

Yvonne Maddox Recognized for Contributions to NICHD; Shares Vision for NIMHD with Advisory Council



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On June 9, the Friends of the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD) sponsored a Congressional briefing, "Celebrating the Career of Dr. Yvonne Maddox: Spotlight on Disparities Research," to recognize Yvonne Maddox, who recently retired after serving nearly 19 years as the deputy director for the Institute. COSSA is a member of the Friends of NICHD's executive committee and was a sponsor of the briefing, which highlighted NICHD's efforts and support for health disparities research, one of

Maddox's greatest interests and passions during her tenure at NICHD.

NICHD director Alan Guttmacher expressed his appreciation for Maddox and noted that she was an "important deputy and a great friend." Guttmacher also expressed his gratitude for the Friends of NICHD, a group that reflects the broad and diverse research portfolio of the Institute. The Friends of NICHD, Guttmacher noted, assists NICHD in making sure the research it supports improves people's lives. He also recognized that not all of the NIH 27 institutes and centers have "friends."

Maddox, who is now serving as Acting Director for the National Institute of Minority Health and Health Disparities (NIMHD), expressed her personal appreciation for the Friends and the contributions by NICHD made possible with the Friends. NICHD's mission "critically important" to the health and development of the citizens of the U.S. and the world, she pointed out.



Health disparities became a focus for Maddox in 1999-2000 when she had the opportunity to serve as acting deputy director for the National Institutes of Health (NIH) under the late Dr. Ruth Kirschstein while continuing her duties as deputy director of NICHD. It is clear that the community plays a big role in reducing disparities, making research into social and behavioral change so necessary. Behavior change has made a big difference in reducing disparities in health, Maddox noted. She cited as an example the NICHD "Back to Sleep/Safe to Sleep" campaign designed to get mothers to put their babies to sleep on their backs and consequential progress made as a result of a change in behavior. From 2000 to 2011, there was a 12 percent drop in the deaths due to Sudden Infant Death Syndrome (SIDS). The rate also dropped in the Black population, she said, noting that the gap is closing. It is the social determinants and behavior modifications that will make the difference, Maddox asserted. During her tenure at NIMHD, Maddox noted that the Institute will be looking at the social determinants associated with disparities in health. The Institute intends to work towards developing the science of health disparities research, including developing and expanding the methodology needed to do the science.

Regina James, Office of Health Equity, noted that health issues are often thought about as something people get as adults. She challenged the Capitol Hill audience to think about health disparities as starting before we are born and continuing across the lifespan, influenced by social determinants—where we live, work and play. James also noted that as a nation, the United States lags behind other developed countries. This was topic of a September 2013 COSSA-led Congressional briefing on the findings and research recommendations of the National Research Council's (NRC) and Institute of Medicine's (IOM) report <u>U.S. Health in International Perspective: Shorter Lives, Poorer Health</u>. The report discussed how NIH and other public health agencies can respond (see Update, October 25, 2013). James also referenced the landmark report, <u>Unequal Treatment: Confronting Racial and Ethnic Health Disparities in Health Care</u>, the subject of another COSSA-led briefing in 2002. The data gathered thus far suggests the need to move data collection to an earlier developmental point, said James. The life course perspective allows for an examination of the early expression of diseases and conditions and how they can affect individuals throughout their lives. There is cumulative damage over time along with a lag before biological embedding occurs and expresses in disease outcomes, James explained.

Jack Yanovski, Section on Growth and Obesity Program on Endocrinology and Genetics, discussed NICHD's pediatric obesity research and the longitudinal investment the Institute has in this research area. Yanovski cited several statistics and noted the greater prevalence of obesity in minority populations. High blood pressure is a major problem for large subsections of these populations. NICHD has been initiating studies looking at the different sectors. Yanovski also noted that many of the behavioral interventions aimed at obesity prevention are ineffectual because they are developed among the disparate populations affected. The engagement of the community is necessary to design these interventions so that they have a greater impact, he argued.

Shavon Artis, Safe to Sleep Campaign, noted that 2014 is the 20th anniversary of the landmark "Back to Sleep" campaign approved by former NICHD director Duane Alexander. She lauded Maddox's and Alexander's efforts to engage the community and its leaders in addressing "how we can save our babies." The effort became a recognizable campaign within hospitals, resulting in a 50 percent decline in deaths from SIDS. In addition, Artis pointed out that back sleeping has increased from 13 percent to nearly 70 percent. Yet, despite all the progress, Blacks and Native Americans remain at a two-to-three times higher risk. Artis noted that this points to the need for culturally tailoring the activities. The campaign, which included strategic partnerships with the communities, is now a model used by other NIH institutes and centers, she noted. It is a shining example of translating the science, concluded Artis.



Maddox Shares Her Vision for NIMHD with its National Advisory Council

On June 12th, Maddox presided over her first meeting with the National Advisory Council for Minority Health and Health Disparities (NACMHD) since her appointment as Acting Director of the National Institute of Minority Health and Health Disparities. She has been serving as acting director of NIMHD since April 1, 2014. John Ruffin, who retired earlier this year, served for 30 years as the first and only director of the Institute, and prior to that as director of the National Center for Minority Health. Maddox informed the Council that Ruffin is on volunteer status for those who would like to contact him.

Maddox welcomed new council member and Office of Behavioral and Social Sciences Research acting director William Riley and noted former OBSSR director Robert Kaplan's active participation as a member. She observed that the council would miss Kaplan, who is now at the Agency for Healthcare Research and Quality, because he reminded them of the behavioral and social aspects of what NIMHD does and NIMHD's research interest in behavior change.

The Council was also introduced to the newly appointed NIH Chief Officer for Scientific Workforce Diversity Hannah A. Valantine. Valantine shared that she accepted the position after reviewing the NIH activities responding to the Ginther et al. <u>article</u> and the speed at which the agency has taken up the issue (see *Update*, <u>June 25, 2012</u>) because she wanted to be a part of the agency's efforts. Maddox noted that the Institute would have a close working relationship with Valantine as NIMHD is one of the three cochairs of the NIH Common Fund Initiative. The third co-chair is National Heart, Lung and Blood Institute (NHLBI) director Gary Gibbons. Maddox recognized NIMHD's deputy director Joyce Hunter as the point person for the Institute. Valantine is scheduled to give a full presentation regarding her office at the Council's September meeting (see <u>related story</u>).

Director's Report: NIMHD to Increase its Focus on the Social Determinants Associated with Health Disparities

Maddox noted that health disparities has been a topic of discussion for the last decade but the conversation has been from the vantage point of morbidity and mortality as it relates to obesity, diabetes, and heart disease, among other topics, as related to measurement. In those areas, she noted, there has been a slight reduction in the rates. Conversely, there has been little movement in the area of HIV/AIDS as it relates to health disparities. When one looks at the international arena, we have done great things but we are not doing so great here in the United States, she noted.

Maddox pointed out that during her stint as Acting Deputy Director of NIH, she and National Institute for Allergy and Infectious Diseases director Anthony Fauci served as co-chairs of the first NIH <u>Strategic</u> <u>Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities</u>. She noted that while there were a lot of topics on the table at the time of that discussion, one of the critical areas was research and the dissemination of information and research. This meant a large and robust outreach program.

Maddox informed the Council that she had initiated a portfolio review for the Institute and during her tenure the Institute intends to focus on what she calls the "science of health disparities research." The NIH does a lot research in health disparities, now a widely used term, she noted. Since the Clinton Administration's launch of the health disparities strategic plan, a lot has been accomplished when it comes to health disparities. She pointed out that the term now goes beyond the dinner conversation and the definition of health disparities has really come to mean measurement. "We look at the bars," said Maddox. That is not health disparities research, she asserted.



Health disparities research, Maddox explained "is what is in between the bars" and used the analogy of an iceberg to describe her view of health disparities research. The things that we are measuring are just the tip of the iceberg, above the surface. Health disparities are "what's under the iceberg." Maddox stressed that she is interested in the things under the water and emphasized to need to have that defined NIH-wide. Those things are the elements that are really going to give us a handle on health disparities research, she stated. Maddox stressed that she thinks that NIMHD will be able to define that science and look at issues associated with education, social, and economic status, all the things that we know. "But incarceration and teen pregnancy," are beneath the water level, Maddox argued. "And we need to have that defined not just for [NIMHD] but for NIH-wide, because if we don't do that we are going to lose NIH as an agency behind us because it is a research agency."

Office of Community Based Participatory Research and Collaboration Created

To that end, Maddox reported that the Institute has created an Office of Community Based Participatory Research and Collaboration that will be head by Francisco Sy. Juanita Doty has been appointed to consult with the new office. The new Office's mission is to "identify and develop innovative community prevention research collaborative partnerships promote and coordinate community-based participatory research (CBPR) activities, and identify high priority community prevention research gaps and opportunities for collaboration with the community and Federal partners on diseases and conditions of major health importance." The Office provides a needed home for this research, said Maddox, emphasizing that the Institute "really wants to increase" its role in this area. "Because if we are going to be looking under the iceberg, that is where a lot of the work is and it is research," Maddox declared and acknowledged that the design of this type of research is different. According to Maddox, Sy will assist the Institute in developing partnerships.

One area of research that the new office will address is HIV/AIDS research and the role that communities can play in the reduction of health disparities in HIV/AIDS. The other area of focus will be on the LGBTI community. Maddox noted that a decision had not been made as whether to make that population one of the Institute's underserved populations. Nevertheless, she explained, NIMHD needs to focus on the LGBTI population because of the unique health needs that the Institute can address. She added that there would be a number of presentations to the Council on this issue at future meetings.

Highlighting NIMHD's seminar series, Maddox noted that she had the opportunity to attend two of the seminars, including the <u>seminar</u> on social determinants of health given by Paula Braveman, Professor of Family and Community Medicine and Director of the Center on Social Disparities in Health at the University of California, San Francisco (UCSF) on April 17, 2014. Braveman provided an "overview of the concept of health disparities and a conceptual framework for thinking about how disparities are created, exacerbated, and perpetuated across lifetimes and generations." She also introduced and discussed the challenges associated with "defining health disparities in ways that capture the most important criteria, are conceptually sound, and at the same time lend themselves to measurement." The second NIMHD seminar Maddox mentioned focused on the black middle class, "a marvelous opportunity to delve a little deeper into some of the principles of socioeconomic status and the African-American and Black community." Videocasts of the seminars are available on the NIH's website.

