

# **NIMHD DIRECTOR'S REPORT**

**National Institute on Minority Health and Health Disparities  
(NIMHD) Advisory Council**

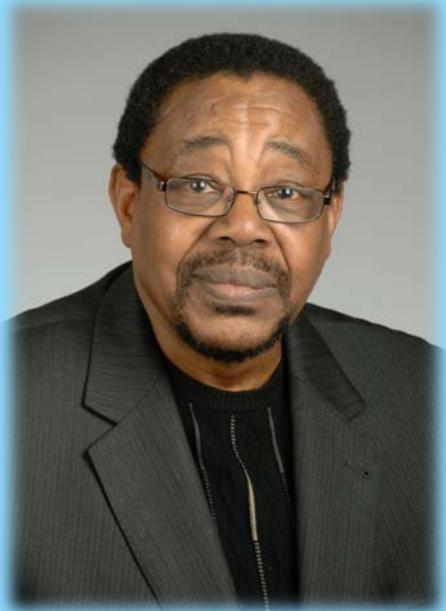
**September 9, 2014**

**Yvonne T. Maddox, Ph.D.**

Acting Director, National Institute on Minority Health and Health Disparities (NIMHD)  
National Institutes of Health (NIH)



# In Memoriam



**William T. Coleman, Jr., Ph.D.**, was the first African American Scientific Director at the National Institutes of Health.

Dr. Coleman had a long and distinguished career at NIH, dating back to 1974.

His most recent work involved innovative research on *Helicobacter pylori* (*H. pylori*) pathogenesis at NIDDK, addressing public health conditions such as gastritis, ulcers, and gastric cancers, which affects millions of Americans, especially Mexican Americans and non-Hispanic blacks.

Bill mentored a notable cadre of students, postdoctoral fellows, and high school science teachers, many of whom are now successful researchers, physicians and leaders of academic departments of major medical schools and universities.

Dr. Coleman died on August 18, 2014, at age 72 after a long and heroic battle with cancer.

*Bill leaves a legacy as a well-respected scientist and teacher; colleagues around NIH have expressed their admiration and sincerest regard for the dedicated researcher with an irrepressible sense of humor and optimism.*

# What's To Come

- News from NIH
- News from NIMHD
- Legislative and Budget Updates
- Operational Planning Activities
- Review of Concepts
- Report on Upcoming Meetings and Initiatives
- Fostering Health Disparities Research
- Discussion with Council

# News from NIH

# NIH To Launch Human Safety Study of Ebola Vaccine Candidate

Sources for information on research,  
international activities and prevention and  
control of Ebola.

National Institute of Allergy and Infectious Diseases

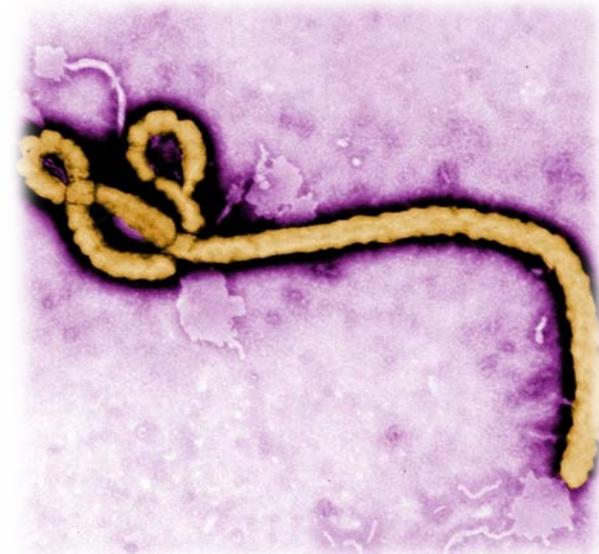
<http://www.niaid.nih.gov/topics/ebolaMarburg/>

Centers for Disease Control and Prevention

<http://www.cdc.gov/vhf/ebola/>

World Health Organization

<http://www.who.int/csr/disease/en/>



# Enhancing Biosafety and Biosecurity in the U.S.



- **Dr. Amy Patterson** named Associate Director for Biosecurity and Biosafety Policy in the NIH Director's Office in mid-July. She will report to the NIH Principal Deputy Director.
- **Notice of National Biosafety Stewardship Month and Health and Safety Requirements for NIH Grantees.** Announcing a new biosafety stewardship initiative and reminding institutions of the NIH to meet all applicable federal, state, and local health and safety standards. August 27, 2014, Notice Number: NOT-OD-14-127

**National Biosafety Stewardship Month September, 2014**

# NIH Announces Genomic Data Sharing



- To promote sharing of human and non-human genomic data and
- To provide appropriate protections for research involving human data

The National Institutes of Health (NIH) has announced a new policy, (available at <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-14-124.html>), and in the Federal Register (available at <https://federalregister.gov/a/2014-20385>) on August 28, 2014. The GDS Policy is also available at <http://gds.nih.gov/03policy2.html>.

Supplemental Information to the GDS Policy (available at [http://gds.nih.gov/pdf/supplemental\\_info\\_GDS\\_Policy.pdf](http://gds.nih.gov/pdf/supplemental_info_GDS_Policy.pdf))

# Other NIH News

- **Intramural Research Program (IRP) Review**  
*“The Future of the Intramural Research Program: Synthesis of Issues, challenges and Opportunities”*

Advisory Committee to the Director Working Group has been charged— one charge is to recommend how the IRP should ensure its distinctive role in biomedical research and how it should differ from extramural research institutions

- **LGBTI Research Coordinating Committee is in place**  
One goal is to develop an NIH LGBTI Health Research Strategic Plan

# News from NIMHD

## **NIMHD COUNCIL MEMBER NEWS**



Dr. Valerie Montgomery Rice to be officially installed on September 11 as the first woman to serve as President, Morehouse School of Medicine, Atlanta, Georgia

# New Appointments: Staff, Fellows, Details and Consultants

- **Dr. Rina Das** joined NIMHD in July 2014 as a new program officer for the Common Fund Diversity Program. Prior to joining NIMHD, Dr. Das was the Acting Chief of the Disparities Research Branch in the NCI Center to Reduce Cancer Health Disparities.
- **Mr. Sy Shackelford** joined NIMHD in July 2014 as a grants management specialist in the Grants Management Branch, OERA. Prior to joining NIMHD, Mr. Shackelford was a senior grants management specialist with NCI.
- **Dr. Fatima Karzai** joined NIMHD in July 2014 as a Clinical Fellow working in the Division of Intramural Research. Prior to joining NIMHD, Dr. Karzai was a Clinical Fellow at NCI.

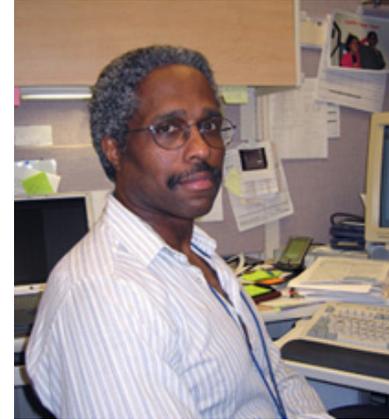
# New Appointments: Staff, Fellows, Details and Consultants (Cont'd)

- **Dr. Sherine El-Toukhy** joined the Division of Intramural Research in August 2014 as a postdoctoral visiting fellow. Prior to joining NIMHD, Dr. El-Toukhy was a postdoctoral research associate at the University of North Carolina at Chapel Hill, Gillings School of Global Public Health.
- **Ms. Angela Bates** joined NIMHD, on detail from Office of Research on Women's Health in August 2014 as a Special Assistant to the Director. Ms. Bates duties include Advisory Council Coordination.

# New Appointments: Staff, Fellows, Details and Consultants (Cont'd)

- **Dr. Anna Bellatorre** joined the Division of Intramural Research in September 2014 as a postdoctoral fellow. Prior to joining NIMHD, Dr. Bellatorre completed her Ph.D. in sociology from the University of Nebraska-Lincoln in sociology.
- **Ms. Kina Hendrick** joined NIMHD in September 2014 as a senior ethics specialist. Prior to joining NIMHD, Ms. Hendrick was an ethics specialist with NCI for eight years.
- **Ms. Karen M. Hendricks, J.D.** will be a consultant working in legislation assisting with the establishment of the Friends of NIMHD.

# Acting Deputy Scientific Director



**Dr. Kevin Gardner** is serving as acting deputy scientific director, NIMHD. Dr. Gardner is a tenured senior investigator in the Genetics Branch, NCI and head, Transcription Regulation Section. Dr. Gardner also holds the position of senior investigator in the NIMHD IRP.

Dr. Gardner received his B.S. from Yale University and earned his M.D. and Ph.D. from the Johns Hopkins University School of Medicine. He was a recipient of NIH Director's awards in 2007 and 2011.

A major research focus in Dr. Gardner's laboratory is the role of epigenetic modifications in the control of gene expression and cellular phenotypic change.

## **Notice of National Institute on Minority Health and Health Disparities (NIMHD) Participation in PA-13-302 “Research Project Grant (Parent R01)”**

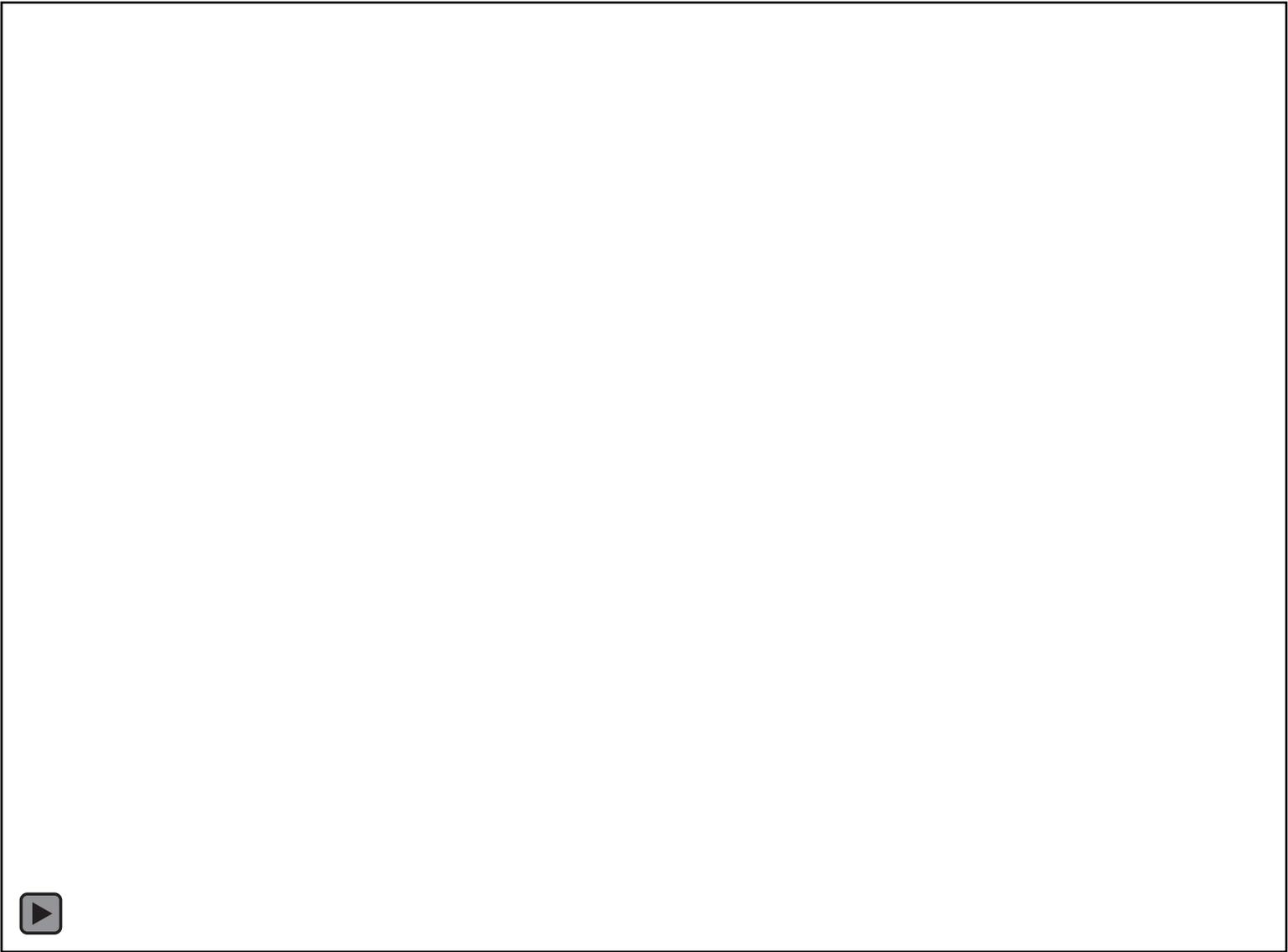
- Release date: July 10, 2014
- Purpose: to inform potential applicants that the NIMHD is participating, effective immediately, in NIH “Research Project Grant R01” investigator-initiated program
- Direct inquires: Michael H. Sayre, Ph.D., NIMHD  
Telephone 301-435-0962  
Email: [Sayrem@mail.nih.gov](mailto:Sayrem@mail.nih.gov)

# NIMHD Operational Planning Meeting, July 30, 31, 2014

- Purpose: To present and discuss current NIMHD portfolio, to pave the way to further define the science of health disparities, and to inform future fiscal decisions

*“What we engage in is of high moral value. What a privilege to be engaged in this noble enterprise that has real promise to give those without the opportunity to have greater health. Using the tools of research and our creativity to address our task, we have a moral responsibility to address health disparities. Thank you for what you are doing”.*

– Dr. Francis S. Collins, NIH director



# Operational Planning: Outcomes I.

- Full Institute participation
- More than 40 initiatives presented over a two-day period
- Opportunity for staff to discuss the institute's current research, programs and mechanisms
- Introduction of new areas of focus and opportunities for enhanced collaborations
- Identified initiatives for 2015 and 2016

# Operational Planning: Outcomes II.

- ❑ Fiscal year 2015 initiatives to include:
  - ✓ Research on health disparities and pain
  - ✓ Systems-level service and policy research on health disparities
  - ✓ Life course research in obesity focused on health disparities populations

# Concepts To Be Cleared for 2015

- NIMHD Academic Research Enhancement Award: Enhancing Health Disparities Research at Undergraduate Institutions (R15)
- NIMHD Technologies for Healthy Living: Improving Minority Health and Eliminating Health Disparities
- Behavioral Interventions to Prevent HIV in Diverse Young Men Who Have Sex with Men

# Staff Presentations and Speaking Engagements (selected) I.

- “Healthy, High-Achieving Schools: The Science, The Stakes, The Support,” GENYOUth’s 2014 Nutrition + Physical Activity Learning Connection Summit, July 16, Arlington, TX (Dr. Maddox)
- “Patients, Populations and Practice,” United Health Foundation Diverse Scholars Forum, July 24, Washington, DC (Dr. Stinson)
- “Strategic Directions for Health Disparities Research,” National Dental Association’s 101st Annual Convention, July 25, New Orleans, LA (Dr. Hunter)

# Staff Presentations and Speaking Engagements (selected) 2.

- Undergraduate Short-Term Education Program for Underrepresented Persons (STEP-UP) Research Symposium, Office of Minority Health Research Coordination, NIDDK, August 4, Natcher Conference Center, Bethesda, MD (Dr. Tabor)
- NIMHD Translational Health Disparities Course, August 11-22, Lister Hill Auditorium, (Drs. Maddox, Dankwa-Mullan, Hunter, and Sy)
- Why We Can't Wait: Conference to Eliminate Health Disparities in Genomic Medicine, September 4, Washington, DC (Dr. Maddox)

# NIMHD 2014 Translational Health Disparities Course

- The annual 2-week intensive course provided an introduction into the principles and practice of health disparities research.
- Out of 340 applications, 94 scholars were chosen to participate and 40 health disparities faculty experts lead the session modules.
- The course featured 12 stimulating modules that integrated science, practice and policy perspectives including: “Health Disparities from a Policy Perspective,” “Social Determinants of Health and Health Disparities,” and “Bioethics: Human Research Subjects Protections and Research Integrity.”
- OCPL captured scholars’ excitement and enthusiasm for the course by conducting video interviews that will be featured on the NIMHD website.
- Scholars also enjoyed touring the Clinical Center and the brand new Porter Neuroscience Research Center.



# Legislative and Budget Updates

# Presidential Action

- **H.R. 4631** – On August 8, 2014, the President signed H.R. 4631, the Autism CARES Act into law (P.L. 113-157). Autism CARES requires the Secretary to designate an official to oversee national autism spectrum disorder research, services, and support activities, and directs the official to implement such activities according to the strategic plan developed by the IACC to ensure cross-agency duplication is minimized.
- **H.R. 3548** – On August 8, 2014, the President signed H.R.3548, the Improving Trauma Care Act of 2014 into law (P.L. 113-152), which amends the Public Health Service Act, with respect to trauma care and research programs, to include in the definition of "trauma" an injury resulting from extrinsic agents other than mechanical force, including those that are thermal, electrical, chemical, or radioactive.

# Bill of Interest

- **H.R. 5294** – On July 30, 2014, Representative Roybal-Allard (D-CA) introduced the Health Equity and Accountability Act of 2014. The bill has 70 co-sponsors and contains ten titles, many of which include provisions for NIH. The titles include: Data Collection and Reporting; Culturally and Linguistically Appropriate Health Care; Health Workforce Diversity; Improvement of Health Care Services; Improving Health Outcomes for Women, Children, and Families; Mental Health; Addressing High Impact Minority Diseases (including cancer, viral hepatitis and liver cancer control and prevention, acquired bone marrow failure disease, cardiovascular disease, and chronic disease, HIV/AIDS, diabetes, lung disease, osteoarthritis and musculoskeletal diseases, and sleep and circadian rhythm disorders); Health Information Technology; Accountability and Evaluation; and Addressing Social Determinants and Improving Environmental Justice. On, August 15, 2014, the bill was referred to the Subcommittee on Health.

# Budgetary Actions Since June 2014 Council

## ***Funds Out:***

Second Secretary's Transfer to support  
Department-wide cybersecurity needs,  
\$53,000

Co-funding to Indian Health Service for Tribal  
Epidemiology Centers program, \$800,000

## ***Funds In:***

National Children's Study transfer from NIH  
project placed on hold, \$881,858

# Competitive Awards From June 2014 Council

RFA/PA Title	No. of Awards	Total Award \$
NIMHD Basic and Applied Biomedical Research on Minority Health and Health Disparities (R01)	10	\$3,985,877
NIMHD Social, Behavioral, Health Services, AND Policy Research on Minority Health and Health Disparities (R01)	19	\$7,595,475
NIH Support for Conferences and Scientific Meetings (R13/U13)	4	\$199,899

# Competitive Awards Continued

RFA/PA Title	No. of Awards	Total Award \$
Systems Science and Health in the Behavioral and Social Sciences (R21) - <i>Funded by NIH Office of the Director</i>	1	\$188,001
Development and Translation of Medical Technologies to Reduce Health Disparities (SBIR - R43/R44)	6	\$1,132,890
Limited Competition: NIMHD Research Centers in Minority Institutions Infrastructure for Clinical and Translational Research (U54)	5	\$15,075,333

# Upcoming NIMHD Activities



National Institute  
on Minority Health  
and Health Disparities

# NIH Health Disparities Seminar Series

All seminars are  
free and open to  
the public

**September 18, 2014**  
3:00 PM to 4:30 PM

**Natcher Conference Center**  
Building 45/ Balcony A



**If You Build It, Will They Come?  
Addressing Mental Health  
Treatment Gaps in Latinos**

**Sergio Aguilar-Gaxiola, MD, PhD**

Director, UC Davis Center for Reducing Health Disparities  
Professor of Clinical Internal Medicine,  
University of California, Davis  
Davis, California

**November 20, 2014**  
3:00 PM to 4:30 PM

**Natcher Conference Center**  
Building 45/ Room E1/E2



**Community Engagement as a Path to Health Equity:  
Promoting both Culture-Centered and  
Evidence-Based Interventions in "Indian Country"**

**Bonnie M. Duran, DrPH**

Director, Center for Indigenous Health Research  
Associate Professor, Department of Health Services,  
School of Public Health and School of Social Work  
University of Washington  
Seattle, Washington

For more information, call (301) 402-1366 or visit [www.nimhd.nih.gov](http://www.nimhd.nih.gov)  
For reasonable accommodations, call (301) 402-1366 or the  
Federal Relay 1-800-877-8339

# **NIMHD/NIH American Indian and Alaska Native Research Forum**

Friday, October 3, 2014

Natcher Conference Center, NIH Campus

- Expanding the pool of scientists, researchers and health professionals with the American Indian and Alaska Native community is essential to addressing the many interrelated causes of disease and ill health in this population
- First-time research forum to showcase NIH-funded American Indian/Alaska Native researchers and their contributions to biomedical research.

# COMMON FUND DIVERSITY PROGRAM KICKOFF



October 27-28, 2014  
Natcher Conference Center, NIH Campus

## **Purpose:**

To bring together the PIs of the Building Infrastructure Leading to Diversity (BUILD) sites, the PI of the National Research Mentoring Network (NRMN), and the PI of the Coordination and Evaluation Center (CEC), NIH Program and Grants Management staff and NIH Common Fund leadership for discussions on procedures, plans and processes for establishing the diversity consortium



2014

MINORITY HEALTH &  
HEALTH DISPARITIES  
GRANTEES' CONFERENCE

TRANSDISCIPLINARY COLLABORATIONS:  
*Evolving Dimensions of US and Global Health Equity*

December 1-3, 2014 National Harbor, Md.

- To highlight excellence and innovation in basic, translational and clinical research from the programs supported by NIMHD
- To focus on early career investigators through training and professional development workshops, mentoring, and meet the experts sessions
- To offer opportunities for sharing research information related to minority health and health disparities in various diseases and conditions

# SCIENCE OF HEALTH DISPARITIES RESEARCH



# NIMHD mission

NIMHD conducts and supports research, training of a diverse workforce, research capacity and infrastructure development, public education and information dissemination programs. NIMHD is the leading entity at the NIH for planning, reviewing, coordinating, and evaluating minority health and health disparities research activities conducted by the NIH Institutes and Centers.

# Health Disparities Definitions

- “A **population is a health disparity population** if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population.” **Minority Health and Health Disparities Research and Education Act United States Public Law 106-525 (2000), p. 2498**
- “**Health inequities** are avoidable inequalities in health between groups of people within countries and between countries. These inequities arise from inequalities within and between societies. Social and economic conditions and their effects on people’s lives determine their risk of illness and the actions taken to prevent them becoming ill or treat illness when it occurs.” **World Health Organization**

# Health Disparities Definitions

- **Health disparities** are differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific **population groups** in the United States. *NIH*
- **Health disparities** as differences in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates. Many different **populations** are affected by disparities including racial and ethnic minorities, residents of rural areas, women, children, elderly and persons with disabilities. *OMH*

# Health Disparities Definition

## Healthy People 2020

**Healthy People 2020:** A health disparity is a “particular type of health difference that is closely **linked with social, economic, and/or environmental disadvantage.**

Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their **racial or ethnic group; religion; socioeconomic status; gender; age; mental status; cognitive, sensory or physical disability; sexual orientation or gender identity; geographic location or other characteristics historically linked to discrimination or exclusion.**

# Minority Health and Health Disparity Populations

## OMB standards – Minority Racial/Ethnic Classification

- African American or Black
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Hispanic or Latino

## Other Populations with Health Disparities<sup>(2012 Health Disparities report AHRQ)</sup>

- LGBTI Populations
- Rural
- Urban
- Poor (low income)
- Child and Adolescent Health
- Immigrant and Migrant
- Special Needs: Disabled, Chronic Care, End-of-life, Medically Underserved

# Minority Health vs Health Disparities

## MINORITY HEALTH (MH)

- Synonymous with HD, health equity, health equality, etc.
- Some minorities have Health Disparities
- MH Research concentrates on

### DIFFERENCES:

- ★ Attributes of **population group**
- ★ Contributing factors to health status

## HEALTH DISPARITIES (HD)

- Lacks standard definition - Needs defining parameters – thresholds of determination
- More than minority populations
- Lacks consensus on Metrics / Benchmarks
- HD Research concentrated on determining when and how differences becomes health burdens – create appropriate interventions

# Minority Health

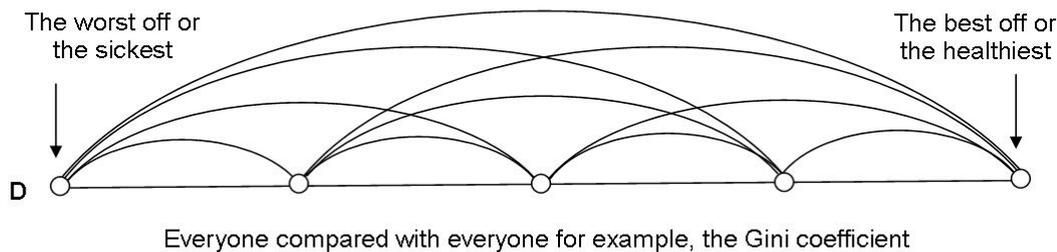
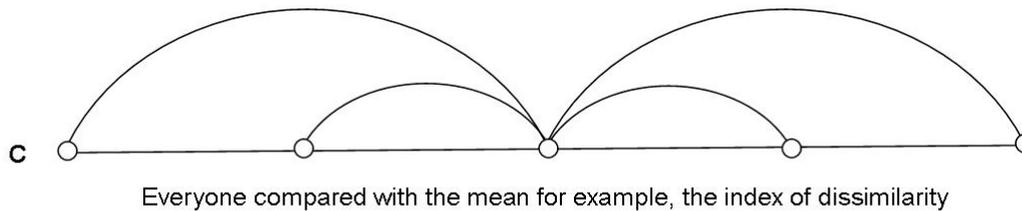
- **Minority Health (MH)**

Attributes associated with a particular **population group** - often correlated with race and ethnicity – that are unique or found significantly within a cluster.

- **Minority Health Research**

- Investigates unique **population** attributes
- Conducts research to identify biological, behavioral, environmental differences

# MEASURING HEALTH DISPARITIES



The choice of the reference group will affect the size of the disparity

## Reference Group or Comparison

**Not all differences  
are health disparities**

# All Differences are not Health Disparities

Most would agree...having red hair and light skin vs. brown hair and dark skin is a “DIFFERENCE”... not a health disparity.



Red Hair – Light Skin

Mainly research focuses on identifying differences rather than understanding when, how, why, where, and with whom does a difference become a disparity.



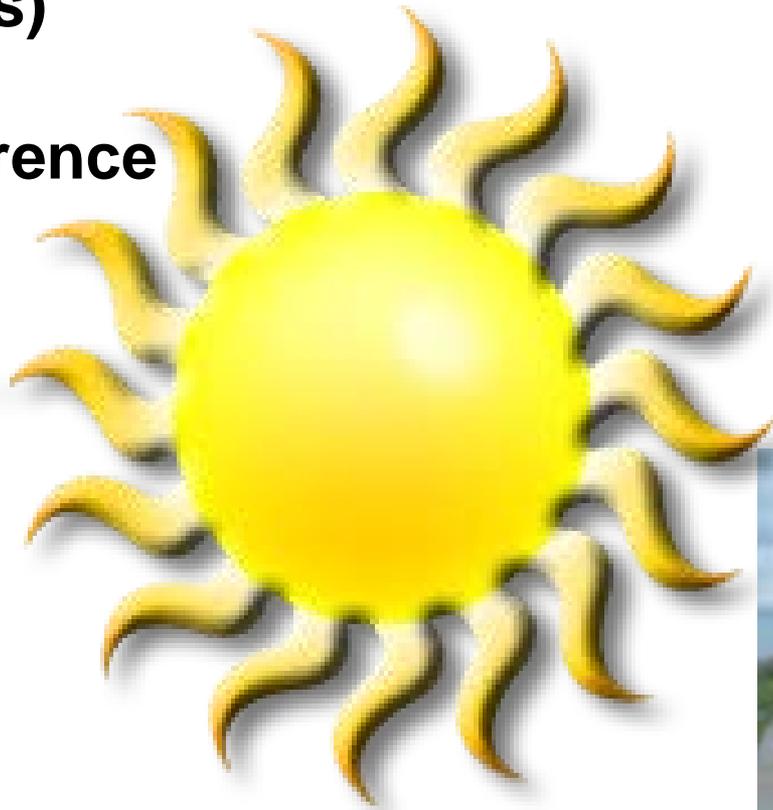
Brown Hair – Dark Skin

# When can a difference become a disparity?

**Some condition(s)  
have to exist to  
transition a difference  
to a disparity**

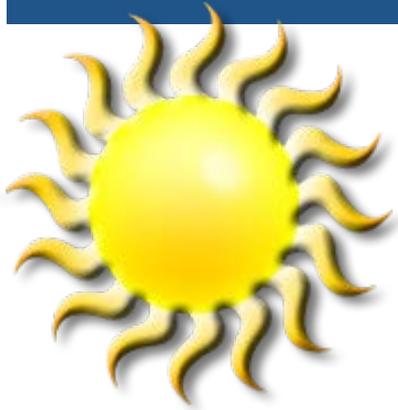


Red Hair – Light Skin

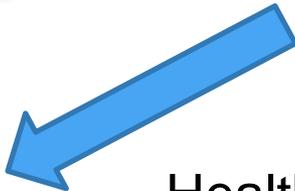


Brown Hair – Dark Skin

# When can one become the other?



Primary Health Consequence:  
sun burn, sun poisoning



Health Disparity:

- Higher incidence - most burn
- Earlier onset – burns with minimal sun exposure
- Faster progression to sun poisoning/2<sup>nd</sup> degree burns
- Poorer Outcomes - risks of cancer, QoL, pain, scars



Red Hair – Light Skin



Brown Hair – Dark Skin

# When can one become the other?



Primary Health Consequence:  
sun burn, sun poisoning



Red Hair – Light Skin



Brown Hair – Dark Skin

# When can one become the other?

## Health Disparities Research

How much sun exposure transitions the difference to a disparity?

What behaviors mediate the different risk?

What are the biological differences?

Are there protective factors?



Red Hair – Light Skin

Did each have the right knowledge?

Could sun screen be afforded?

Shelter needed?



Brown Hair – Dark Skin

# When can one become the other?

## Health Disparities Research

### Answers to Research Questions:

- Provide evidence for the right interventions
- Evidence for the right time



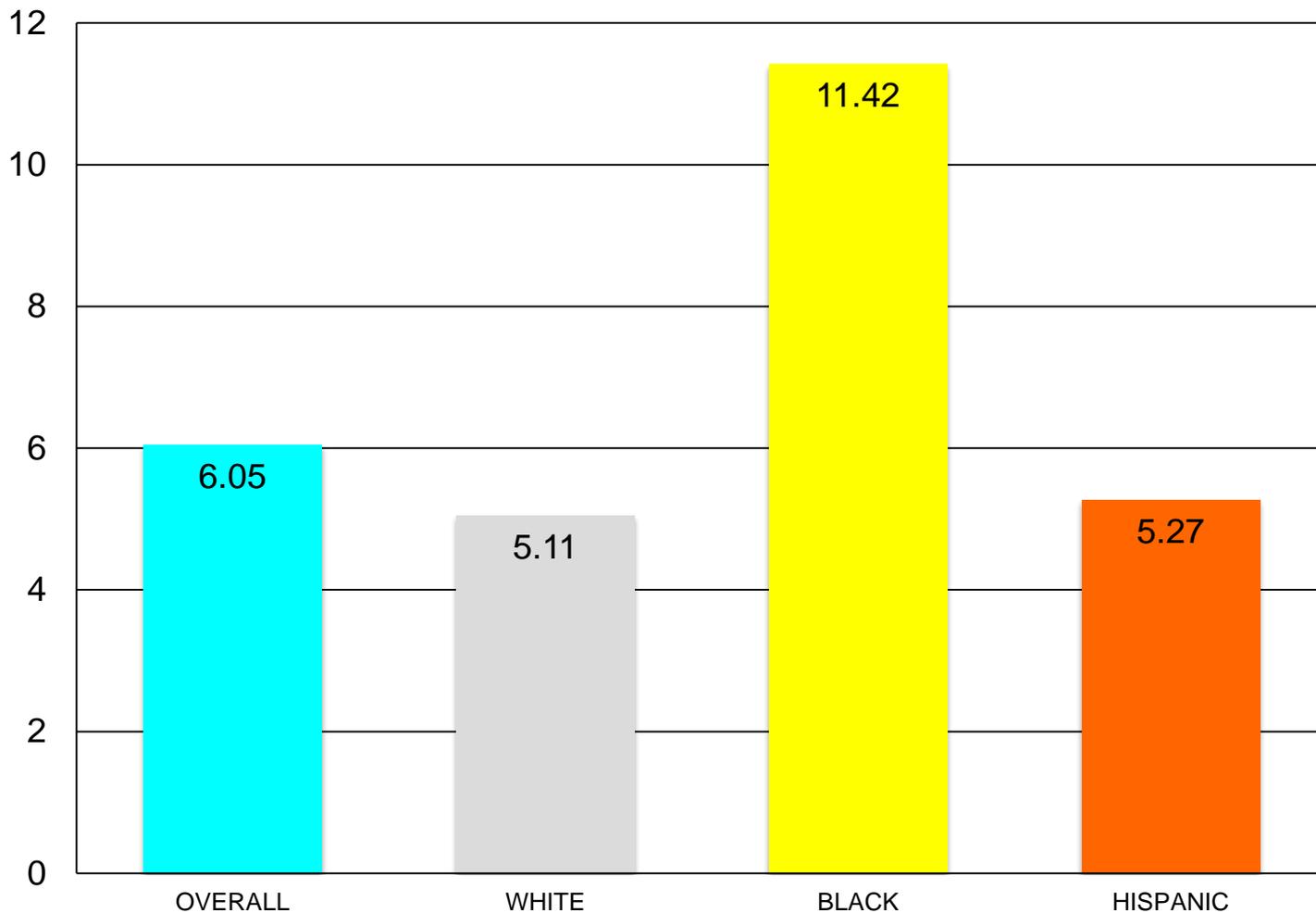
Red Hair – Light Skin

**Best chance to  
reduce the  
disparity**



Brown Hair – Dark Skin

# U.S. Infant Mortality Rate – 2011 (Per 1,000 live births)



# Infant Mortality

An iceberg floating in the ocean, with the tip above water and a much larger base below. The tip is labeled with 'Premature Births', 'Congenital Anomalies', and 'SUID'. The submerged part is labeled with 'Maternal Pregnancy Complications' and 'Placental or Cord Anomalies'. The background shows a sunset or sunrise over the water.

Premature Births

Congenital Anomalies

SUID

Maternal Pregnancy Complications

Placental or Cord Anomalies

# Infant Mortality and Health Disparities

## Health Determinants

Racism

Fatherless households

Poverty

Limited Access to Care

Under-Education

Poor Working Conditions

Teen Births

Biology

Neighborhoods

No Insurance

Housing

Smoking

Lower graduation rates

Genetics

“Medical baggage”

Family Support

Nutrition

Unemployment

Substance Use

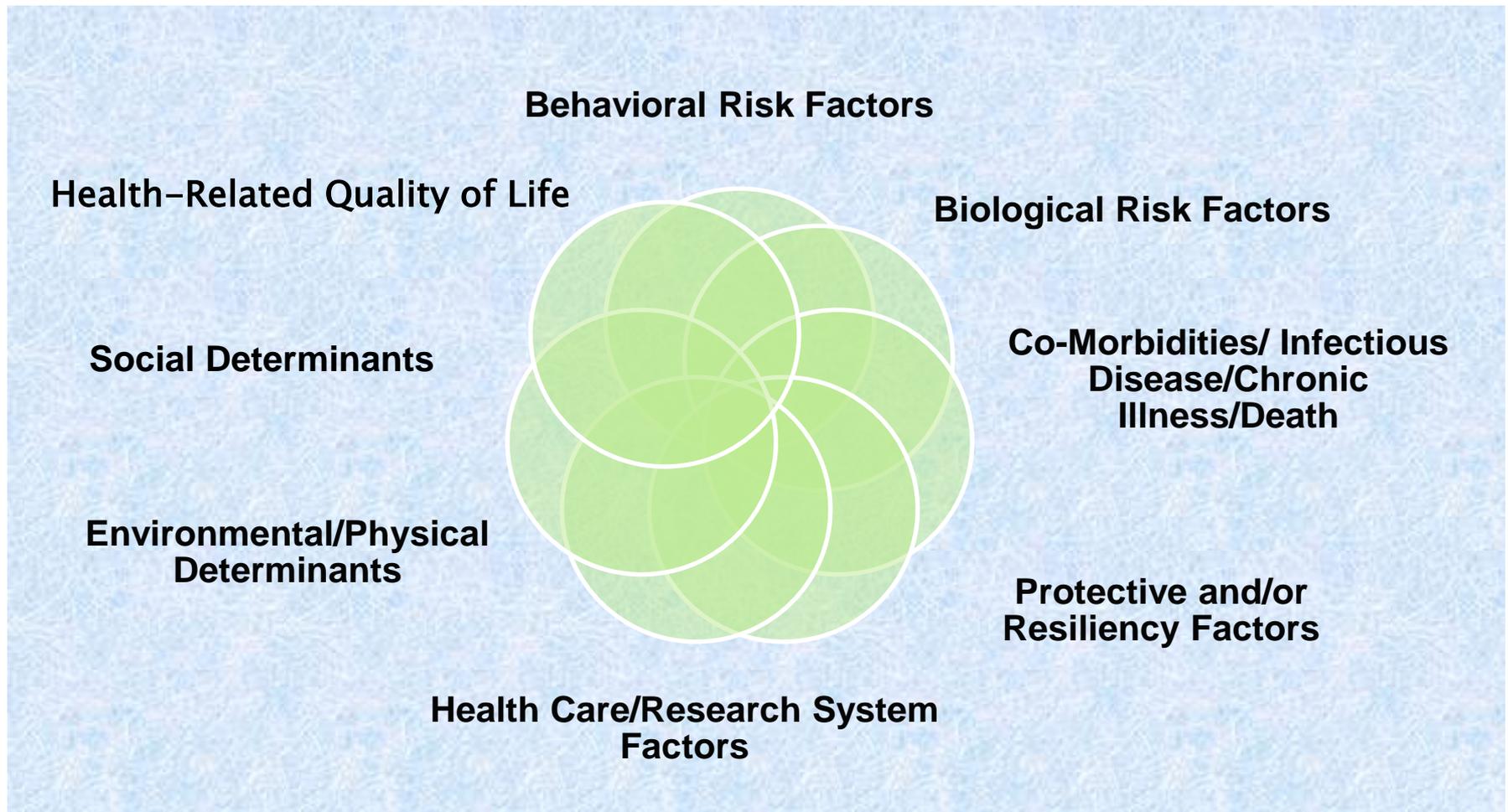
Incarceration rates

Hopelessness

Stress

# Domains of Health Disparities' Determinants

(8 contributing factors)



# Health Disparities Research

- Determines which combination/patterns of attributes and differences results in a health disparity condition (higher incidence, earlier onset, faster progression, poorer outcomes)
- Assesses known information in order to understand how to impact disparities - what, where, when, how, who
- Designs and tests interventions to reduce these disparities

# Health Disparities Research Model

1

- Identify differences among **populations** (MH)

2

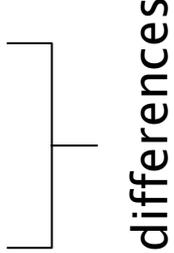
- Validate if, how & when these differences lead to health disparities (HD)

3

- Design interventions to reduce health disparities (HD)

FRAMEWORK  
FOR  
IDENTIFYING,  
UNDERSTANDING  
AND  
REDUCING  
HEALTH  
DISPARITIES

# Science of Health Disparities

1. Target one or more of the following:
  - Higher incidence/prevalence
  - Earlier onset
  - Faster progression
  - Poorer outcomes

differences
2. Examine health determinants interactions to verify contributing factors
3. Use results to determine the best intervention, applied at optimum time points
4. Test intervention to impact health disparity
5. Validate intervention – generalizability studies
6. Assess impact on health disparity–Measure variables and determine if this process reduced the disparity
7. Disseminate findings into practice and communities

# Discussion...

Comments, questions?