

NIMHD Vision and Agenda

Research on American Indian and Alaska Native Health

Eliseo J. Pérez-Stable, M.D.

**Director, National Institute on Minority
Health and Health Disparities**

eliseo.perez-stable@nih.gov

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Committee Meeting**

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NIH National Institute
on Minority Health
and Health Disparities

NIMHD History

- **Established as an Office under the NIH Director through DHHS Secretary Louis W. Sullivan, M.D. in 1990**
- **Transitioned to a Center through legislation championed by Representative Louis Stokes (D-OH) in 2000**
- **Patient Protection and Affordable Care Act contained language championed by Senator Ben Cardin (D-MD) to transition to an Institute in 2010**
- **John Ruffin, Ph.D. led all the entities until his retirement in March 2014; Yvonne T. Maddox, Ph.D. became Acting Director**
- **Eliseo J. Pérez-Stable, M.D., started September 1, 2015**
- **FY 2016 budget was about \$280 million**



NIMHD Mission

- **Support research that advances understanding and improvement of health and disease in minority racial/ethnic groups in U.S.**
- **Support research to understand the causes of and define mechanisms leading to interventions that reduce health disparities in specific populations**
- **Supports the training and development of a diverse scientific workforce as part of broad NIH mandate**



Minority Health Definition

- **Minority Health Research focuses on health determinants that lead to specific outcomes within a minority group and in comparison to others**
- **Race and ethnic minorities share a social disadvantage and/or are subject to discrimination as a common theme**



OMB Race/Ethnic Classification

- **African American or Black**
- **Asian (>20 countries)**
- **American Indian or Alaska Native**
- **Native Hawaiian or other Pacific Islander**
- **Latino or Hispanic (20 countries)**
- **White**



Health Disparity Populations

- Health disparity populations include:
 - racial/ethnic minorities
 - less privileged socio-economic status
 - underserved rural residents, and/or
 - sexual gender minorities
- Populations have poorer health outcomes often attributed in part to social disadvantage, being subject to discrimination, and underserved in the full spectrum of health care.



Health Disparities Definition

- **A health disparity is defined as a health difference that adversely affects disadvantaged populations, based on one or more of the health outcomes**
- **Health disparities research is devoted to: 1) advancing scientific knowledge about defining mechanisms of how health determinants affect disparities; and 2) how this knowledge is translated into interventions to reduce disparities**



Health Disparity Outcomes

- Higher incidence and/or prevalence
- Burden of disease measured by *Disability-Adjusted Life Years (DALYS)*
- Premature and/or excessive *mortality* in areas where populations differ
- Poorer health-related quality of life and/or daily functioning using standardized measures



Mechanisms Leading to Health Disparities

- **Individual Behaviors, Lifestyle, Beliefs, and Response to Stress:** racism, adverse conditions, food insecurity, witness to violence, immigration, LEP status
- **Biological processes and Genetics:** Earlier age of onset, gene variants, metabolic differences, susceptibility, faster progression, greater severity
- **Physical Environment:** place, social system, neighborhood, infrastructure
- **Cultural Environment:** family, social interactions, network, community cohesion
- **Clinical Events and Health Care:** Differential treatments, poor communication, adverse events to medications, falls, progression of disease, access, use/abuse of appropriate services end of life care



Minority Health and Health Disparities Research Framework

Fundamental Factors: Race/Ethnicity, Low Socioeconomic Status, Rural Residence

Domains: Health Determinants	Levels of Influence			
	Individual	Interpersonal	Community	Societal
Biological	Vulnerability Mechanisms	Caregiver-Child Interaction Family Microbiome	Infectious Disease Prevalence Herd Immunity	Sanitation Immunization Pathogen exposure
Behavioral	Health Behaviors Coping Strategies	Family Function School/Work Function	Community Function	Welfare Immigration Language access
Physical Environment	Personal Environment	Household School Work	Community Environment, Resources	Government Education Housing
Sociocultural Environment	Sociodemographic Cultural Identify Discrimination	Networks Family/Peer Discrimination	Community Norms Discrimination	Societal Norms Structural Discrimination
Healthcare System	Access Limited English Proficiency	D/P Relationship Collaborative care	Availability Health Services	Quality of Care Health Care Policies
Health Outcomes	Individual Health	Family Health	Community Health	Population Health





Inclusion of Diverse Participants

- **All disparity populations are historically underrepresented in biomedical research**
- **Inclusion of minorities in clinical studies is an important and separate domain from research**
- **Inclusion is not to be confused with minority health or health disparities research**
- **Social justice, good science, and common sense mandate inclusion (40% US population)**





We Have to be at The Table

- **Yes, it is harder to recruit minorities and it usually takes more resources and different skills**
- **More face time and personal messages**
- **Minority scientists are generally better at it**
- **We need greater granularity (SES, birthplace, language) and accountability**
- **End myth that barriers are insurmountable**





Workforce Diversity is an Urgent Issue

- About 5% of all NIH R01 grants are awarded to African American and Latino PIs
- Apparent bias in funding: less re-submission, mentoring, “low success” topics
- Medical school graduates in 2014: 5% Latino, 6% African American, **<1% American Indian**
- See more uninsured and Medicaid patients, greater intent to work in underserved areas



NIMHD Scientific Programs

- **Clinical and Health Services Research**
- **Integrative Biological and Behavioral Sciences:
Mechanisms and Etiologies**
- **Community Health and Population Health Sciences**



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Life Expectancy in the U.S., 2014

	Men	Women
Whites	76.5	81.1
Blacks	72.0	78.1
Latinos	79.2	84.0
AI/AN and NH (2007-09)	68.0	74.3

Arias E, NCHS, CDC, 2016



Rural Residence is a Health Disparity

- **National Vital Statistics compare mortality for leading causes of death by urban/rural**
- **Heart disease, cancer, COPD, accidents and stroke**
- **Compared with metropolitan areas, nonmetropolitan areas have higher age-adjusted death rates and greater percentages of potentially excess deaths from the five leading causes of death.**

MMWR Surveillance Summary, January 13, 2017, Vol 66, No 1



Trends in Premature Mortality

U.S. 1999-2014, age 25-64

- **Death certificates from NCHS and Census data using age-period cohort models**
- **Increase in Whites and AI/AN from accidental OD, CLD/cirrhosis, suicide**
- **Women at age 30: +2.3% W; +4.3% AI/AN**
- **Marked decreases in Latinos (−3.2%), Blacks (−3.9%) and Asian/PI (−2.6%) from decline in HIV, cancer and heart disease**
- **AI/AN highest mortality; Blacks second**

Shiels MS, et al, Lancet. Online January 25, 2017



Diabetes Related ESRD

Age-adjusted Incidence, 1996-2013, age 18 y and older
MMWR, January 13, 2017, 66: 26-32

	1996	2013	%
Whites	12.1	15.5	+28
Blacks	52.2	42.7	-18
Asians	23.1	22.2	-4
AI/AN	57.3	27.5	-54
Latinos	40.1	34.2	-15



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American Indian/Alaska Native Research at NIH: FY 2015

- **NIMHD had 78 Projects and subprojects**
- **\$18,901,522 or about 9.8% of NIMHD**
- **Centers (COE/TCC), R01, R24, R43, T37)**
- **NIH-wide: 422 Projects and subprojects**
- **\$180,558,688**
- **Content analysis to identify needs**



"Hope and Healing Through Living Kidney Donation and Transplant"

Principal Investigator: Nancy Fahrenwald, PhD (U54MD008164)

<https://www.youtube.com/watch?v=YHV3QY9qIAk&feature=youtu.be>

AI/ANs have highest prevalence of Type 2 diabetes of any U.S. racial Minority and high rate end-stage renal disease

Living kidney donation and transplantation (LKDT) could save lives, but there are many cultural, geographic, and economic barriers to learning about it.

Project uses an interpersonal approach and story-telling to present LKDT information. Target audience is AI/AN people on renal dialysis, eligible for transplant.



Bias in Emergency Department Clinicians Caring for American Indian Children

Puumala, SE; et al (2016). The Role of Bias by Emergency Department Providers in Care for American Indian Children. *Medical Care* 54(6): 562-569. (U54MD008164)

American Indian children have high rates of emergency department (ED) use and face potential discrimination in health care settings.

- To assess both implicit and explicit racial bias, cross-sectional survey of clinicians at 5 hospitals; questions included American Indian stereotypes (explicit attitudes), clinical vignettes, and the Implicit Association Test. IATs created to assess implicit bias toward the child or the parent/caregiver.**
- Agreement with negative American Indian stereotypes was 22%-32%; 84% of clinicians had an implicit preference for White adults or children. Older clinicians (>50 y) had less implicit bias.**
- American Indian children were seen as increasingly challenging (P=0.04) and parents/caregivers less compliant (P=0.002) as the proportion of American Indian children seen in the ED increased.**



Risk, Resilience, and Natural Recovery

Mohatt, G. V., et al. (2008). "Risk, resilience, and natural recovery: a model of recovery from alcohol abuse for Alaska Natives." *Addiction* **103**(2): 205-215. (R24MD001626)

The People Awakening (PA) study explored an Alaska Native (AN) understanding of the recovery process from alcohol abuse and consequent sobriety.

- Cross-sectional, qualitative research design and community-based participatory research methods. State-wide convenience sample of 57 participants representing all five major AN groups: Aleut/Alutiiq, Athabascan, Inupiaq, Yup'ik/Cup'ik and Tlingit/Haida/Tsimshian. Participants were nominated and self-identified as being alcohol-abstinent at least five years following a period of problem drinking. Open-ended and semi-structured interviews gathered extensive personal life histories. Narratives analyzed using grounded theory and consensual data analysis techniques.
- AN participants recovery model describes recovery as a development process understood through five interrelated sequences: (i) the person entered into a **reflective process** of continually thinking over the consequences of his/her alcohol abuse; (ii) that led to periods of **experimenting with sobriety**, typically, but not always, followed by repeated cycling through return to drinking and sobriety; culminating in (iii) a **turning point**, marked by the final decision to become sober. Subsequently, participants engaged in (iv) Stage 1 sobriety, active coping with craving and urges to drink followed for some participants, but not all, by (v) Stage 2 sobriety, moving beyond coping to what one participant characterized as 'living life as it was meant to be lived.

The PA heuristic model points to important cultural elements in AN conceptualizations of recovery.



Sensation-seeking Predicts Daily Smoking Behavior

Spillane, N. S., et al. (2012). "Sensation-seeking predicts initiation of daily smoking behavior among American Indian high school students." Addictive Behaviors **37**(12): 1303-1306. (P60MD000507)

Sensation-seeking, defined as the tendency to seek novel and thrilling experiences, has been associated with smoking initiation in other groups but has never been examined in American Indian (AI) youth.

- **Data were from the Voices of Indian Teens Project (VOICES), a longitudinal study of AI youth from seven high schools in four AI communities in the western United States. A sample of 764 non-smoker students completed baseline and annual surveys in school over a three-year period. Smoking initiation was defined as endorsement of daily smoking after baseline.**

Participants were 353 males and 411 females aged 13 to 21 years at baseline.

- **After adjusting for covariates, baseline sensation-seeking correlated with smoking initiation differently by sex.**
- **Sensation-seeking did not predict daily smoking in males. Among females, however, higher sensation-seeking scores at baseline predicted daily smoking in both the unadjusted (odds ratio=1.4; 95% CI=1.1-1.8; p=0.005) and covariate-adjusted (odds ratio=1.3; 95% CI=1.0-1.6; p=0.04) models.**

Gender-specific prevention programs may be warranted in addressing different risk-factor profiles in this high-risk population.



Racial Disparities in Health Status: Diabetes among AI and US Adults

O'Connell, J., et al. (2010). Racial disparities in health status: a comparison of the morbidity among American Indian and U.S. adults with diabetes. Diabetes Care **33**(7): 1463-1470. (P60MD000507)

- American Indians and Alaska Natives are 2.3 times more likely to have diabetes; compare morbidity among American Indian and U.S. adults with diabetes.
- Demographic and health service utilization data for an adult American Indian population aged 18-64 years (n = 30,121) served by the Phoenix Service Unit from the Indian Health Service clinical reporting system. Comparison data for a U.S. population (n = 1,500,002) from commercial health insurance, matched by age and sex to the American Indian population, were drawn from the Market Scan Research Database. Diagnostic Cost Groups to identify treated medical conditions for which each individual was treated and to assign a risk score to quantify his or her morbidity burden
- American Indians with diabetes had **significantly higher rates of hypertension, cerebrovascular disease, renal failure, lower-extremity amputations, and liver disease** than commercially insured U.S. adults with diabetes ($P < 0.05$). AI prevalence rates were 61.2, 6.9, 3.9, 1.8, and 7.1%, respectively. The morbidity burden among the American Indian with diabetes exceeded that of the insured U.S. adults with diabetes by 50%
- The morbidity burden associated with diabetes among American Indians far exceeded that of commercially insured U.S. adults.



The Native Children Always Ride Safe (Native CARS)

Lapidus, J. A., et al. (2013). Trends and correlates of child passenger restraint use in 6 Northwest tribes: the Native Children Always Ride Safe (Native CARS) project. Am J Public Health 103(2): 355-361. (R24MD002763)

Compare children properly restrained in vehicles in 6 Northwest American Indian tribes in 2003 and 2009, and evaluated risks for improper restraint.

- 2009: conduct a vehicle observation survey in Oregon, Washington, and Idaho tribal communities. Estimate proportions of children riding properly restrained and evaluate correlates
- 1853 children aged 12 years and younger in 1207 vehicles; 49% rode properly restrained
- children aged 8 years and younger rode properly restrained 51% in 2009 c/w 29% in 2003 ($P < .001$); Only 25% of older booster seat-eligible children rode properly restrained in 2009
- American Indian children were more likely to ride improperly restrained than nonnative children in the same communities
- Other risk factors: riding with an unrestrained or nonparent driver, riding where child passenger restraint laws were weaker than national guidelines, and taking a short trip.

Proper restraint has increased, but it remains low. Tribe-initiated interventions to improve child passenger restraint use are being developed

NIMHD Scientific Workshops

- **Use of Information Technologies in Minority Health and Health Disparities (NSF partner)**
- **Self-Identified Race and Ethnicity in Genomic and Biomedical Research (NHGRI partner); held October 2016**
- **Structural Racism and Cultural Competence: Impact on Minority Health and Health Disparities (OMH partner)**



New Research Areas for FY 2017

- **HIV Infected Youth and Young Adults from Health Disparity Populations in Treatment**
- **Immigrant Populations**
- **Disparities in Surgical Care and Outcomes**
- **Social Epigenomics**
- ***Caribbean Initiative***
- ***Sleep Disparities***
- **Chronic Liver Disease and Liver Cancer**
- ***Research with Tribal Epidemiology Centers***



NIMHD Health Disparities Research Institute August 15-19, 2016, NIH Campus, Bethesda, MD



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