



# COSSA Washington Update

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## GAO REPORTS ON INDEPENDENCE AND BALANCE OF ADVISORY BOARDS

Rebuffed by House Science Committee Chairman Rep. Sherwood Boehlert (R-NY) in their attempt to get a hearing on complaints about the Bush administration's "manipulation of science," Democrats on the panel held their own briefing on the subject on May 19. The centerpiece of the briefing was a report from the General Accounting Office (GAO) *Federal Advisory Committees: Additional Guidance Could Help Agencies Better Ensure Independence and Balance* (GAO-04-328). <http://www.gao.gov/new.items/d04328.pdf>.

Reps. Eddie Bernice Johnson (D-TX) and Brian Baird (D-WA) requested the GAO report and co-chaired the briefing. Johnson is the ranking Democrat on the Basic Research Subcommittee and Baird is one of four psychologists in the Congress. Johnson's opening statement referred to reports issued by Rep. Henry Waxman's (D-CA) and the Union of Concerned Scientists (see *Update*, May 3, 2004 and November 3, 2003) that attempt to document "the Administration's scientific shenanigans."

Both of these earlier reports included allegations that the Administration had appointed "ideologues or those with clear conflicts of interest" to Scientific Advisory panels. Robin Nazarro, who led the team that prepared the GAO report, appeared as a witness at the briefing. Although there are approximately 950 federal advisory committees with 62,000 members, she explained that the report examined the policies and procedures at six federal departments and agencies that make extensive use of scientific and technical advisory committees – the Departments of Agriculture, Energy,

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## SCIENCE AND BELIEF: CONFERENCE SEEKS COMMON GROUND

On May 24th, a diverse group of nearly 400 researchers, advocates and policymakers, all with widely differing views, came together to discuss the need for a strategy to address sexual health issues. The conference — "The Call to Action on Sexual Health: Science and Belief, and Seeking Common Ground" — was convened by former U.S. Surgeon General David Satcher, who served for three years under former President Bill Clinton and a year under President George Bush, before resigning in February 2002. He also served simultaneously as Assistant Secretary for Health and previously led the Centers for Disease Control and Prevention.

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## **NSF DIRECTOR, (Continued from Page 1)**

Health and Human Services (HHS), and Interior, as well as NASA and EPA. At HHS, which sponsors 36 percent of these kind of advisory committees, the GAO looked specifically at CDC, FDA, and NIH.

The Federal Advisory Committee Act (FACA) requires that committee memberships be “fairly balanced in terms of points of view presented and the functions to be performed by the advisory committees.” GAO notes that the Courts have interpreted this requirement as “providing agencies with broad discretion in balancing their committees.” Under FACA, the General Services Administration and the Office of Government Ethics issue regulations and guidance to federal agencies, which also have their own policies and procedures with regard to their advisory committees. These panels are, according to the report, “inherently controversial” because they deal with sensitive personal and ideological matters, such as stem cell research, genetic engineering, or potential regulatory matters dealing with food, drugs, and the environment.

In the report, GAO recommended: obtaining nominations from the public, using clearly defined processes to obtain and review pertinent information on potential members regarding potential conflicts of interest and points of view, and prescreening prospective members using a structured interview. It also called on agencies to make public information about how members are identified and screened as another way to “better ensure independence and balance and promote transparency in the federal advisory committee system.” In addition, one of the problems GAO identified is the practice of appointing “representatives” from groups to provide stakeholder advice. These folks are outside the purview of government conflict-of-interest rules. GAO recommended that agencies designate these people as “special government employees,” so that they are subject to the conflict rules.

In addition to the GAO report, the National Academies is investigating the selection of scientists, engineers, and health professionals to federal advisory committees addressing science-based policy or reviewing research proposals. Its report is planned for release in November 2004. An earlier report in 2003, focusing on the perceived politicization of the advisory committee appointment process, asserted that such appointments should be based solely on a person’s scientific or clinical expertise or his or her commitment to and involvement in issues of relevance to the mission of the institute.

On the evening prior to the briefing, Waxman and Rep. John Tierney (D-MA) sponsored an amendment to

the Paperwork Reduction bill that sought to create an expert commission to study the politicization of science and make recommendations for how to protect science in the regulatory process from political and ideological manipulation and interference. The amendment lost by a recorded vote of 201 ayes to 226 noes. During debate on the amendment, Rep. Doug Ose argued that the House Science Committee was the place to discuss the issue. Boehlert in an earlier letter to that panel’s Ranking Democrat Bart Gordon (D-TN) rejected Ose’s suggestion. Noting the bipartisan history of the Science Committee, Boehlert indicated that a hearing on the politicization charges “would be a radical departure from that way of doing business,” since this would be “expending energy on political point-scoring.”

## **CHILDREN AND MEDIA RESEARCH LEGISLATION PROPOSED**

Senators Sam Brownback (R-KS), Hillary Rodham Clinton (D-NY), and Joe Lieberman (D-CT) held a press conference on May 19 to unveil their Children and Media Research Advancement (CAMRA) Act. The act would establish a program to support grants that would examine the effects of viewing and using all types of electronic media, including computer games, television and the internet, on children’s physical and psychological development.

A study from the Henry J. Kaiser Family Foundation and Children’s Digital Media Center at the University of Texas at Austin shows that the average child spend six hours a day using electronic media, and 30 percent of children 0-3 years of age and 46 percent of children 3-6 years of age have televisions in their bedrooms. CAMRA was designed to address the lack of scientific research that provides data about the effects media have on the brain development of children.

“Now unfortunately, we’re conducting this vast social experiment without knowing much of what this is doing to our children,” said Clinton. “To ignore the impact of the huge amounts of time spent by children using electronic media is to ignore the consequences of what this is doing to them.”

CAMRA would authorize \$90 million to establish a federal grant program within the National Institute of Child Health and Human Development aimed at “energizing research” into all forms digital, analog, and print media on the cognitive, social, emotional, physical, and behavioral development of children from infants through adolescence. The National Academy of

Sciences would vet the research agenda and scientists would report to Congress on the empirical evidence and make recommendations on how the scientific findings may be used to improve the healthy developmental and learning capacities of children.

In addition to Senators Brownback, Clinton and Lieberman, Senators Mary Landrieu (D-LA) and Rick Santorum (R-PA) are also co-sponsors of the CAMRA ACT. A broad array of representatives of children's advocacy organizations also attended the press conference to show their support for the CAMRA Act and the American Psychological Association also provided a letter of support for the legislation. Said Lieberman, "This bill is not about launching a moral crusade against electronic media, rather it's about putting us on a fact-finding mission... We need to know what is the effect of all the [electronic media] on children's attitudes, practices, and development."

## **SCIENCE & BELIEF** (Continued from Page 1)

As Surgeon General, Satcher issued the groundbreaking report, *The Surgeon General's Call to Action To Promote Sexual Health and Responsible Sexual Behavior 2001* which stressed the need to "begin a national dialogue on sexual health and responsible sexual behavior that is honest, mature and respectful, and has the ultimate goal of developing a national strategy that recognizes the need for common ground."

Welcoming participants, Satcher, who currently leads the National Center for Primary Care at Morehouse University, expressed his excitement over the opportunity for participants to "get together to decide to how we move forward together in advancing this national dialogue." Such a dialogue is "important to promoting sexual health and responsibility. Regardless of sexual orientation or planned sexual behavior, human sexuality must be understood by all, including those committed to celibacy," Satcher declared.

Sponsored by a grant from the Ford Foundation, the conference is part of an ongoing initiative by Satcher to encourage a national conversation on human sexuality and build upon the findings of the *Call to Action*.

As surgeon general, Satcher noted that he had a "tremendous opportunity to make a difference." He released an unprecedented 14 surgeon general reports during his tenure, including reports on tobacco and health, mental health, suicide prevention, oral health, youth violence prevention; and overweight and obesity. But he had the most "trouble," however, he related,

releasing the *Call to Action* on responsible sexual behavior.

There was resistance to releasing the report for variety of reasons, from both the Clinton and Bush administrations. That resistance is exhibited in that it is the only Surgeon General report not signed off on by the Secretary of Health and Human Services. Despite this resistance, Satcher stressed that the issue was much too important to dismiss. The *Call to Action*, explained Satcher, exposes that "this struggle with sexual health is real." Individuals and society as a whole "pay a tremendous price because of that. It is so much a part of our lives," Satcher related.

The *Call to Action*, Satcher emphasized examined the "best available science, not politics, not opinion." Accordingly, the *Call to Action* took a public health approach, Satcher explained and also called for promotion of basic research in human sexual development, sexual health, and reproductive health, as well as social and behavioral research on risk and protective factors for sexual health.

## **Major Points of Controversy**

Satcher acknowledges that there are major points of controversy for those who are involved in the dialogue. First is the area of sex education – who provides it and what is provided? Emphasizing that schools are the great equalizer and should have a role, Satcher also stressed the need for parents and religious institutions to be involved in the conversation.

On the second question, the conference participants heard from speakers challenging abstinence-only programs favored by the Bush administration, as well as those arguing that these programs work in delaying onset of sexual activity and the spread of sexually transmitted diseases. Satcher noted: "Young people need to know that sex is special and is not be dealt with as a sport. But the message does not end there;" they "deserve to know how to optimally protect themselves."

With regard to sexually-transmitted diseases, Sheppard Smith of the Institute for Youth Development showed conference attendees a video that discussed the influence of ABC programs in decreasing the prevalence of AIDS in Uganda. ABC stands for Abstinence, Be Faithful to one partner, and use Condoms when necessary. This focus, along with strong leadership from Ugandan President Yoweri K. Museveni reduced the HIV prevalence rate from 21 percent to 6 percent of the population. Edward Green of the Harvard School of Public Health also spoke about Uganda and credited Museveni's leadership, which also included scare tactics

demonstrating the devastating effects of the AIDS virus.

Some groups have also criticized the *Call to Action*, Satcher admitted, because it did not talk about marriage. The report stressed the “value and benefits of remaining abstinent until involved in a committed, enduring, and mutually monogamous relationship,” particularly with regard to sexually-transmitted diseases. Since research suggests that one-third of marriages are not mutually monogamous, marriage is not the answer to the problem, he stated.

Another major area of controversy that Satcher mentioned is sexual orientation. “The report stated the scientific evidence as it exists. . . The research is pretty clear. The science is not there to support that sexual orientation can be changed.” A few conference participants disputed that assertion. Noting that gays and lesbians are abused and many of them go through life hiding their sexual orientation, he added, that “young gay men of color are not looking for another reason to be discriminated against.” For more information about the conference, including video, go to: <http://www.kaisernet.org/health>.

## CONFERENCE EXPLORES ENVIRONMENTAL FACTORS IN OBESITY

On May 24-25, more than 500 individuals from a variety of disciplines, urban planners, public health practitioners, along with representatives of environmental, health, planning, and transportation agencies of federal, state and local governments, came together to discuss the role of the built environment in the current obesity epidemic.

Sponsored by the National Institute of Environmental Health Sciences (NIEHS) the three-day meeting focused on how environmental health research and interventions can address this public health problem. The goal of the conference was to begin to develop research and practice agendas to examine the relationship between the built environment and obesity; enhance interagency coordination; inform elected officials; partner researchers, planners, health care providers, developers, policy makers, and community and business leaders; and highlight evidence-based strategies for interventions. NIEHS defines the built environment as encompassing all of the buildings, spaces, and products created or modified by people. It includes buildings (schools, housing, and the workplace); land use (industrial or residential);

public resources (parks, museums); zoning regulations; and transportation systems.

### Information Gaps and Research Needs

This meeting is to explore the linkages and identify information gaps and research needs in the battle against the current obesity epidemic, observed Samuel Wilson, Deputy Director of NIEHS. While the current trend “arises in part from individual behavior, environmental factors . . . provide the greatest opportunity for action and interventions designed to prevent” the trend from increasing, Wilson said. He stressed that obesity is the result of complex interactions between genetic and environmental factors. “Behavior is a key issue here,” he added, emphasizing the need to examine historical, cultural/social, and psychological behavior. Historically, our eating patterns have adjusted for quite a different lifestyle. Our cultural/social lives are centered on food and the increase stress of society can be offset by greater food intake, he explained. These behavior patterns are being passed along to our children. Accordingly, related Wilson, “an innovative and new way of thinking” is needed.

National Institutes of Health (NIH) Director Elias Zerhouni shared his perspective of why such a conference was needed. While the NIH will do the research on the neurobiology of obesity, combating obesity is an important challenge for society in general. Consequently, said Zerhouni, an interdisciplinary approach to this challenge is needed. We cannot succeed without a multi-pronged, comprehensive approach, he stressed.

In December 2001, the then-U.S. Surgeon General David Satcher issued the first-ever *The Surgeon General's Call to Action to Prevent and Decrease Overweight and Obesity*, which outlined strategies that communities can use in helping to address these problems. “Communities can help when it comes to health promotion and disease prevention,” Satcher said at the press conference releasing the report. (See *Update*, January 2002). Satcher, a keynote speaker at the conference, reiterated many of the issues and concerns of his 2001 report. Again, he called on parents, public health officials, and educators to make the effort to reverse the current obesity trend.

“We have a real crisis,” declared James O. Hill, University of Colorado Health Sciences Center and another keynote speaker. “We are the people who have to do something,” Hill told the conference’s participants. To combat obesity, Hill emphasized the need not to concentrate on one area. He stressed the

need to look at biology, behavior and the environment.

## CDC DIRECTOR OUTLINES NEW DIRECTION FOR AGENCY

On May 21, Julie L. Gerberding, Director of the Centers for Disease Control and Prevention (CDC), addressed participants at the Institute of Medicine Clinical Research Roundtable on Creating Infrastructure to Improve the Public's Health. She emphasized the changes the CDC will undergo in implementing its Futures Initiative directive, which includes significantly increasing the role of translational research as a means of fundamentally shaping outcomes in public health.

Eschewing a broad overview on the goals and organizational restructuring of the CDC that has been characteristic of the many talks Gerberding and her staff have given recently on the subject of the Futures Initiative (see *Update*, December 8, 2003), Gerberding's presentation before the roundtable honed in on changes that particularly pertained to translational research.

Cutting straight to her core message, Gerberding said, "I think the evidence gap between what we see in front of us as the major health challenges of the decade and the data evidence that we have to address them is growing and that we have to move well beyond the bench and into the communities to really understand how we can effectively translate the knowledge we've obtained and make it relevant to all of the populations at risk."

### 'Funding to Follow Goals'

According to Gerberding, the CDC intends to pursue "a much more rigorous" research agenda by rebalancing its portfolio and budgeting research with specific goals and measures in mind. Under the Futures Initiative, "funding will follow goals" and the focus will be on improving the overall health of the CDC's "customers" through the enhanced marketing of research output to improve health impact and reduce disparities. Citing an imbalance in the CDC's research portfolio between health care delivery and health care promotion, Gerberding went on to explain that the CDC will allocate additional funding to support research and programs aimed at protection for the general public and targeted populations.

Describing the CDC as becoming very "customer focused," Gerberding explained that health

prevention/ promotion goals have been established by life stages and that "this is not really anything new, but what's different is that it's driving the organization at CDC. We have made a decision to invest very heavily into a [health] marketing function...which is really to help us get the evidence base to determine how best to provide communications and tools then deploy them to the populations."

### Gaps in Evidence-Based Research

The CDC director also pointed out where the gaps in evidence-based research and knowledge exist within the CDC portfolio. These include the lack of knowledge on the impact of prevention interventions, particularly with regard to fractions of the target group who are affected. Gerberding explained, "Now that people are mobilized [around obesity], we're spending hundreds of millions of dollars on various campaigns and activities that we think make sense, but in fact the science has nothing to say about that. So there is a huge gap just in understanding the associations and the preventable fractions, let alone how to make use of that information to assist segments of the population that are harder to reach or experience health disparities." Consequently, research on preventable fractions is "a huge and major driving force of public health research agenda." The CDC is using this knowledge gap as a starting point for how they prioritize their future research investments.

She also stressed that priority funding would go to extramural research that includes community-based participatory health research, which requires for the investigator to engage the affected community in the design of the research and the development, in addition to health communications research and public health informatics.

Concerned about the lack of a pipeline for public health research, the CDC under the Futures Initiative has also created career development awards and scholarship training programs for public health research and grant programs that are directed towards businesses as a way of engaging a broader cadre of individuals in the economics of health promotion.

## MANY AMERICANS LACK HEALTH LITERACY

Before a crowded audience at the National Press Club, the Institute of Medicine (IOM) recently released the executive summary of their report *Health Literacy: A Prescription to End Confusion*. The report was produced by the Committee on Health Literacy, chaired by David Kindig of the Wisconsin Public Health Policy Institute at

the University of Wisconsin, Madison. The full report, not yet published in book form, is available online at: <http://books.nap.edu/catalog/10883.html>.

According to the study, nearly 90 million American adults lack the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions and yet they are inundated daily with information from healthcare providers, the media, the marketplace and government organizations that directly pertains to the choices they make about their health.

The National Adult Literacy Survey, informs us that forty million Americans cannot read complex texts, such as research consent forms, consumer privacy notices, and patient information sheets, and another 50 million have difficulty understanding these sorts of complex texts. Over 300 studies reveal that a mismatch exists between individuals' skills and the kinds of demands U.S. health systems place on them with respect to seeking information, understanding their rights and responsibilities, and making informed health decisions for themselves. Current research also shows that health literacy can be an undetected problem that policy makers and health care providers often do not recognize. In addition, people with low literacy skills or who are confused about health care are often ashamed to speak up about the problems they encounter.

Moreover, most of the tools currently available to measure health literacy primarily measure reading skills and do not include other critical skills, such as numeracy, listening, speaking, cultural and conceptual knowledge. While current health literacy measures have produced valuable findings, current assessment tools cannot differentiate among reading ability, lack of background knowledge in health related domains, lack of familiarity with language and types of materials or cultural differences in approaches to health and health care.

Because of these difficulties, the Committee on Health Literacy found that while individuals' health literacy skills and capacities are mediated by their education, culture, and language, the communication and assessment skills of the people they interact with regarding health, and the ability of the media, the marketplace, and the government to provide health information in an understandable context is equally important. Furthermore, most of the assessed materials exceed the reading skills of the average high school graduate.

More critical, however, are findings that show adults with limited health literacy, as measured by reading and numeracy skills, have less knowledge of disease

management and of health promoting behaviors, report poor health status and are less likely to use preventative services. Two studies used by the committee show a higher rate of hospitalization and use of emergency services among patients with limited literacy. This high utilization has been associated with increased health care costs.

Unavoidably, socioeconomic status, education level, and primary language all affect whether consumers will seek out health information, where they will look, what type of information they prefer, and how they will interpret that information. Even within the educational system, significant obstacles and barriers to successful health literacy education exist.

Some recommendations for increasing health literacy mentioned by the committee panel members and incorporated into the executive summary of the report include:

- The Department of Health and Human Services (HHS) and other government and private funders should support research leading to the development and causal models explaining the relationships among health literacy, the educational system, the health system, and relevant social and cultural systems; support the development, testing, and use of culturally-appropriate new measures of health literacy; and support multidisciplinary research on the extent, associations and consequences of limited health literacy.
- Educators should take advantage of the opportunity provided by existing reading, writing, oral language skills, and mathematics curricula to incorporate health-related tasks, materials and examples into existing lesson plans. The Department of Education in association with HHS should comprise task forces to improve health literacy through the nations k-12 schools, 2-year and 4-year colleges and universities, and adult and vocational education.
- Health care systems should develop and support demonstration programs to establish the most effective approaches to reducing the negative affects of health literacy. To accomplish this, these organizations should engage consumers in the development of health communications, using creative approaches to communicated health information, and including cultural and linguistic competency as an essential measure of

quality of care.

## GORDON CONFERENCE ON SCIENCE AND TECHNOLOGY POLICY

The third Gordon Conference on Frontiers of Science and Technology Policy will take place from August 15-20 at the Big Sky Resort outside Bozeman, MT. The conference, titled *Science & Technology Policy: Who Wins, Who Loses, and Who Cares?* will explore a number of questions. First, what are the distributional impacts of science policy decisions? Do some groups of people generally "win" and others "lose" or does everyone "win?" What underlying values drive policy-making, and what values emerge from the results of decisions? Is science policy just another form of politics as usual, differing only in the specifics of interest group politics? Or does science policy involve a special sort of politics, ones with different rules about winners and losers?

Second, the group will examine science as politics. How, who, to what end, and based on what values should science be conducted? What role should scientists play in science policy? What role should non-specialists play? How should these roles relate to one another?

A third area of discussion will look at who, when, and how do we think about what goes on the policy agenda? What is science policy, who makes it, what role should the scientists play, what are our goals, and what will be considered a success? In the constellation of policy issues, science is rarely at the forefront. Why? Should it be? Or is science policy best viewed as an instrument of defense, transportation, health, welfare, agriculture and other such policies? How do we distinguish between science policy and science budget policy?

The structure of the meeting is as follows: Participants arrive Sunday, have dinner, and an opening session. The daily schedule is anchored with a morning session, unscheduled afternoons, and an evening session. On one of the afternoons, there will be a field trip to Yellowstone National Park. Evening poster sessions offer a relaxed environment for social exchange and discussion. The emphasis remains on creating the best possible environment to foster intellectual interaction and exchange of ideas and research advances. The approach is (small d) democratic with everyone taking meals together and rooming in lodge settings to facilitate chance encounters, impromptu

meetings, and open interactions. Though the program includes a roster of official presenters, each participant is expected and encouraged to take an active part.

For further information about the conference, the program, and how to register, please go to: <http://grc.org/programs/2004/policy.htm>.

### COSSA BRIEFINGS ON HOMELAND SECURITY

On Monday June 7, COSSA will present a briefing on *Risk and Crisis Communication: Building Trust and Explaining Complexities When Emergencies Arise*. The speakers will be: H. Dan O'Hair, Ph.D., University of Oklahoma; Havidan Rodriguez, Ph.D., University of Delaware; and Katherine Rowan, Ph.D. George Mason University. The American Sociological Association and the National Communication Association are joining COSSA in co-sponsoring the event.

In addition, edited transcripts of the COSSA briefing on *Detecting Deception: Research to Secure the Homeland* are now available. The speakers at this event were Judee Burgoon of the University of Arizona, Charles Bond of Texas Christian

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The Consortium of Social Science Associations (COSSA), an advocacy organization for Federal support for the social and behavioral sciences, was founded in 1981 and stands alone in Washington in representing the full range of social and behavioral sciences.

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