

ZERHOUNI MEETS WITH BEHAVIORAL AND SOCIAL SCIENCE ADVOCATES

Emphasizing that there needs to be a balance in the National Institutes of Health (NIH) research portfolio, NIH Director Elias Zerhouni explained that his Agency is confronting a “new frontier.” At the same time NIH is facing “a challenge in the social and behavioral sciences,” he emphasized. In a meeting with the Coalition for the Advancement of Health Through Behavioral and Social Sciences Research (CAHT-BSSR) on October 31, Zerhouni echoed many of the remarks he made before the House Appropriations Subcommittee on Health and Human Services and Education earlier in the month. (See *Update*, October 21, 2002).

Zerhouni further explained to the group of representatives of social and behavioral science organizations that it is his view that “discoveries cannot be made without interdisciplinary teams and multidisciplinary studies.” The challenge over the next 25 – 50 years is to modify the spectrum of diseases that will increase the already large health care burden we will confront if we do not address this reality. The disease burden will become an ever-larger part of health care spending if we do not, he emphasized. Accordingly, stressed the Director, “we cannot ignore the behavioral and social sciences.”

Explaining that his is a systematic view of NIH’s research portfolio, Zerhouni indicated that he would like to prioritize the 10 areas that get 80 percent of the payoff. The NIH, he continued, is not oblivious to behavioral and social scientists. To further illustrate this point, he observed that behavioral and social scientists are at the forefront on issues related to obesity.

Noting that Office of Behavioral and Social Sciences Research (OBSSR) “is doing an excellent job,” he praised the work that the Office and its Director Raynard Kington are doing on behalf of the social and behavioral sciences. He further observed that at this year’s annual NIH Director’s retreat, (see **Zerhouni, page 6**)

CHARTERS OF DISSOLVED HHS ADVISORY COMMITTEES REVAMPED

On October 1, 2002, without public announcement, Secretary of Health and Human Services (HHS) Tommy Thompson signed the charter for a revamped human research protections advisory committee. In addition to being renamed, the Secretary’s Advisory Committee on Human Research Protections (SACHRP), formerly known as the National Human Research Protections Advisory Committee (NHRP AC), also had its charter expanded to include “human embryos” as human subjects. (See *Update*, September 23, 2002).

SACHRP’s charter specifies that the committee will provide advice relating to the responsible conduct of research involving human subjects with particular emphasis on:

- Special populations, such as neonates and children, prisoners, and the decisionally impaired;
- Pregnant women, embryos, and fetuses;
- Individuals and populations in international studies;
- Populations in which there are individually identifiable samples, data or information;
- Investigator conflicts of interest.

Inside *UPDATE* ...

- **Congress Concerned that Scientific Decisionmaking is Being Subverted by Ideology**
- **Bush Signs Election Reform Bill into Law; Political Scientists React**
- **Baldwin to Leave NIH for University of Kentucky**
- **Doubling of NIH’s Budget Good for Social and Behavioral Science Research**
- **Source of Research Support**

The Charter also stipulates that SACHRP will be responsible for reviewing “selected ongoing work and planned activities” of the Office of Human Research Protections (OHRP) along with other entities within HHS responsible for human subjects protection.

The reconstituted Committee will consist of 11 members, including the chair. It will also have non-voting ex-officio members representing the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the National Institutes of Health (NIH), and others as deemed necessary by the Secretary. As with NHRPAC, the director of OHRP will serve as the Executive Secretary of the Committee.

Members shall be appointed to serve for overlapping terms of up to four years, subject to the renewal of the Committee charter. “Unless renewed by appropriate action prior to its expiration,” SACHRP will expire two years from the date the charter is filed.

Genetics, Health and Society Committee

On October 22, HHS announced the establishment of the Secretary’s Advisory Committee on Genetics, Health, and Society

CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Executive Director:	Howard J. Silver
Government Affairs:	Angela L. Sharpe
Public Affairs:	John A. Wertman
Govt. Affairs Ass’t:	William A. Tatum
President:	Janet L. Norwood

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.

Update is published 22 times per year. Individual subscriptions are available from COSSA for \$80; institutional subscriptions - \$160; overseas mail - \$160. ISSN 0749-4394. Address all inquiries to COSSA: 1522 K Street, NW, Suite 836, Washington, D.C. 20005. Phone: (202) 842-3525, Fax: (202) 842-2788.

<http://www.cossa.org/>

(SACGHS). The new advisory committee replaces the Secretary’s Advisory Committee on Genetic Testing (SACGT).

The Advisory Committee is established to:

1. Provide a forum for expert discussion and deliberation and the formulation of advice and recommendations on the range of complex and sensitive medical, ethical, and social issues raised by new technological developments in human genetics;
2. Assist HHS and, at their request, other Federal agencies in exploring issues raised by the development and application of genetic technologies; and
3. Make recommendations to the Secretary of HHS concerning how such issues should be addressed.

The scope of SACGHS’s charge includes assessing how genetic technologies are being integrated into health care and public health; studying the clinical, ethical, legal, and societal implications of new medical applications, such as pre-implantation genetic diagnosis, and emerging technological approaches to clinical testing; identifying opportunities and gaps in research and data collection efforts; exploring the use of genetics in bioterrorism; examining current patent technologies; analyzing uses of genetic information in education, employment, insurance, including health, disability, long-term care, and life, and law, including family, immigration, and forensics; and serving as a public forum for discussion of emerging scientific, ethical, legal, and social issues raised by genetic technologies.

SACGHS will consist of 12 members selected by the Secretary or designee from individuals knowledgeable about molecular biology, human genetics, health care, public health, bioterrorism, ethics, forensics, law, psychology, social sciences, education, occupational health, insurance and other relevant fields. At least two of the members will be “specifically selected for their knowledge of consumer issues and concerns and the view and perspectives of the general public.” Unless renewed by “appropriate action prior to its expiration,” SACGHS will expire two years from the date of its establishment.

CONGRESS CONCERNED THAT SCIENTIFIC DECISIONMAKING IS BEING SUBVERTED BY IDEOLOGY

In a letter to Secretary of Health and Human Services (HHS) Tommy Thompson, a dozen Members of Congress, mostly Democrats led by Rep. Henry Waxman (D-CA), have expressed concern about “a pattern of events at [HHS] suggesting that scientific decision making is being subverted by ideology and that scientific information that does not fit the Administration’s political agenda is being suppressed.”

The Members explained that this concern arises as a result of “a series of troubling reports [that] have come out casting doubt on the Administration’s commitment to the tradition of scientific excellence and science-based decision making at HHS.”

Specifically, the Members note that “scientific information that does not serve the Administration’s ideological agenda is being removed from HHS websites. Expert appointments to scientific advisory boards are going to individuals with specific ideological viewpoints rather than scientific credentials.”

The signatories asked the Secretary to provide responses on six matters by October 30. These are:

1. All instances in which scientific information has been removed from any HHS website since January 2001 on the basis of a request from someone inside or outside the Department, the name of the requester, and the reason for the removal. If there was a scientific basis for the removal, please describe it in detail.
2. The name of each HHS advisory committee that has been terminated or has not been re-chartered since January 2001, with the basis for each termination or failure to re-charter.
3. The names and scientific qualifications of each expert who was recommended for the position of Chair of the Reproductive Health Drugs Advisory committee, from whom the recommendations were received, and the reason for the final selection if any.
4. The names of each HHS advisory committee on which the Administration has replaced,

or plans to replace within the next year: (a) members whose terms have not expired, and the names of the members to be replaced; or (b) more than 2 members within a six-month period. In each case, to the extent known, provide the names and qualifications of the individuals who will replace the removed members, and if they were recommended by an industry group or other outside organization, from whom the recommendation was received.

5. HHS and CDC policies on audits, and a description of the controls in place to ensure that the process is not subject to political abuse.
6. The number of audits HHS or CDC have undertaken or planned of: (a) HIV/AIDS prevention education groups, (b) groups that oppose abstinence-only policies, and (c) abstinence-only programs.

The other congressional signatories on the letter to Thompson include: Reps. Sherrod Brown (D-OH), Nita Lowey (D-NY), Rosa DeLauro (D-CT), Diane Watson (D-CA), Bernard Sanders (I-VT), Edolphus Towns (D-NY), Carolyn Maloney (D-NY), William Lacy Clay (D-MO), Elijah Cummings (D-MD), Tom Allen (D-ME) and Dennis Kucinich (D-OH). As of November 4, Secretary Thompson had yet to respond to the letter.

BUSH SIGNS ELECTION REFORM BILL INTO LAW; POLITICAL SCIENTISTS REACT

On October 29, nearly two years after the Florida election controversy that put him in the White House, President Bush signed into law H.R. 3295, the Help America Vote Act of 2002. For details on the legislation see *Update*, October 21, 2002.

Last March, COSSA held a seminar on Capitol Hill entitled *The Mechanics of Election Reform: From Registration to Results*. The session allowed a panel of distinguished social scientists to weigh in on the fall-out from the Florida controversy, address issues facing the Congress as legislators began working on H.R. 3295 and competing measures, and discuss problems inherent to the American electoral system. With the bill now law, COSSA asked two of the panelists, Charles Stewart from the

Massachusetts Institute of Technology (MIT) and Rodolfo O. de la Garza of Columbia University, to give their reactions to the enacted reforms.

Stewart, who was one of the leaders of the Cal Tech-MIT voting technology project, noted: "The election reform bill was a major step forward in improving voting technology. It will provide communities with money to move away from the two antiquated systems that cause the most problems, punch cards and mechanical lever machines. It provides a framework for further monitoring of the performance of election technologies." Despite these positive comments, Stewart also sounded a note of caution about implementation of the law.

He asserted that attention must be focused on local officials, saying: "The danger is that communities will rush to upgrade equipment without careful consideration of whether an upgrade is even necessary or what the alternatives are. The discretion that local officials have, coupled with widespread naiveté about how voting equipment can fail, may lead to a round of reform horror stories in the future." He also noted that not enough attention was given in the bill to issues of election administration and that technological upgrades can only go so far to improve the voting process.

De la Garza, who specializes on immigration and Latino political behavior, focused on problems not addressed in the law. He stressed that: "The election reform law will not solve the ongoing problem of low voter turnout. It is important to have votes accurately counted. But if that is all you do, then nothing is being done to alleviate the marginal disenfranchisement of the lower sectors of the population." He then turned to the loss of voting rights due to felony convictions, stating: "The current reform does nothing to alter the problem resulting from how violations of drug laws are dealt with by criminal courts. Minorities are much more likely to be convicted of felony drug charges than are whites who engage in the same behavior. Consequently, minorities, especially African Americans, will continue to be disproportionately disenfranchised because of felony convictions than are whites, which is to the detriment of the minority community."

The law was passed too late to have any meaningful effect on the midterm elections. As of

November 4, there are several races around the country that are likely to be settled by small numbers of votes. Several political experts are predicting turmoil that could leave the control of Congress unknown for days or weeks. To request a copy of the transcript from the COSSA seminar, please e-mail cossa@cossa.org.

BALDWIN TO LEAVE NIH FOR UNIVERSITY OF KENTUCKY

National Institutes of Health (NIH) Deputy Director for Extramural Research Wendy Baldwin is leaving NIH in January 2003 to become the Vice President for Research at the University of Kentucky in Lexington.

Baldwin, key to creating the landmark "National Longitudinal Survey of Youth – Child Cohort," also was instrumental in developing a research program in adolescent reproductive behavior while at the National Institute of Child Health and Human Development (NICHD). More recently, she led an initiative to advance human subjects protections for the Office of the Director, including leading the development of the Human Subjects Research Enhancement Program.

NIH Director Elias Zerhouni expressed his sorrow at Baldwin's departure from the NIH. "She has had a great career here and is responsible for so many creative approaches to extramural challenges," he related.

DOUBLING OF NIH'S BUDGET GOOD FOR SOCIAL AND BEHAVIORAL SCIENCE RESEARCH

Recent efforts by the Congress to double the budget of the National Institutes of Health (NIH) has allowed for a broadening and deepening of the social and behavioral research being funded by the various NIH institutes and centers, observed Office of Behavioral and Social Sciences Research (OBSSR) Director Raynard Kington. Congress's effort to double the agency's budget over five years has also allowed social and behavioral scientists the opportunity to translate research findings to address real world circumstances, he explained to an audience of congressional staff at a recent Decade of Behavior event, *Behavior and Health: New*

Research, New Hope, held September 25th on Capitol Hill.

The event was designed to show the great strides in health research and application made by the NIH, particularly in the social and behavioral sciences. According to Kington, research in these disciplines supported by the Institutes has grown dramatically and is seen as an important part of the Institutes' core missions and research portfolios. The NIH Institutes, including Mental Health, Aging, Child Health and Human Development, Nursing, Alcohol Abuse and Alcoholism, and Heart, Lung, and Blood have a long history of supporting social and behavioral science research, Kington observed.

In addition, several of the other Institutes that have not traditionally been as supportive of social and behavioral science research, including the Digestive Diseases and Kidney, Environmental Health Sciences, and Arthritis, Musculoskeletal and Skin Diseases, "have substantially expanded in very exciting directions to advance the science to deal with adverse conditions," Kington related.

Researchers supported by the National Institute of Mental Health, the National Cancer Institute, and the National Institute on Drug Abuse presented some of their recent findings. They included: Terrance Albrecht (University of South Florida), *The Role of Physician-Patient Communication in Clinical Trials*; Timothy Baker (University of Wisconsin, Madison), *Relapse Back to Tobacco Smoking: Core Role of the Tobacco Withdrawal Syndrome*; and James Gold (Maryland Psychiatric Research Center), *Control of Attention in Schizophrenia*.

Introducing Albrecht, Robert Croyle, Associate Director for Behavioral Research at the National Cancer Institute (NCI) explained that the collaboration of social and behavioral science research across the National Institutes of Health could serve as a model for other disciplines. NCI, the largest NIH Institute, noted Croyle, has the largest social and behavioral research program and is committed to funding research in this area. He further noted that research in these areas have undergone an expansion, through the funding of different kinds of research.

Croyle cited NCI's funding of health communication research as an example of this expansion, explaining that health communication

and technology development has a lot to do with cancer prevention and control. He also emphasized that social and behavioral science can inform the clinical trials process, a key policy and funding issue. Albrecht's research on the role of physician-patient communication in cancer clinical trials is a good example of how behavioral and social science interacts to inform the biomedical enterprise.

Albrecht and his collaborators looked at the numerous problems associated with clinical trials: insufficient numbers of patients on studies; underrepresentation of minority and elderly populations; unmet needs of patients, family members/significant others, and physicians; wide variation in physician communication behavior; and negative press reports that create resistance from eligible patients and families. Their current NCI grant supports an effort to demonstrate the impact of communication on patients' treatment decision-making compared to other determinants.

Albrecht's group has increased the number of participants in clinical trials by training physicians to: invite patient/family member questions; check patient/family knowledge and offer culturally and linguistically appropriate explanations; become well versed in types of available services; and provide social support and hope.

Future directions for research included investigations to develop communication strategies for increasing quality of life and survivorship of cancer patients (i.e., assisting parents of children undergoing painful procedures); improving public education about genetic risks; and reducing health disparities in cancer care for minority and underserved patients.

Bruce Cuthbert, Branch Chief for Adult Psychopathology & Prevention Research at the National Institute of Mental Health (NIMH) explained that the Institute has been able to use the recent budget increases to develop a behavioral and translational science agenda. Cuthbert noted that the NIMH has a whole range of programs that covers a wide variety of activities sometimes referred to as "from science to practice" or "bench to bedside" designed to get treatments to the community. (See *Update*, February 8, 2000)

The event was sponsored by the American Psychological Society, the American Psychological

Association, and the Federation of Behavioral, Psychological, and Cognitive Sciences.

(ZERHOUNI, from Page 1)

many of the long-time institute directors shared with him that there was greater discussion of social and behavior science than at any time in the past.

Training: Creative Leaders Needed

Acknowledging NIH's role as a leader in directing training resources to health research in the behavioral and social sciences, CAHT-BSSR inquired of the director what steps he might take to ensure NIH training resources continue to address the growing demand for social and behavioral scientists in diverse backgrounds and disciplines in the health sciences, and how NIH can adequately incorporate research on social and behavioral factors for a stronger, more valid health research enterprise.

The Coalition noted that its organizations "strongly believe that the 2000 National Research Council (NRC)/Institute of Medicine report, *Addressing the Nation's Changing Needs For Biomedical and Behavioral Scientists*, misconstrued the central issue that the health sciences face. It was also emphasized that the Coalition shares the perspective of John Kihlstrom's (a member of the NRC Committee that completed the report) minority position: It is not *how many* behavioral and social scientists there are, but *how many are doing critical research* related to health and health care. (See *Update*, September 11, 2000).

The challenge is to prepare the scientific teams of the future, responded Zerhouni. He observed that science has changed and that there are needs for large scaled data bases, advance analysis, and objective measures and markers. The 21st Century problem is that we have a variable, diverse population that makes research very difficult to do.

Training, related Zerhouni, is "very important" to him, pointing out that he would like to get a view across the disciplines. Training "clearly needs to be looked at as a system. How does it accomplish the goal?," he asked. "I need creative leaders," he added and noted that he was just starting to look at training across the NIH. According to Zerhouni, his examination of the NIH training system will look

"all the way back," including looking at the training provided to high schools by the NIH.

Restructuring the NIH

Zerhouni communicated that his views regarding the restructuring of NIH "have evolved but not changed" as he has become more familiar with the Agency. He noted that it "not realistic" to believe that there will be a wholesale restructuring of the NIH. He shared his view that there will be resistance to merge or eliminate Institutes and Centers as has been proposed a number of times. It will be hard to change authorized entities, he further noted. Citing the OBSSR as a good example, Zerhouni emphasized that there are alternative ways to achieve desired outcomes. The exercise of looking at possible restructuring opportunities, however, is a task he welcomes, he reiterated. Zerhouni added that the practice of having an outside analysis, now underway at the National Academies, is useful to any organization.

The Coalition echoed his concerns and stated that the social and behavioral sciences feel strongly that they have benefited greatly by OBSSR's work reaching out to the Institutes and Centers and would not want to see a restructuring plan jeopardize the very effective work of that Office.

'You Can Do Basic Research from All Spectrums of Science'

Responding to the group's concerns of ways to strengthen support for basic social and behavioral research at NIH, Zerhouni stressed that he does not subscribe to the conceptualization of research into basic, translation, and application. He also emphasized that "you can do basic research from all spectrums of science." According to Zerhouni, he divides research into "discovery research" and "application of derivative research." Discovery research, he related, "is knowledge that was not known before." It does not imply molecules and pipettes, he further noted. What is currently being called basic research by many is "fill in the blank research" from his perspective. He argued against the need to create "symbolic labs." At the end of the day, "people make the difference," the Director said.

He stressed that the NIH needs leaders who are "creative and visionary." "Leadership needs to come from the bottom up," he asserted and cited newly

appointed National Institute of Mental Health Director Thomas Insel as an example of the type of leader he is seeking. (For more on Insel, see *Update*, September 23, 2002).

'Health Disparities Should Permeate the Entire Concern of NIH'

When it comes to health disparities research, Zerhouni expressed his hope that health disparities would become "a core measure." To call it a priority is "wrong." A priority, from his point of view, related Zerhouni, implies that it is temporary. "Health disparities should permeate the entire concern of NIH," he stressed. The National Center on Minority Health and Health Disparities should be a fulcrum for many of the Institutes, according to the Director. It is clear to him that "it is a priority that needs to be ingrained until it is no longer a priority." But it is not yet core, he concluded.

National Children's Study

CAHT-BSSR informed the Director that the National Children's Study (NCS), which has been mandated, but not funded, by the 2000 Children's Health Act is of concern to the Coalition because of the size and implications of the study. The National Institute of Child Health and Human Development (NICHD) has the responsibility for coordinating the study across the NIH as well as all of the Federal government. It is feared by supporters of the Institute that the study will supplant resources dedicated to other areas if sufficient additional resources are not allocated to NICHD.

Zerhouni agreed and likened the study to "an ark." One needs to be very careful and thorough going forth, he noted. It is important to understand the ins and outs of the study. He acknowledged that the interagency budget required to go forth with the NCS is "very complicated."

CAHT-BSSR is co-chaired by COSSA's Associate Director for Government Affairs Angela Sharpe and the American Psychological Association's Senior Science Policy Analyst Patricia Kobor. Other Member organizations include: American Anthropological Association, American Educational Research Association, American Sociological Association, National Council on Family Relations, Institute for the Advancement of Social Work, National Association of Social

Workers, Population Association of America, The Association of Population Centers, Society for Research in Child Development, The Alan Guttmacher Institute, Center for Advancement of Health, The Federation of Behavioral, Psychological, and Cognitive Sciences, and Sexuality Information and Education Council of the United States.

SOURCE OF RESEARCH SUPPORT

COSSA provides this information as a service and encourages readers to contact the sponsoring agency for further information. Additional application guidelines and restrictions may apply.

Fogarty International Center: Health, Environment, and Economic Development

The Fogarty International Center (FIC) of the National Institutes of Health (NIH) has announced a new research program to support international collaborations to study the relationships between health, environment, and economic development. The FIC, joined by the National Institute of Environmental Health Sciences (NIEHS), the National Institute of Child Health and Human Development (NICHD), the National Institute on Drug Abuse (NIDA), the Office of Behavioral and Social Sciences Research (OBSSR), and the United States Geological Survey (USGS), has issued a Request for Applications (RFA #TW 03-005) for the first phase of the program.

The RFA invites proposals for interdisciplinary, international research collaborations to examine the health effects of major economic development trends that affect the natural environment. The Agencies are committing \$1.5 million per year to support two-year planning grants. The partners expect to follow these planning grants with a request for full research and training proposals for five-year projects.

Applications for the first phase of the program are due by December 30, 2002, and the deadline for receipt of Letters of Intent is November 30, 2002. The Request for Applications is available on the web at <http://grants1.nih.gov/grants/guide/rfa-files/RFA-TW-03-005.html>.