Building the body of science

- Although these relationships are well established in the literature across several racial and ethnic populations few studies have examined the links between perceived discrimination and health among AI/ANs
- Advancing our understanding of perceived discrimination and health among AI/ANs requires measures that produce consistent and accurate measures of perceived discrimination.

# Limitations of Current Measures

- Most measures originate with African Americans
- The psychometric properties of the most commonly used measures have not been examined among AI/ANs
- Previous studies use a variety of measures of perceived discrimination neither commonly used nor standardized
- Such inconsistency limits our ability to compare estimates within and across groups, and our confidence about the links between perceived discrimination and health in AI/AN populations

# Building the body of science

- To address these limitations, we examined the reliability and validity of one of the most widely used measures of perceived discrimination, the **Everyday Discrimination Scale**, drawing upon data from a large, culturally and geographically diverse sample of AI/ANs (SDPI-HH data)

# Everyday Discrimination Scale

Sometimes people feel as though they are treated differently than others because they are Indian/Native. What are your experiences?

Are you treated with less courtesy than other people?

Are you treated with less respect than other people?

Do you receive poorer service in restaurants or stores?

Do people act as if they are better than you?

Do people act as if they are afraid of you?

Are you called names or insulted?

Are you threatened or harassed?

Do people act as if you are not smart?

Do people act as if you are dishonest?

(1 \_ never, 2 \_ rarely, 3 \_ sometimes, and 4 \_ often).

# Methods and Findings

- Data source: SDPI-HH
- 3,039 AI/ANs,
- Results from this study provide evidence that the EDS performs in a reliable and valid manner among these AI/ANs

# Future Direction

- Our analyses draw from secondary data, we were unable to explore issues of content validity
  - The EDS was originally developed to assess perceived discrimination within African American groups, and it may not capture the depth and dimension of discrimination that reflects the unique history, perceptions, and circumstances of AI/AN peoples



# Future Direction

- Such information will make it possible to determine whether new measures of perceived discrimination specific to AI/ANs are warranted
- Development of a new and specific measure is not always feasible
  - Important to know if modifying the measure is needed
  - Consistent use across studies helps build the science

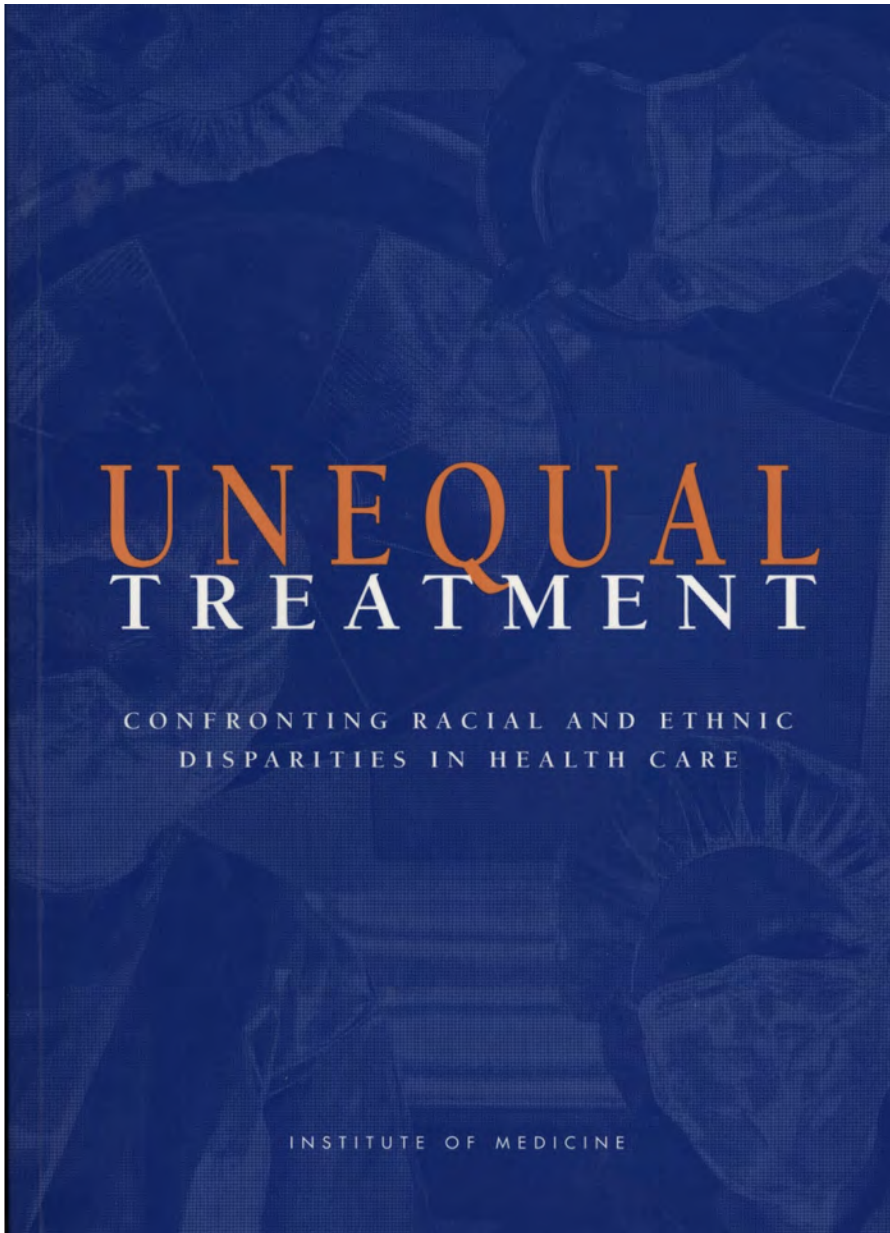
# Future Direction of Research

- Here the stories of healthcare experiences
- Draw on strengths, values, and teachings to
  - reduce stress to promote engagement
  - stand our sacred ground to practice asking for what we need within systems
- Decolonize social-justice and equity work so systems consider and prioritize our needs
  - Not as pity or as victims; reflection within systems; trauma informed
- Healing and our best selves

# Thank you

- Kelly Gonzales

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- Minorities receive fewer procedures and poorer quality medical care than whites even after accounting for access factors

*“Disparities in health status between American Indians and other groups in the United States have persisted throughout the 500 years since Europeans arrived in the Americas. Colonists, traders, missionaries, soldiers, physicians, and government officials have struggled to explain these disparities, invoking a wide range of possible causes.”*

Jones, D.S. (2006). The Persistence of American Indian Health Disparities. *Am J Public Health*, 96:2122–2134

# What explains these disparities?

## Discussion:

- Using our public health “hat” how do we explain the emergence and persistence of these striking health disparities in Indian Country?
  - What is the role of:
    - historical and inter-generational trauma
    - culture



## Perceived Experience of Discrimination in Health Care among American Indian Women



Bead work by Stella Washines



# Introduction



# The diabetes epidemic

- Type 2 diabetes is a prominent health concern
  - Compared to the general population in the U.S.
    - 2-3 X higher in American Indians (AIs)
    - Mortality from diabetes is 3 X higher

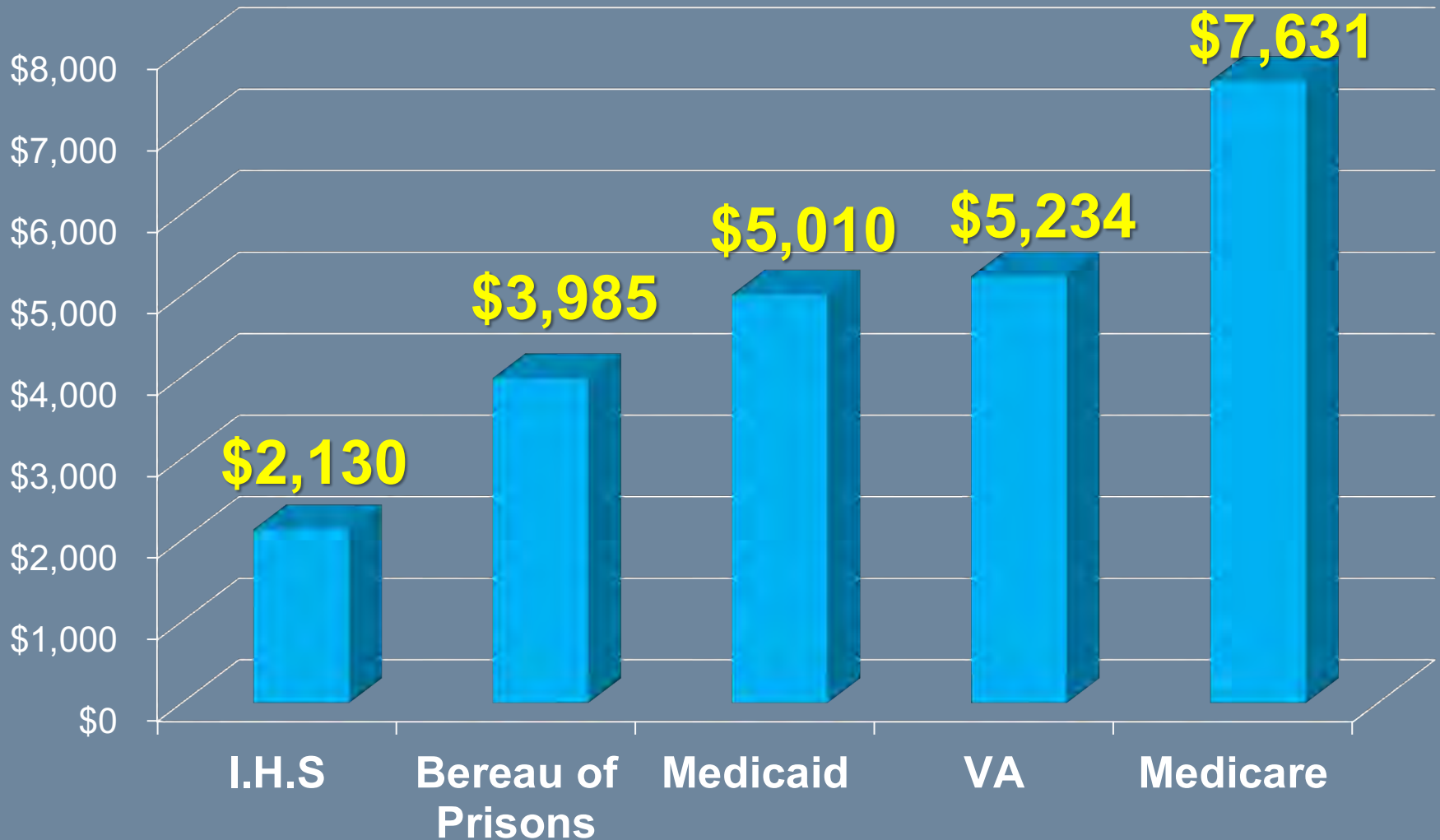
# Addressing the diabetes epidemic

- Through the Indian Health Service, the U.S. Congress has allocated new funds since 1997
  - New diabetes programs & resources
  - Better surveillance and reporting
    - Health improvements have been documented
    - Diabetes-related disparities remain, even after adjusting for medical access factors

# Addressing the diabetes epidemic

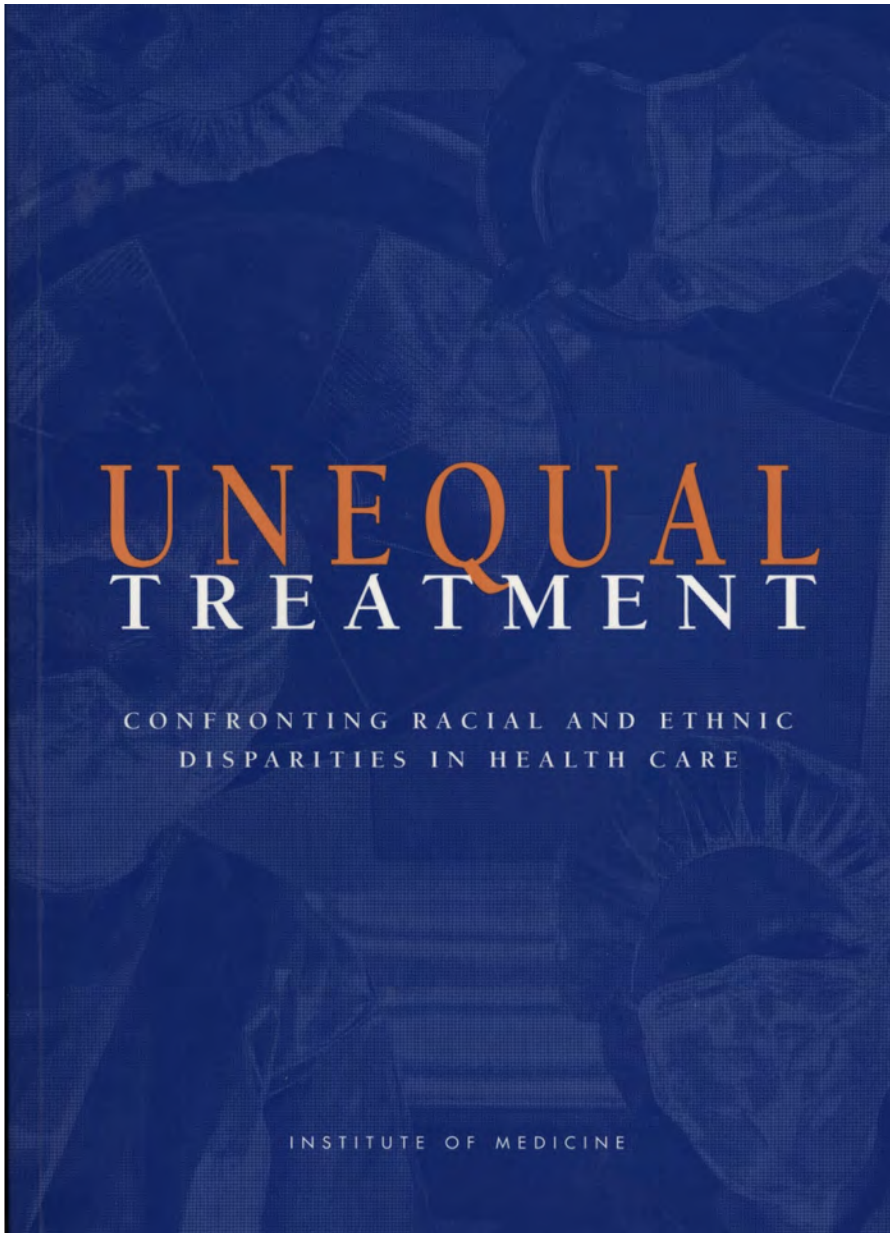
- Reasons for these persistent disparities may be explained by
  - Low use of health care services
- Improving diabetes-health outcomes requires understanding & addressing the reasons AIs under-use available health care services

# AI Healthcare Resource Disparities



# Examining factors beyond medical care

- Characteristics of the health care system & patient experience



- Minorities receive fewer procedures and poorer quality medical care than whites even after accounting for access factors

# Federal Government & Medical Maltreatment



- Doctrine of Conquest
  - Health care in exchange for land
  - Health care quality cited as *deplorable*
- Medical Maltreatment
  - 1970s—sterilization of AI women without informed consent
  - 1950's – 70's experimental surgery, procedures—without informed consent & even though less invasive procedures existed
    - Deeply rooted medical mistrust



# Examining factors beyond medical care

- More recent studies examine discrimination in the context of health care
  - Patients perceived experiences of unfair or negative treatment when obtaining health care based demographic characteristics
  - May lead to patient disengagement



# Perceived Discrimination

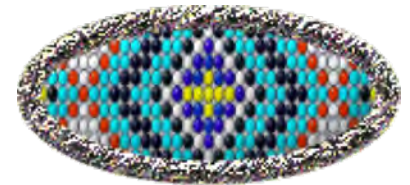
- May have important implications for health conditions, such as diabetes, that require on-going and routine health care
- Among patients with diabetes those who perceived discrimination in health care:
  - Receive fewer standards of diabetes-related health care services
  - Report poorer patient-provider communication
  - Worse glycemic control

# Discrimination & Health Care

- Discrimination in health care
  - Not uncommon
  - Occurs among diverse populations
- May contribute to disparities
  - health care
  - health status

# Gaps in the Research

- Research mainly focuses on African American populations
  - Only 3 studies to date examine perceived discrimination in health care among AIs
    - None of these studies have considered associations with:
      - Health status
      - Use of health care services



# The Research—methods & findings



# Methods

- Sample
  - 4-Northwest Indian health care facilities
  - AI women (ages  $\geq 18$ ) with diabetes
    - Generated from local RPMS
    - Confirmed by local medical staff
- Data Sources
  - Self-administered survey & medical records
- Data Collection
  - Community based survey sessions/mail
  - \$10 gift card



# Dependent Variables

- **Medical Health Records Data**

- Receipt of standard diabetes care services
  - Annual Exams (immunizations, screening...)
  - Measures of diabetes control (blood glucose levels...)

- **Self-report Data**

- Status for breast and cervical cancer screening
- Health care decisions



# Perceived Discrimination Measure

Thinking about your experience getting health care, in general, how often do each of the following happen to you because you are American Indian or Alaskan Native? **(Answer EACH Item)**

	Never	Rarely	Sometimes	Most of the Time	Always
a. Not treated courteously	1	2	3	4	5
b. Not treated with respect	1	2	3	4	5
c. Receive poor medical service	1	2	3	4	5
d. A doctor or nurse acts as if you are not smart	1	2	3	4	5
e. A doctor or nurse acts afraid of you	1	2	3	4	5
f. A doctor or nurse acts as if they are better than you	1	2	3	4	5
g. You feel like a doctor or nurse is not listening to you	1	2	3	4	5

\*(Bird et al., 2001, 2003, 2004; Thorburn et al., 2005)



# Results

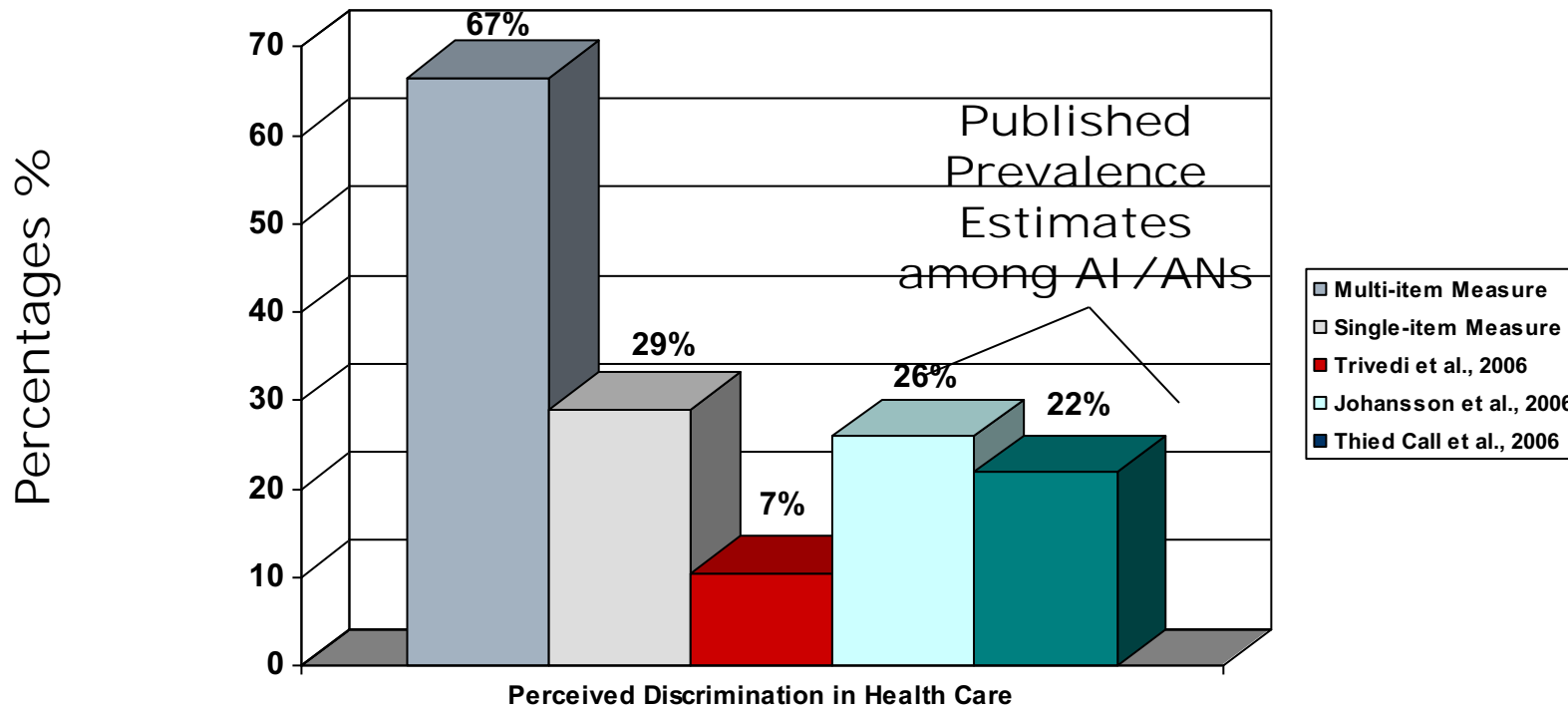


# Respondent Characteristics

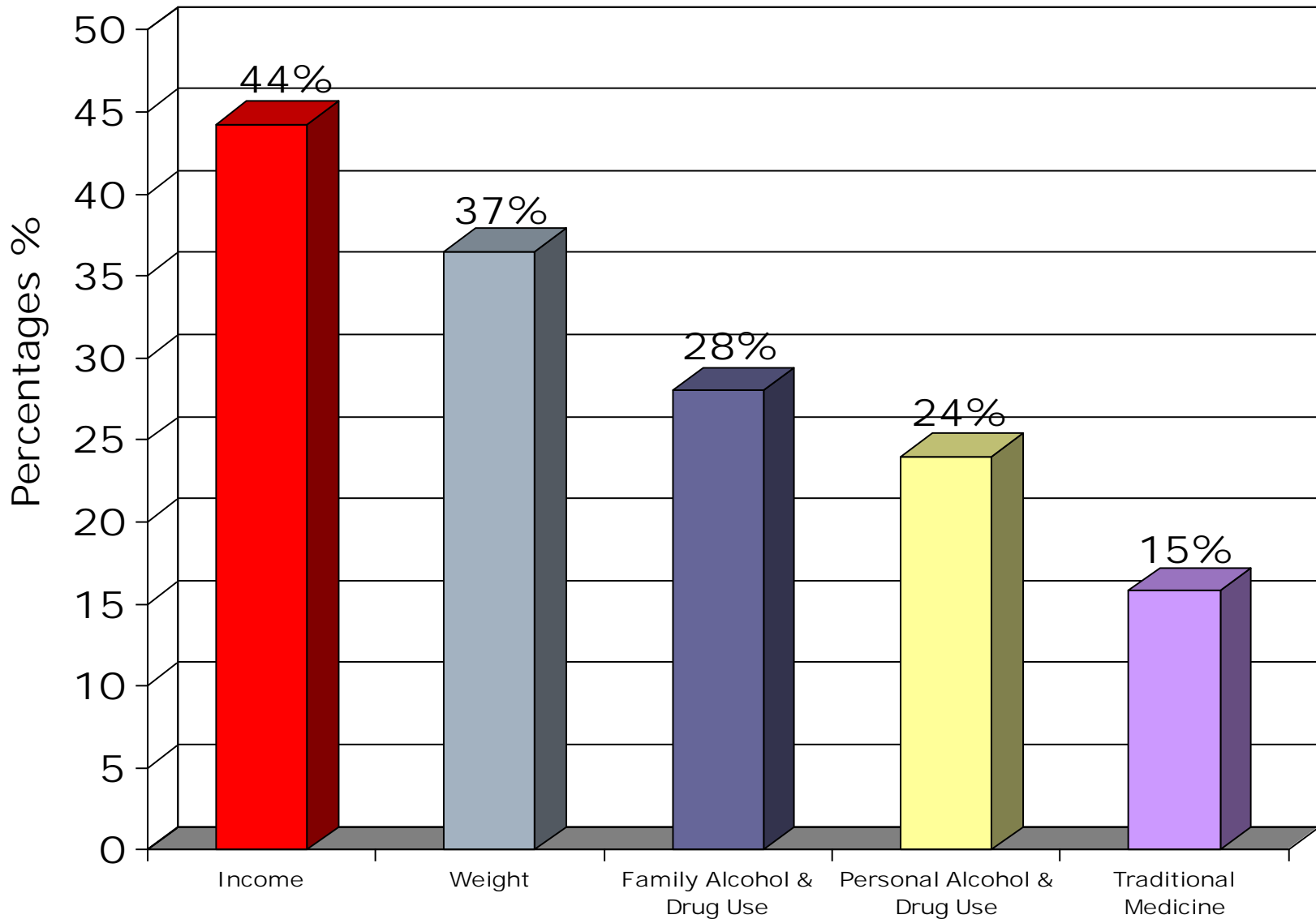
- 79% Response Rate
- 200 surveys collected
- Age (range 18 – 75 years)
  - More between 50-64 yrs
- Perceived health status
  - More thought their health was “good” vs. great or fair/poor
- Source of health insurance
  - Most (77%) had IHS and other sources of insurance
- Duration of diabetes
  - More had diabetes for 1-5 years



# Estimate of Perceived Experience of Discrimination in Encounters Among American Indian Women (n=200)



## Reasons for Perceived Discrimination in Health Care Among American Indian Women, Beyond Race.



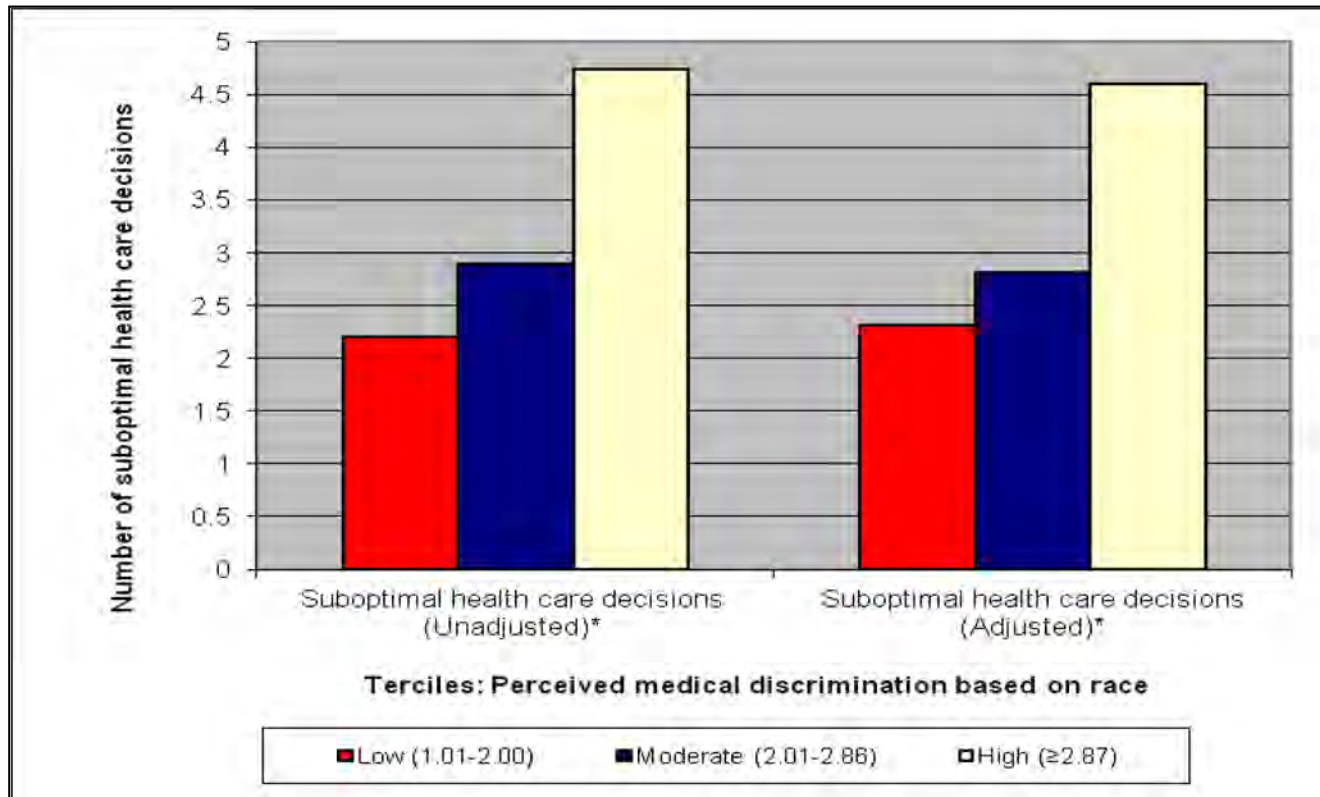
# Perceived Provider Bias & Belief the Quality of Health Care is Substandard

*“I won’t come here [local Indian health care facility] unless I pretty much know what’s wrong with me...and that’s just, I don’t know...this is a small community, they [local medical care providers] know your aunties, your parents, your grandparents, your sisters, and your brothers...you walk in the door and you come with your families baggage...not just yours...so, I’ve got a drug addicted, schizophrenic sister, and I have two parents who they [the doctors] assume were narcotic-pill addicted, and grandpa was and had been to treatment for it, and so I walk in the door [the Indian health clinic] with all of that baggage...I’m already down two, three notches...and then they [medical providers] open my file [medical record] and they think...“oh, you were a drug addict, alcoholic, smoker, and your obese”, ya know, down the whole list...and one doctor read it to me”...*

# Perceived Provider Bias & Negative Health Care Decisions

- *“...what I finally did was find my own doctor. And I drive into town [40 minutes away from the Tribal health clinic] to see a doctor now. And within two weeks of seeing this new doctor, he’d already diagnosed me with high blood pressure, high cholesterol, ya know the heart...irregular heart beat, and he sent me out for an MRI, and I’ve got crushed disks in my neck...I’ve got herniated disks in my back that have never been treated or diagnosed because they [referring to the local health care providers] down here just assume I was there for a pain killer....and so they [the local health care providers] didn’t even bother to send me out to be diagnosed...but to just know that I wasn’t crazy...I wasn’t makin up those back and neck pains...they really did exist...that was total violation for me”.*

**Figure 1.** Suboptimal health care decisions (out of a possible 7 decisions) by mean perceived medical discrimination tertiles among American Indian patients with Type 2 diabetes



<sup>a</sup>Denominator includes only participants with self-report of perceived medical discrimination.

<sup>b</sup>Perceived medical discrimination tertiles: low (1.01-2.00); moderate (2.01-2.86); high (≥2.87).

<sup>c</sup>Adjusted for age, duration of diabetes diagnosis, perceived health status, and source of health insurance coverage.

\*p<.001

The number of indicators of health care disengagement increased with higher mean levels of perceived discrimination

## Adjusted<sup>1</sup> Odds Ratios and 95% Confidence Intervals for Estimating Cancer Screening<sup>3</sup> Among American Indian Women

	Clinical Breast Exam		Pap Test <sup>2</sup>		Mammography Screening <sup>2</sup>	
	Adj. OR	95% CI	Adj. OR	95% CI	Adj. OR	95% CI
Not current	2.64	1.12, 6.19*	2.64	1.13, 6.18*	1.97	0.96, 4.03
Current	1.00	REF	1.00	REF	1.00	REF

\*p<0.05

<sup>1</sup>Adjusted: age, perceived health status, duration of diabetes, source of health insurance

<sup>2</sup>Pap test & Mammography, limited to those eligible for screening based on national screening criteria.

<sup>3</sup>Self-reported cancer screening



# Associations

## Receipt of health care services & diabetes-health status

	Adjusted Odds Ratios
Mammography <sup>a</sup>	1.97 (0.96, 4.03)
Pap Testing <sup>a</sup>	2.64 (1.13, 6.18)
Lower receipt of diabetes-standards of care	Some significant associations
Poorer diabetes control	Some significant associations •(higher mean blood glucose levels)

<sup>a</sup>Adjusted for age, duration of diabetes diagnosis, perceived health status, and source of health insurance coverage.

# Take Away & Next Steps



# Take Away

1. Als experience in health care has important health implications
2. Improving health care “access” may not be enough

# Solutions

- “Culturally unique, historically rooted stressors are important, understudied, and underappreciated considerations for understanding the social determinants of AI health.”
- “Any real effort to address Indigenous health disparities will respectfully incorporate due consideration of the socio-historical origins of contemporary health into policy and planning efforts.”


Source: Walls & Whitbeck, 2011

# Decolonizing Research & Health Care Practice

- Enables indigenous communities to theorize their own lives connecting with past and future generations.
  - Community Based Participatory Research Methods
  - Strength Based Approaches
  - Culturally Relevant
- Source: Bonnie Duran: from Smith, L.T. (2005) On Tricky Ground.

# Take Away

- Addressing the gaps in the science for Indigenous populations using a culturally relevant lens
  
- What are the connections with history and health?
  - Consider our findings regarding Pap testing
    - Legacy of medical mistreatment
    - Forced sterilization
  - Consider our findings regarding Mammography
    - Community-based efforts
    - May help to overcome the negative consequences of discrimination in the context of health care

- 
- Trust
  - Viscous cycle of intergenerational trauma happening now
  - Intersection of indigenous perspectives & dominant culture
  - Native community is diverse, traumas are profound

# Next Steps

- Qualitative research to “unpack” the meaning and experiences of discrimination in health care
- Create & implement training for health care providers to raise awareness and change practice



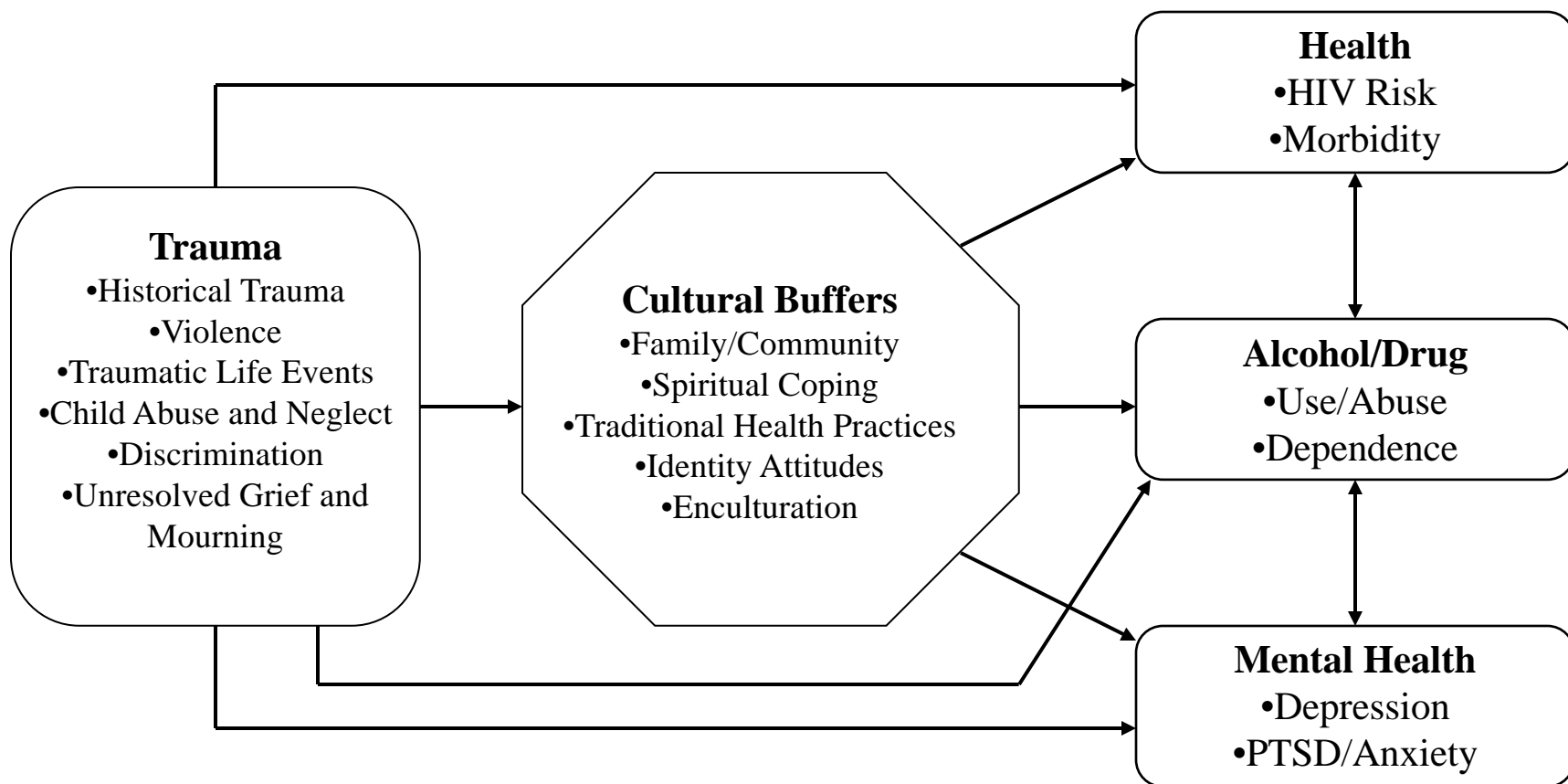


# Indigenist Stress Coping Model

*Stress*

*Coping*

*Health Outcomes*



# More research needed

- What are the triggers in the health care experiences that lead patients to perceive they've been treated unfairly?
- What's important?
  - Unresolved historical trauma & its influence on patient bias toward provider and health care systems
  - Provider bias & stereotyping

# Unresolved Historical Trauma

- Indian Health Service, an agency that is funded & administered by the federal government
- Inadequate services
- Despite improvements in the system, challenges remain:
  - Contract health
  - No standardized cultural competency training
  - Majority non-Native providers



**Indian Health Service Medical Providers**

# Discussion

- Any thoughts or questions about these findings?
- Do these experiences reflect your own?

# Discussion

- What did you think, feel, see or hear?
- How does this story relate to the stories you hear in your own work?
- What questions do you have?