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/
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


Other NIH News

- **Intramural Research Program (IRP) Review**


  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 Shackleford joined NIMHD in July 2014 as a grants management specialist in the Grants Management Branch, OERA. Prior to joining NIMHD, Mr. Shackleford 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 inquiries: Michael H. Sayre, Ph.D., NIMHD
  Telephone 301-435-0962
  Email: 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
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.


- “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)
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.
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

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

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

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
For reasonable accommodations, call (301) 402-1366 or the Federal Relay 1-800-877-8339
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.
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 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*
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 (2012 Health Disparities report AHRQ)
- 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

<table>
<thead>
<tr>
<th>MINORITY HEALTH (MH)</th>
<th>HEALTH DISPARITIES (HD)</th>
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<tbody>
<tr>
<td>Synonymous with HD, health equity, health equality, etc.</td>
<td>Lacks standard definition - Needs defining parameters – thresholds of determination</td>
</tr>
<tr>
<td>Some minorities have Health Disparities</td>
<td>More than minority populations</td>
</tr>
<tr>
<td>MH Research concentrates on DIFFERENCES:</td>
<td>Lacks consensus on Metrics / Benchmarks</td>
</tr>
<tr>
<td>Attributes of population group</td>
<td>HD Research concentrated on determining when and how differences becomes health burdens – create appropriate interventions</td>
</tr>
<tr>
<td>Contributing factors to health status</td>
<td></td>
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</table>

**Minors 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
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

A framework for measuring health inequity — Asada, Y. 2005
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.

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

Some condition(s) have to exist to transition a difference to a disparity.
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/2nd degree burns
- Poorer Outcomes - risks of cancer, QoL, pain, scars
When can one become the other?

Primary Health Consequence:
sun burn, sun poisoning
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

Brown Hair – Dark Skin

Did each have the right knowledge?

Could sun screen be afforded?

Shelter needed?
When can one become the other?

Health Disparities Research

Answers to Research Questions:

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

Best chance to reduce the disparity
U.S. Infant Mortality Rate – 2011 (Per 1,000 live births)

- Overall: 6.05
- White: 5.11
- Black: 11.42
- Hispanic: 5.27

B/W: 2.2

X : HP 2020 Goal

NVSS
Infant Mortality

- Premature Births
- Congenital Anomalies
- SUID
- Maternal Pregnancy Complications
- Placental or Cord Anomalies

Arthur R. James
Infant Mortality and Health Disparities

Health Determinants

Racism

Fatherless households

Poverty

Limited Access to Care

Biology

No Insurance

Housing

Lower graduation rates

Under-Education

No Insurance

“Medical baggage”

“Medical baggage”

Unemployment

Neighborhoods

Nutrition

Family Support

Incarceration rates

Stress

Hopelessness

Substance Use

Poor Working Conditions

Teen Births

A. R. James
Domains of Health Disparities’ Determinants
(8 contributing factors)

- Behavioral Risk Factors
- Biological Risk Factors
- Co-Morbidities/Infectious Disease/Chronic Illness/Death
- Protective and/or Resiliency Factors
- Health Care/Research System Factors
- Environmental/Physical Determinants
- Social Determinants
- Health-Related Quality of Life
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

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?