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Stories Related to the National Institutes of Health and Health Research  
COSSA WASHINGTON UPDATE, Volume 19, Year 2000

## COMINGS . . . AND GOINGS

*January 10, 2000, Number 1*

Although NSF claims it is “very close” to appointing a new Assistant Director for the Social, Behavioral and Economic Sciences Directorate (SBE), it has named **Wanda E. Ward** the Acting Assistant Director, until the new person arrives. Ward replaces Bennett Bertenthal, who has returned to academia as Professor of Psychology at the University of Chicago, after a three year stint as head of the SBE. Ward had recently been appointed Deputy Assistant Director for SBE. She came to the Directorate from her previous position as Assistant to the Deputy Director for Human Resource Development in NSF’s Education and Human Resources Directorate (EHR). She also held the position of Senior Staff Associate for Planning and Policy for the EHR. Ward arrived at NSF in 1992 from the University of Oklahoma where she was an Associate Professor in the Department of Psychology and Founding Director of the Center for Research on Multi-Ethnic Education. She has a Ph.D. in Psychology from Stanford and a B.A. from Princeton. Also at SBE, **Hilleary Everist** has announced her intention to leave as Director of the Division of Behavioral and Cognitive Sciences this Spring. The job announcement can be found at <http://www.nsf.gov/home/chart/work.htm>.

**Lisa Towne** was recently named Assistant Director for the Social and Behavioral Sciences at the White House Office of Science and Technology Policy (OSTP). She came to OSTP in January 1999 from the U.S. Department of Education to assist David Stevenson, who had been appointed Assistant Director. Following Stevenson’s untimely death in March, Towne served as Acting Assistant Director. At the Department of Education, she worked as an evaluation and policy analyst in the Office of the Undersecretary covering K-12 education issues, including systemic reform and school choice. She was also as an evaluation consultant for federal agencies administering programs that serve children and families, including the Departments of Health and Human Services, Justice and Defense. She has an undergraduate degree in mathematics and a graduate degree in public policy and is an adjunct professor of quantitative methods at the Georgetown Public Policy Institute.

The Council of Graduate Schools has named **Debra Stewart**, Vice Chancellor and Dean of the Graduate School at North Carolina State University, as its new President, effective July 1, 2000. Stewart succeeds Jules LaPidus, who is retiring after 16 years as head of CGS. At N.C. State Stewart has developed new interdisciplinary degree programs, established professional development programs, and spearheaded a successful research ethics initiative. She has served on many committees concerned with graduate education and research including the Board of Trustees of the Educational Testing Service, the Graduate Record Examination Board, the National Research Council Committee of the Assessment of

the Research Doctorate, and the Editorial Board of the *International Journal for Graduate Education*.

Stewart has a B.A. from Marquette University, an M.A. in government from the University of Maryland, and a Ph.D. in Political Science from the University of North Carolina, Chapel Hill. She is the co-author of *Organizational Behavior and Public Management*, now in its third edition.

The Urban Institute has appointed **Robert D. Reischauer** as its new President, effective February 1, 2000. Reischauer replaces William Gorham, who has led the social and economic policy research institute since its founding in 1968. Since 1995, Reischauer has been a senior fellow of economic studies at the Brookings Institution. Before that he spent six years as the director of the Congressional Budget Office (CBO), where he also held other management and research positions. He was the Urban Institute's senior vice president from 1981 to 1986. In 1982-83, he served on the COSSA Board of Directors. He is a nationally recognized public policy expert on the budget, health, poverty, state and local fiscal problems, and welfare. He holds an A.B. in political science from Harvard, a Master's in International Affairs, and a Ph.D. in Economics from Columbia University.

On January 1, 2000, **Ruth Kirschstein** was appointed Acting Director of the National Institutes of Health. She replaces Harold Varmus. Before her appointment, Kirschstein served as the NIH deputy director between November 1993 and December 31, 1999. She previously served as NIH Acting Director between July and November 1993.

**Laurie Robinson**, Assistant Attorney General for the Office of Justice Programs (OJP), has announced that she will leave the job at the end of February. Robinson, the longest-serving Assistant Attorney General for OJP, was confirmed by the Senate in September 1994. During her tenure, OJP expanded greatly from an \$800 million, 300 staff agency to an agency that administers over \$4 billion in grants annually with a staff of around 900. The OJP, a component of the U.S. Department of Justice, focuses on improving state and local criminal and juvenile justice systems. It is responsible for administering grant programs, providing training and technical assistance and conducting research and collecting statistics relating to criminal and juvenile justice. Most recently, Robinson has overseen OJP's reorganization effort, which some expect to be approved by Congress in the upcoming legislative session.

## **SURGEON GENERAL RELEASES MENTAL HEALTH REPORT**

*January 10, 2000, Number 1*

United States Surgeon General David Satcher recently released the first-ever *Surgeon General's Report on Mental Health*. The report, according to Satcher "makes evident that the neuroscience of mental health — a term that encompasses studies extending from molecular events to psychological, behavioral, and societal phenomena — has emerged as one of the most exciting arenas of scientific activity and human inquiry. We recognize that the brain is the integrator of thought, emotion, behavior, and health. Indeed one of the foremost contributions of contemporary mental health research is the extent to which it has mended the destructive split between 'mental' and 'physical' health."

Key themes include "the importance of a solid research base for every mental health and mental illness intervention." In the foreword, Substance Abuse and Mental Health Services Administration Administrator Nelba Chavez, National Institute of Mental Health Director Steven Hyman, and Center for

Mental Health Services Director Bernard Arons state the report “recognizes the inextricably intertwined relationship between our mental health and our physical health and well-being.”

The Surgeon General’s Report states that to “realize further advances in treatment and, ultimately, prevention, the Nation must continue to invest in research at all levels.” Noting that the timing of the release comes at a time of “unprecedented scientific opportunity,” it observes that “high quality research is a potent weapon against stigma, one that forces skeptics to let go of misconceptions and stereotypes concerning mental illness and the burdens experienced by persons who have these disorders.”

The Report further emphasizes that special effort is needed to address “pronounced gaps” in the mental health knowledge base. Each chapter identifies specific gaps. For example, the “urgent” need for research evidence that supports strategies for mental health promotion and illness prevention.

A copy of the Surgeon General’s Report on Mental Health can be viewed at <http://www.surgeongeneral.gov/library/mentalhealth/index.html>.

### **NAMI Alleges NIMH’s Portfolio Shortchanges the Mentally Ill**

Just a couple of days before the release of the Surgeon General’s Report on Mental Health, *USA Today* carried a front page story alleging that the NIH’s National Institute of Mental Health (NIMH) had shortchanged the mentally ill. The story was based on a report by the Stanley Foundation Research Program, an affiliate of the National Alliance for the Mentally Ill (NAMI), which alleged that the NIMH “has failed in its primary mission to support research into schizophrenia, manic-depressive illness and other severe mental illnesses.” According to the NAMI report, it analyzed NIMH’s 1997 research portfolio and found that “NIMH is funding a large number of behavioral research projects on diverse aspects of human behavior but almost no behavioral research that is relevant to severe mental illness.”

COSSA, which strongly disagrees with NAMI’s assertions, drafted a letter to key congressional leaders defending NIMH. COSSA and two of its member organizations, the American Psychological Association (APA) and the American Sociological Association (ASA), as well as NIMH Director Steven Hyman, wrote that the NAMI-sponsored report seriously misrepresents NIMH’s mission. The report, which calls for hearings on this topic, omits the following part of the ADAMHA Reorganization Act (Public Law 102 - 321), which defines NIMH’s mission, as: ***the conduct and support of biomedical and behavioral research, health services research, research training, and health information dissemination with respect to the cause, diagnosis, treatment, control and prevention of mental illness . . . [and] shall be designed to further treatment and prevention of mental illness, the promotion of mental health and the study of psychological, social, and legal factors that influence behavior.***

COSSA noted that NIMH’s mission is to support basic, clinical, and epidemiological research on the behavioral, biological, genetic, and social factors and psychological processes and mechanisms that underlie mental illness that have an impact on physical health and the maintenance of emotional well-being. Further, COSSA emphasized its strong belief that if NIMH’s research portfolio was limited only to “severe mental illness,” as suggested by NAMI’s report, scientific progress to understand, prevent, and treat other mental disorders would be seriously and immeasurably compromised. These would include:

the most common forms of depression, anxiety disorders, panic disorder, post-traumatic stress disorder, social phobia, attention deficit hyperactivity disorder, autism, eating disorders, as well as other mental disorders.

Finally, COSSA noted that while it understands the sense of urgency in finding a cure for severe mental illness, we must be careful not to ignore the breadth and forms of mental illness, the need for knowledge that can promote mental health, and the serendipitous nature of research. To do so would result in the endorsing of a limited and myopic research strategy. COSSA urged congressional leaders to continue their support of a balanced program of grant funding in mental health and mental illness, including basic and applied behavioral, social, and neuroscience research at the NIMH.

A copy of COSSA's correspondence can be seen on our website: <http://members.aol.com/socscience/COSSAindex.htm>.

## **BEHAVIORAL AND SOCIAL SCIENCE PART OF NIDDK PLANS**

*January 10, 2000, Number 1*

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) held a two day workshop on *Behavioral Science Research in Diabetes*, November 18-19, 1999 on the National Institutes of Health (NIH) campus. NIDDK hopes to use the meeting as a mechanism for setting future directions in diabetes research, according to Sanford Garfield, Senior Advisor for Biometry and Behavioral Research.

NIDDK Director Allan Spiegel, in only his second day in the position, attended the meeting and admitted to knowing very little about behavioral and social science, but stressed that his major goal is to propel advances that make a difference to patients. "Every illness has a behavioral component," said Spiegel, who has been at the NIH for more than 25 years and most recently served as NIDDK's scientific director and chief of the metabolic diseases branch.

Office of Behavioral and Social Science Research (OBSSR) Director Norman Anderson stressed that workshops like NIDDK's "landmark meeting" are helping the NIH do a better job at what it is supposed to do — improve the public's health. A focus on behavioral and social science research, he said, will help achieve that goal. Anderson expressed his satisfaction that the Institute has recognized critical behavioral and social science factors to understanding and treating diabetes. The OBSSR co-sponsored the workshop.

Workshop participants focused discussions on four areas that are primary in diabetes research: lifestyle modification, psychosocial therapies, health care delivery, and risk and primary prevention. Workgroups addressing each of these areas looked at why the topic was significant for diabetes research, key advances, barriers to progress, and recommended research priorities.

### **Lifestyle Modification**

This workgroup looked at: 1) environmental factors related to lifestyle behaviors; 2) adoption and maintenance of health eating, exercise, and weight; 3) etiology of eating and exercise behavior and weight regulation; and 4) multiple behavior change. Recommended research priorities include:

g Correlational studies to document associations between environmental/policy variables and behavior; investigation of environmental influences as they interact with cultural and SES (socioeconomic status) differences in populations; and

g Intervention studies to examine the effect of specific environmental manipulations on outcome (eating/behavior/exercise behavior and biological endpoints).

(Continued next page)

### **Psychosocial Therapies**

Emphasizing that large numbers of children are currently affected by diabetes, with many more expected to be affected in the next four years, the recommendations offered by the psychosocial therapies workgroup include:

g Longitudinal studies to determine causal relationships between psychosocial factors, regimen adherence, and metabolic control; and

g Studies that focus on the integration of behavioral and psychological services into routine pediatric diabetes care in clinical settings and that address issues such as clinical significance, social acceptability, and cost effectiveness.

For adults the workgroup noted that diabetes is a psychologically and behaviorally demanding disease so psychosocial factors are relevant to nearly all aspects of its management. Recommended research priorities include:

g More studies that focus on the identification of specific psychosocial factors that influence regimen adherence and glycemic control in adults with type 1 and type 2 diabetes; and

g Studies to determine how to individualize psychosocial therapies to improve regimen adherence, glycemic control, and quality of life in various patient populations.

### **Health Care Delivery**

Good patient self-management is critical for good long-term outcomes. Patients and family members are responsible for and carry out the great majority of diabetes care on a daily basis. It is not enough to provide basic knowledge of what to do to manage diabetes; patients need skills and support in how to do this in the face of real world challenges. Given this knowledge, the workgroup's recommendation's:

g Changes of attitudes and behavior of primary care physicians toward diabetes, its seriousness, and the need for a patient-focused, team-managed, proactive chronic disease theme; and

g Collaborative management in chronic disease, population-based, including home-based lifestyle and psychosocial intervention programs; and

g Application of behavioral assessment and intervention methodologies to affect systems changes (health care teams, organizations, communities).

### **Risk and Primary Prevention**

The risk and primary prevention workgroup examined four areas: 1) risk of diabetes and its complications: analysis/assessment and communication; 2) prevention through screening for at-risk identification; 3) prevention through community/environmental change; 4) behavior, psychology, and education in use of preventive medications. Recommended research priorities include:

- g Research on public perception of diabetes: seriousness, susceptibility, etc.; and
- g Research on the best methods to accurately inform patients and families about at-risk status; and
- g Research on the psychological, behavioral and social impact of at-risk notification.

For a complete list of recommended research priorities offered at the workshop, contact Sanford Garfield at 301/594-8803 or [Garfields@extra.niddk.nih.gov](mailto:Garfields@extra.niddk.nih.gov).

### **PANEL COMPLETES PEER REVIEW REPORT**

*January 24, 2000, Number 2*

On January 7, 2000, the Panel on Scientific Boundaries for Review (PSBR), submitted to the Center for Scientific Review (CSR) Advisory Committee its Phase I final report that offers many recommendations for revising the CSR's peer review system. The report, according to Panel Chair and National Academy of Sciences (NAS) President Bruce Alberts, is to "position the CSR peer review system so that it best fosters the expanded research opportunities created by the stunning successes of the *health-related research* enterprise, as well as permitting this review system to keep pace with the accelerating rate of change in the way that health-related research is performed." At the urging of COSSA and its allies, "health-related research" replaced "biomedical research" from the Panel's earlier version (See UPDATE, September 13, 1999, No. 16).

The Panel received more than 800 comments on the first iteration of the report, including ones from COSSA, the American Anthropological Association, the American Psychological Association, the American Sociological Association, and members of the Health and Behavior Alliance. In her reply to those who commented on the draft report, CSR Director Ellie Ehrenfeld noted that "this has been a very challenging task."

### **Peer Review: The Guidelines**

The Panel recommends that the CSR's peer review panels be organized into 24 Integrated Review Groups (IRGs), as compared to the current structure of 20 IRGs. As advocated by COSSA, the Panel will leave intact for several years the seven IRGs and component study sections that were recently created for the behavioral and social sciences, AIDS, and neuroscience until an evaluation of their effectiveness can be conducted.

The implementation of the Panel's recommendations will occur during the next three years. (It can be followed at: <http://www.csr.nih.gov>.) Expert groups of extramural scientists and the NIH will create the 24 IRGs based on the principles outlined in the Panel's report. The Panel also suggests that

adjustments to its proposed organization, including new study sections, may be made during the implementation effort.

The report lays out **three guiding principles** that the expert groups should follow when determining the structure of the IRGs:

- ! There should be at least one appropriate venue for the review of all science that is relevant to contemporary health-related research.
- ! The research topics encompassed by each IRG should be sufficiently cohesive to allow an external advisory group of scientists for that IRG to judge the content of its entire portfolio.
- ! The organization should be flexible enough to adjust to the rapid changes in scientific opportunities expected in the years ahead.

In considering the design of the IRGs, the Panel underscores that it “attempted to cluster, whenever possible, all types of research whose major emphasis is focused on a given organ system or disease in an IRG devoted to that system or disease.” IRGs were also created for the review of basic scientific discovery and the development of methods that do not apply to any specific system or disease. “To ensure a vigorous foundation for future progress, NIH must continue to support a sizable proportion of research that has no immediate or specific application to human health.”

### **Cultural Norms**

The final report also outlines some cultural norms the Panel believes should govern the CSR review process. The Panel notes that “an appropriate peer reviewer is an active researcher, who can understand and judge both the research goals and the research means being proposed by the applicants.” They should be experienced researchers who have achieved recognition for their own research, and are reasonably diverse in seniority, outlook, geographical location, gender, and ethnicity. The role of a peer reviewer is to judge the research proposed and provide the Institutes with honest and informed advice about the merits of the proposals under review. These cultural norms also address the following questions:

- w What are the roles and responsibilities of the Scientific Review Administrators (SRAs), Chairs, and Members of study sections?
- w What is the appropriate relationship between study sections and disciplines?
- w What types of research have the potential to impact the ability of the NIH to achieve its mission?
- w What should a grant application propose?
- w What perspective should be used in review, and how should the results of the review be communicated?
- w What is the role of preliminary data?
- w What procedures can be introduced to improve the operation of study sections?

### **NIDA HOLDS 6<sup>TH</sup> ANNUAL CONSTITUENT CONFERENCE**

*January 24, 2000, Number 2*

For the sixth year, the National Institute on Drug Abuse (NIDA) of the National Institutes of Health brought together representatives from a variety of disciplines and affiliations, including COSSA,

for its annual constituent conference. The meeting is important, said NIDA Director Alan Leshner, because it “provides a forum for discussion” and an opportunity for the Institute to get advice from its constituency in establishing its research agenda. He stressed that a major purpose for the meeting is “to find out what NIDA needs to be doing.”

Leshner noted that drug use and related adverse behavioral and social consequences are increasingly becoming a focus of drug abuse and addiction research. He used a slide of a puzzle — with behavior [and social science] as the center piece — as a metaphor for all the types of research required to find a solution to the problems of drug abuse and addiction. He talked of his recent appearance at the COSSA Annual Meeting in November and of his desire to find a way to most effectively describe drug addiction as a brain disease (See *UPDATE*, December 6, 1999, No. 21). He said he received an email from Social Science Research Council (SSRC) President Craig Calhoun suggesting drug abuse and addiction be described as a “brain disease shaped by behavioral and social context.” Leshner liked this explanation, but said he is still looking for an even clearer way of communicating the complicated phenomenon of drug abuse and addiction.

Leshner noted that NIDA is in the process of releasing a request for application, “Drug Use and Related Adverse Behavioral and Social Consequences.” This RFA, he said, is significant because the risk factors for drug abuse and addiction are also the risk factors for most everything bad that can happen to an individual. It is not just about risk, he said. The majority of the people who have the majority of the risk factors do not use drugs, he continued. What is it that protects them? Why don’t they use drugs? He stressed that this nuance is a very important factor in the development of new and improved prevention strategies.

According to Leshner, NIDA’s next set of initiatives will focus on several areas including: vulnerability to addiction, transition to addiction, neuroscience, next generation of prevention research, AIDS, and other medical consequences.

As in previous years, NIDA prepared a “Report Card” that describes how the Institute has responded to the recommendations made the preceding year. Several core issues continue to be concerns for both NIDA and the field including: collaborative efforts, children and adolescents, HIV/AIDS, special populations, treatment, prevention, education, and information dissemination. Additional issues that have been identified by NIDA constituents as priorities for this year include: research on the prevention of drug abuse and HIV; prenatal drug exposure; prevention interventions for children, adolescents, and families; Hepatitis C; treatment for special populations; criminal justice and drug courts in relation to health issues and approaches; the translation of interventions into clinical practice; and the impact of organizational structure and management on treatment, access, quality, cost, and patient outcomes.

### **Recently Released Requests for Applications (RFAs)**

Fulfilling Leshner's promise of increased research, NIDA has released several requests for applications (RFAs).

Noting that the treatment and management of HIV/AIDS in drug users are complicated by social, behavioral, clinical, and pharmacological factors which may alter the long-term effectiveness of HIV therapies, NIDA invites applications for research on access, adherence, and effectiveness relevant to the treatment of drug users with HIV. The mechanism of support for this RFA will be the investigator-initiated research project grant (R01). A letter of intent is due by February 28, 2000; the application is due March 29, 2000. For more information see the announcement at <http://grants.nih.gov/grants/guide/rfa-files/RFA-DA-00-007.html>.

A second RFA, the "Next Generation of Drug Abuse Prevention Research," encourages a new generation of drug abuse prevention research. Applications are being solicited to examine components of empirically validated drug abuse prevention interventions that may account for program effectiveness. Prospective applicants are asked to submit a letter of intent by February 28, 2000; the application is due March 28, 2000. For more information see the announcement at <http://grants.nih.gov/grants/guide/rfa-files/RFA-DA-00-004.html>.

NIDA is also seeking applications for research projects in basic behavioral, cognitive, and neuroscience research that can address the complex relationship between drug abuse and addiction and HIV/AIDS transmission and progression. Prospective applicants are asked to submit a letter of intent by February 29, 2000; the application is due March 29, 2000. For more information see the announcement at <http://grants.nih.gov/grants/guide/rfa-files/RFA-DA-00-005.html>.

Finally, NIDA has launched a new initiative in response to the increasing popularity of substances known as "club drugs" — substances commonly used by young adults at dance clubs and bars — and has issued a notice to inform the research community that it is interested in expanding its research portfolio on all aspects related to the use, abuse, and the short- and long-term effects of "club drugs." Applications can be in response to several NIDA Program Announcements (PAs):

**Z** Drug Abuse Prevention Intervention Research (<http://grants.nih.gov/grants/guide/pa-files/PA-00-002.html>); and

**Z** Drug Use and Related Adverse Behavioral and Social Consequences (<http://grants.nih.gov/grants/guide/pa-files/PA-99-113.html>).

## **PRESIDENT RELEASES FY 2001 BUDGET PROPOSAL: SCIENCE GETS BIG BOOST** *February 7, 2000, Number 3*

President Clinton released the FY 2001 proposed budget on February 7<sup>th</sup>. As promised, it contained what Presidential Science Adviser Neal Lane called "a historic science and technology budget." What the administration has called "The 21<sup>st</sup> Century Research Fund" will increase by \$2.9 billion over the FY 2000 level. The Fund is an attempt to present science and technology budgets as one package.

As noted at a recent speech at Cal Tech, Clinton's proposed budget for the National Science Foundation (NSF) provides the largest dollar increase in its history. The \$675 million, or 17 percent boost, would bring NSF funding to \$4.6 billion. Almost one-half the increase, \$320 million, would go to enhance support for core programs, rather than for new Foundation wide initiatives. NSF's Research and Related Activities account would increase by almost 20 percent to \$3.54 billion. The Social, Behavioral, and Economic Sciences Directorate (SBE) would share in this enhancement with a potential increase of close to 20 percent to a total of \$175 million. NSF has also made the cognitive, psychological, and linguistic sciences a special emphasis area in the proposed budget. NSF Director Rita Colwell called her proposed largesse, "a 21<sup>st</sup> Century budget for 21<sup>st</sup> Century science and engineering."

The **National Institutes of Health** would receive a \$1 billion increase to almost \$19 billion. Although only a 5.6 percent increase, it is widely expected that the Congress will keep NIH on the "doubling track" and provide a much larger increase than the President's proposal. NIH Acting Director Ruth Kirschstein has noted that NIH's priorities for FY 2001 include increased attention to health disparities research. NIH has established a working group, headed by NIH Acting Deputy Director Yvonne Maddox and National Institute of Allergy and Infectious Diseases Director Anthony Fauci, to examine this topic. The NIH budget also includes \$20 million to establish within the Office of Research on Minority Health (ORMH) a Coordinating Center for Health Disparities. Members of Congress have been pushing to create such a center to replace the ORMH, currently located within the Office of the Director.

The President's budget requested a total of \$3.5 billion for the **Centers for Disease Control and Prevention (CDC)**, a \$201 million or 6 percent increase over FY 2000. If Congressionally approved, the FY 2001 budget for the **Agency for Healthcare Research and Quality** would provide a program level of \$250 million, a \$46 million or 22.6 percent increase over FY 2000.

The **Office of Educational Research and Improvement (OERI)** received \$199 million for research, development, and dissemination activities — \$30 million more than its FY 2000 level. The increase includes funds to double OERI's commitment to \$20 million from \$10 million for the Interagency Education Research Initiative (IERI) which would increase. The **National Center for Education Statistics (NCES)** received a 24 percent increase to \$84 million from \$68 million in the current year.

The **National Institute of Justice (NIJ)** received an increase in its base funding to \$49 million from its current funding of \$43.4 million. NIJ's overall funding, when including budget transfers, will likely be four times its base funding. The request includes language that would set aside one percent of the sums appropriated to the programs of the OJP for the NIJ to carry out research and evaluation. The **Bureau of Justice Statistics (BJS)** received a nearly 30 percent increase — to \$33.2 million from \$25.5 million in FY 2000.

The **Census Bureau's** funding for the decennial census was reduced, as is common in the year that it is conducted since most of the preparation work is performed in the years leading up to the census. For FY 2001, the Bureau received \$421 million to complete the head count and to compile and publish the data. Additionally, the President's request included \$25 million for continued development and implementation of the American Community Survey (See related story, page 6).

For **Agriculture and Rural Development** spending, the President has proposed increasing the National Research Initiative Competitive Grants program to \$150 million from its current \$119.3 million. The administration also announced that it intends to continue spending for the Initiative for Future Food and Agriculture Systems and the Fund for Rural America. Unlike the past few years, the administration is not proposing to cut Hatch Act funds, but to keep it level funded at \$181 million.

**COSSA will fully report on the proposed budgets of all federal agencies affecting social and behavioral science research in its annual special issue of *UPDATE*. Look for it the week of March 6.**

### **NIH TO CONTINUE THE COURSE SET BY VARMUS, SAYS TOP OFFICIAL**

*February 7, 2000, Number 3*

While former Director Harold Varmus may have already left the National Institutes of Health (NIH), current Acting Director Ruth Kirschstein says the NIH “expects to continue the course set by” Varmus. Speaking at the National Institute of Diabetes and Digestive and Kidney Diseases Advisory Council, Kirschstein discussed the future of NIH and the upcoming appropriations process.

Before turning the microphone over to the NIDDK’s new director, Allen Spiegel, Kirschstein noted that the NIH plans to continue meeting scientific opportunities as they occur. She said that the NIH would “continue to encourage the best science possible.” She also noted that she had no idea how long she would be in the Acting Director position. Rumors suggest that Gerald Fischbach, director of the National Institute of Neurological Disorders and Stroke (NINDS), is the White House’s choice to succeed Harold Varmus as NIH director.

Kirschstein stressed that NIH knows that Congress has “been extraordinarily generous” in providing it resources. She said, however, if the NIH is to meet the goal of doubling the agency’s budget in five years, the coming fiscal year requires a considerable increase in resources over the current fiscal year. She acknowledged that some question whether the NIH can absorb the funding increases in an effective manner. In other words, critics question whether the agency is funding new scientifically creative research or if it is just adding dollars to the coffers of experienced investigators. Kirschstein countered that mindset by stressing that there is “plenty of good science to do,” and that it is a “question of how [NIH] tells our story.” She has instructed Institute directors to emphasize what the agency has done with the increases provided by Congress and what the agency plans to do in “specific terms that can be understood.”

### **NIMH REPORT: BEHAVIORAL SCIENCE CAN HELP MENTAL HEALTH**

*February 7, 2000, Number 3*

According to the Report of the National Advisory Mental Health Council Behavioral Science Workgroup, “[b]ehavioral science can offer critical insights into the nature of mental illness and health and the processes and interventions that can prevent illness or lead from disorder to remission, recovery, and rehabilitation.” The Workgroup, chaired by Anne C. Petersen of the W.K. Kellogg Foundation, and

Robert W. Levenson, of the University of California, Berkeley, presented the Report at the National Advisory Mental Health Council at the February 4 meeting. The report, *Translating Behavioral Science into Action*, notes that the behavioral science field “which has yielded great practical benefits for education, the military and industry, as well as many health areas, has much more to offer in mental health. Many findings that might inform interventions have not yet been applied in the clinical services domain; others remain to be explored and developed.”

The report makes recommendations that are designed to help NIMH overcome the barriers to fostering translational research which in the behavioral and social sciences “addresses how basic behavioral processes inform the diagnosis, prevention, treatment, and delivery of services for mental illness, and conversely, how knowledge of mental illness increases our understanding of basic behavioral processes.”

The report targets three specific areas of study in which the push of research progress converges with the pull of public health need to create prime targets for intensified study: 1) basic behavioral processes in mental health; 2) functional abilities in mental illness; and 3) contextual influences on mental illness and its care. The Workgroup believes that these priority areas “are critical starting points for progress in translational science because they are at the interface of what end-users have identified as important and what behavioral science researchers regard as areas of opportunity.”

Observing that because the three priority behavioral research areas are so central to the core mission of NIMH, the report suggests it may seem puzzling that it would have to highlight them for “special encouragement.” The Workgroup notes that such research is sparse at best in the Institute’s portfolio, “suggesting that these are difficult areas to develop.” The report further notes that presently there are too few researchers attempting to bridge across basic, clinical, and services research. Additionally, there are not enough researchers working with colleagues in related allied disciplines to move research advances out of the laboratory and into clinical care, service delivery, and the policy making fields.

The Workgroup also notes that NIMH “stimulates outstanding mental health research through a blend of scientific leadership and efficient research administration. As the leading supporter of basic and clinical behavioral science, as well as treatment research and services research related to mental illness, NIMH is strongly positioned to build a successful and enduring program of translational behavioral research.” The Workgroup further believes that in order to establish a strengthened program of translational behavioral science research at NIMH it will require special effort and incentives to overcome extensive structural, financial, and attitudinal barriers.

Some of the report’s recommendations include:

- " Establish and publicize translational behavioral science research as priority funding area for NIMH and to develop a coherent strategy for its systematic development.
- " Stimulate NIMH-funded research centers to provide an infrastructure for new research, speed the translational findings, and encourage interaction across basic, clinical and services research.
- " Develop innovative approaches to supporting translational research.
- " Train researchers at all career levels to conduct translation behavioral research.

" Facilitate appropriate and rapid funding of outstanding translational research.

For more information, contact the National Institute of Mental Health at <http://www.nimh.nih.gov>.

## **NIH OFFICIALS APPEAR BEFORE HOUSE APPROPRIATORS**

*March 20, 2000, Number 5*

In an effort to have its bill marked up and through the House by July, two months earlier than usual, the House Labor, Health and Human Services, and Education and Related Agencies Subcommittee, chaired by Representative John Porter (R-IL), started its hearing process in February.

Acting National Institutes of Health Director (NIH) Ruth Kirchstein, appearing before the Subcommittee regarding her agency's budget, promised to provide appropriators with an advance blueprint of how the NIH would utilize another 15 percent budget increase. Ranking Member David Obey (D-WI) requested that the information be provided in increments of \$500 million. Porter, Obey, and the other Subcommittee members were very interested in the agency's ability to provide them with the information needed to convince their colleagues that NIH can spend the increases wisely. Kirchstein emphasized that opportunity has never been greater. There are many questions that we can answer, she said. The agency, she declared, will not spend its resources on bad science.

**National Institute of Child Health and Human Development (NICHD).** According to NICHD Director Duane Alexander, the Institute is exploring ways to improve reading skills in populations of culturally and linguistically diverse students. Alexander noted that data from the three year old Early Intervention Project are currently being collected and analyzed, but preliminary data show a pattern of remarkable improvements in reading ability. Reading scores in schools that have historically been at the 10<sup>th</sup> and 15<sup>th</sup> percentile have improved to better than the 50<sup>th</sup> percentile, said Alexander. Additionally, entire classes in intervention schools are now performing at the national average. The Institute and the Department of Education are jointly soliciting research proposals for systematically studying the most effective ways to teach reading English to children whose primary language is Spanish. Representative Anne Northup (R-KY) described the program as "phenomenal" and urged the Subcommittee to visit the schools and see the results for themselves.

Alexander highlighted the National Longitudinal Study of Adolescent Health (Add Health) which has "provided new insights into the ways that peers, families, schools, and neighborhoods can influence positive health outcomes, as well as negative outcomes, such as violent behavior, smoking, drinking, illegal drug use, and sexual behavior." The study, said Alexander, will help identify the major determinants of health and health behaviors during the transition from adolescence to early adulthood. Alexander noted that the data collected this year may be the most important part of Add Health Study because they follow up the study of the original cohort.

Alexander also noted that culturally sensitive materials and programs designed by and for African American communities are needed to combat the Sudden Infant Death Syndrome (SIDS) rate in these communities. The rate, said Alexander, remains more than double that of white infants. As a first step,

the Institute is conducting research with African American caretakers (e.g., parents, grandparents, relatives, and child care workers) to identify effective ways to communicate the “back to sleep” message. NICHD’s goal, he said, is to eliminate the racial disparity in SIDS within three years.

**National Institute on Aging (NIA).** Director Richard Hodes told Subcommittee members that studies have shown that the disability rates for people 65 and older have been falling at an accelerating pace since 1982. The benefits of this trend, he said, extend to both men and women and to minority groups. He emphasized “that more research is necessary to understand the causes and economic consequences of the decline in disability rates and to further accelerate these improvements.”

Hodes noted that increasingly researchers are understanding the benefits of exercise, especially for older people, as a key to preventing or delaying the onset of disease and disability. There is also scientific evidence that suggests that exercise may be a factor related to increased life expectancy and the number of years people live free of disability, he said. He cited a clinical trial involving chronically ill older adults, aged 70 and older, where researchers reported that one year of increased physical activity, combined with chronic-illness self-management, resulted in fewer reported hospitalizations and total hospital stays.

Porter, noting that much of what we find out about disease and health relates to good diet and exercise, questioned whether we are doing enough in prevention to keep people healthy in the later years? “Clearly, we are not,” answered Hodes. Trying to understand and sustain a change in lifestyle are not as easy as they appear, he said. Northup prodded Hodes to continue to encourage multidisciplinary efforts — including those that incorporate psychology and sociology.

**National Institute on Mental Health (NIMH).** Director Steven Hyman emphasized the importance of basic behavioral science. Basic behavioral science could bring treatment and people involved in public policy closer together, he said. Behavioral scientists could also serve to educate the public about the findings of research. Hyman also stressed the need for more minority researchers to enhance the inclusion of minorities in study populations.

Referring to the recent shooting of a six-year old by a classmate, Porter asked Hyman what is the connection between youth violence and mental disorders? Hyman said, to head off such violence, more needs to be done with families and family involvement regarding appropriate supervision. In his written testimony, Hyman noted “youth with conduct problems often exhibit inattention and impulsiveness, often coexisting with hyperactivity.” Most youth violence occur between the hours of 3 p.m. and 10 p.m. Additional after-school programs are needed to keep youth active and out of trouble, Hyman further explained. Pushing them into delinquency programs and special needs schools just creates a “graduate school for delinquent youth.”

**National Cancer Institute (NCI).** Director Richard Klausner noted that drops in mortality rates continue to be seen for lung, colorectal, breast, and prostate cancer. “Remarkably, the magnitude of these drops are such that, for the first time, between 1996 and 1997, the total number of cancer deaths did not rise, despite a growing and aging population.” Klausner noted that for the second time in its history, the NCI released 25-year cancer mortality maps. He further noted that the maps do not tell the “causes of cancer or indeed whether a geographic pattern reveals either a localized environmental factor, a

behavioral pattern, or a socio-economic pattern.” Nevertheless, because they provide the starting point for addressing these issues, the maps are crucial resources, said Klausner.

He noted that one of the themes of NCI activities is to address gaps — gaps between what we need to know and our current state of knowledge, gaps between the burden of cancer across different segments of our population, and gaps between scientific discovery and medical breakthroughs. Klausner said that “one of the most important gaps is between evidence-based best practice and actual practice, which the Institute plans to address via a new initiative — the Quality Cancer Care Committee (QCCC). The QCCC will be a trans-agency initiative led by the NCI to develop a comprehensive research infrastructure to address the issues of quality cancer care across the cancer continuum from prevention to treatment to survivorship and end-of-life care. The research agenda will focus in four areas: 1) developing measures of cancer outcomes, 2) strengthening the meteorologic and empiric base for quality assessment, 3) strengthening the national clinical trials infrastructure, and 4) improving the quality of cancer communications.

Referencing the Institute of Medicine Study, the *Unequal Burden of Cancer* (See *UPDATE*, January 25, 1999, No. 2), Representative Jesse Jackson, Jr. (D-IL) pushed Klausner on what his Institute was doing to address the issues in the report, particularly that less than one percent of NCI’s resources were granted to understanding the disparities in cancer research. Jackson stressed his interest in pursuing data that depict an absence of minority and women researchers in cancer research. He was not pleased with Klausner’s response citing the creation of Special Population Networks for cancer control and research. Jackson declared that creating special centers is wrong, stressing that “set asides” are not what is required. Minorities need a seat at the power table.

**Office of AIDS Research (OAR).** Director Neal Nathanson, responding to the Subcommittee’s support last year for research to address the international dimension of the AIDS epidemic, noted that “AIDS in Africa is killing ten times as many people as war, sabotaging economic development, leading to massive social breakdown, and creating a new generation of orphans.” Quoting Ambassador Richard Holbrooke, Nathanson said that AIDS is “a direct, cancerous growth on the political, social, and economic security of Africa.”

He emphasized that in the United States, while therapeutic interventions are delaying death, we have not slowed the epidemic. HIV infection rates are continuing to climb in women and minority populations, he said. Adding that drug resistant strains of HIV present a serious public health concern, Nathanson stressed that these “data forebode an epidemic of even greater magnitude ahead, and shapes” the OAR’s most urgent research priorities. These priorities, he said, address two critical populations — those living in developing countries, and the minority populations of the U.S. He emphasized a two-pronged agenda: therapeutic research to treat those already infected, and prevention research to reduce HIV transmission. OAR’s prevention agenda, he continued, includes non-vaccine strategies such as behavioral research.

Nathanson also informed the Subcommittee of OAR’s establishment of an Ad Hoc Working Group on Minority Research to advise the Office on the scientific priorities in this research area, and of the addition of a new section on research targeting minorities in the OAR research plan. The Office, he said, is directing resources toward new interventions that address the co-occurrence of other STDs,

hepatitis, drug abuse, and mental illness; and interventions that consider the role of culture, family, and other social factors in the transmission and prevention of these disorders in minority communities.

**Fogarty International Center (FIC).** Director Gerald Keusch explained to the Subcommittee that while one-fifth of the world's population enjoys an average life expectancy approaching 80 and live comparatively disability free, two-thirds of the world's population suffer overwhelmingly from the world's burden of illness and premature death. The toll in sickness and life-long disability, he continued, has even greater social, economic, and political consequences.

Keusch emphasized that research on conditions related to poverty in resource-poor nations have universal applications. The FIC's mandate is to serve as the NIH's international catalyst by enabling U.S. institutions to extend the geographic scope of research and training. Keusch emphasized that the FIC's priorities are in four foundation disciplines: 1) information science and technology, 2) epidemiological and clinical methodologies, 3) human genetics and genomics, and 4) ethical principles and practice in patient-oriented research. The Center, he said, will launch an effort directed at prevention and management of mental health disorders — an unseen epidemic in most developing countries. FIC will generate epidemiological data on the incidence of mental health disorders and risk factors, including sociocultural determinants of mental health in societies undergoing transition to industrialized economies.

Keusch, said Porter, is really changing the way FIC is operating. Responding to Porter's concern with how FIC deals with cultural differences, Keusch noted that it is important to understand particular cultures and not project cultural imperialism. Echoing NIA Director Richard Hodes, Keusch stressed that behavior change is very difficult. He further noted that the Center is collaborating with NIMH to better understand issues in changing behavior.

**National Center for Complementary and Alternative Medicine.** Director Stephen Strauss told the Subcommittee that "approximately 42 percent of U.S. healthcare consumers spent \$27 billion on complementary and alternative medicine (CAM) therapies in 1997." Strauss emphasized that a number of practices, once considered unorthodox, have proven safe and effective and have assimilated seamlessly into current medical practice. He cited diet and exercise as examples of practices used to prevent and control diseases.

Strauss stressed that in order to best seize the opportunities, NCCAM's strategy must differ from that of the rest of NIH. NCCAM, he said, "must focus first on definitive clinical trials of widely utilized modalities that, from evidence-based reviews, appear to be the most promising." He noted that NCCAM is currently developing a strategic plan. Five strategic areas have been identified: investing in research, training CAM investigators, expanding outreach, facilitating integration, and practicing responsible stewardship.

## **KAUFMANN APPOINTED ACTING OBSSR DIRECTOR**

*March 20, 2000, Number 5*

On February 25, Acting NIH Director Ruth Kirchstein announced the appointment of Peter Kaufmann, as NIH's Acting Associate Director for Behavioral and Social Sciences Research and head of the Office of Behavioral and Social Sciences Research (OBSSR) effective April 1, 2000. Kaufmann will be working with current OBSSR Director Norman Anderson over the next few weeks to help ensure a smooth transition. Kaufmann has most recently been Group Leader of the Behavioral Medicine Research Group in National Heart, Lung and Blood Institute's (NHLBI) Division of Epidemiology and Clinical Applications. He began his career at NIH as a Health Scientist Administrator in the Behavioral Medicine Branch of NHLBI in 1983.

### **CHAIRMAN TO SEEK ANOTHER 15 PERCENT INCREASE FOR THE NIH**

*April 3, 2000, Number 6*

Labor, Health and Human Services, and Education, and Related Agencies Appropriations Subcommittee Chairman Arlen Specter (R-PA) announced at the Subcommittee's annual hearing on the National Institutes of Health (NIH) that he will seek the third consecutive installment toward doubling the agency's budget in five years, despite the spending constraints of the budget.

During floor consideration of the Senate budget resolution this week, Specter and Ranking Member Tom Harkin (D-IA) are expected to offer an amendment to ensure that the budget contains sufficient resources to increase the agency's budget by \$2.7 billion in FY 2001. This 15 percent increase for the NIH would continue the effort by Specter, Harkin and Representative John Porter (R-IL) to double the agency's budget by FY 2003. The budget resolution, as passed by the Senate Budget Committee, contains only a \$1 billion increase for NIH.

Specter noted during the Subcommittee's hearing that he and Harkin have offered similar amendments for the past three years, with steadily increasing support from the rest of the Senate, but without the "enthusiasm of as many members as we would like to see." Noting that over the last two years Congress has added substantial funding (\$4.3 billion) to the NIH's budget, he added that this feat was accomplished because of "NIH's good work and [their] persistence." Specter said he consistently get the question: "Is too much money being thrown at the NIH." He answers by saying the agency is worth it.

Dropping in on the Subcommittee's hearing, Senate Appropriations Committee Senator Chair Ted Stevens (R-AK) stated that he was "ready to do battle" on behalf of the NIH and continue the efforts towards doubling the NIH's budget in five years. Stevens acknowledged that there is "a very tight budget this year." Despite this fact, he said from a "strictly conservative point of view, we ought to increase the investment [in NIH] now" to reduce the impact on government health programs when the baby boomers retire. The budget, he continued, cannot absorb the costs associated with aging of the baby boomers if the rate of disease for that population is comparable to that of his generation. He added, however, that it is imperative that a way be found to ensure that the dollars provided to NIH are going to research. Stevens noted that he is not "too keen on providing funding for bricks and mortar."

Specter was particularly interested with the success rate, or the rate at which NIH funds applications — the ratio of applications funded to total number of applications. The current NIH-wide success rate is 26-28 percent. Specter asked Acting NIH Director Ruth Kirchstein how much funding it would take for NIH budget to increase its success rate to 40 percent. He then asked each Institute Director to provide him: the Institute's current success rate, the total number of grants funded last year, the desired success rate for the Institute, and the amount of funding required to reach that rate. National Cancer Institute (NCI) Director Richard Klausner noted that NCI's current success rate is 30-31 percent and 4,000 applications were received last year. A meritorious success rate for the NCI would be 35 -37 percent, which would take approximately 20 percent increase in funding for the NCI to reach, he concluded.

### **NIH Champion Warns Against Complacency**

At the 10 year anniversary celebration of the formation of the Congressional Biomedical Caucus, Representative John Porter (R-IL), warned NIH advocates against complacency. Speaking on March 27 before a group consisting mainly of House staffers, Porter cautioned advocates for the NIH to not "make the assumption" that the case for a 15 percent increase and doubling the agency's budget in five years is "so compelling that Congress will do it."

Obtaining the 15 percent increase in FY 2001 represents "a particular challenge," Porter continued. He encouraged the advocates to "not sit on the sidelines but to let their voices be heard." He further encouraged them to inform their members of how "much good science" there is and that funding cannot keep up with the opportunities that exist, noting that National Institute of Allergy and Infectious Disease Director Anthony Fauci had indicated that if his Institute's budget was doubled immediately "he would still be funding good science." Porter stressed that he "can think of no better spent dollars anywhere. The lives saved are incalculable," he stated.

### **ALTERNATIVE AND MIND-BODY MEDICINE SUBJECT OF HEARING**

*April 3, 2000, Number 6*

The National Institutes of Health's (NIH) support for complementary and alternative medicine (CAM) research is "woefully inadequate," said the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies Ranking Member Senator Tom Harkin (D-IA) at a March 28 hearing on alternative and complementary, and mind/body medicine. Acknowledging his "deep interest in the field of complementary and alternative medicine," Harkin said that his "basic belief is that we need to take advantage of every possible method of keeping people healthy."

Harkin, an ardent supporter of the National Center for Complementary and Alternative Medicine (NCCAM) and largely responsible for increasing the recognition surrounding complementary and alternative medicine at NIH and in the Congress, stressed that the NCCAM receives about \$67 million annually, "less than one half of one percent of the total funding for the entire NIH" (See *UPDATE*, March 20, 2000, Number 5). He expressed his concern that research in this area remains underfunded given its prevalence. Articulating his skepticism regarding the amount of funding that the various ICs

have indicated is for CAM, Harkin said that he has “some real questions about just what they are spending their money on and listing as CAM.” He further noted that he intended to address the issue with each of the NIH Institute directors.

Making his first appearance before the Subcommittee, National Center for Complementary and Alternative Medicine Director Stephen E. Straus noted that the hearing reflected the “growing public interest in complementary and alternative medicine.” Peter Kauffman, the Acting Director of the Office of Behavioral and Social Sciences Research (OBSSR), accompanied Straus to respond to questions regarding the overall NIH research portfolio on behavioral and mind/body research supported across the NIH Institutes and Centers.

Strauss told the Subcommittee that as NCCAM’s first permanent director, he is “excited by the challenge” before him. The Center’s strategy, he said, for taking on this challenge is different from that used by other NIH Institutes and Centers (ICs). “While the research conducted by the other ICs is usually driven by basic scientific discoveries, NCCAM has chosen to focus most heavily on definitive clinical trials of widely utilized modalities that, from evidence-based reviews, appear to be most promising,” said Strauss.

### **Mind/Body Research Not a Priority**

Strauss pointed out that “mind-body medicine encompasses a spectrum of behavioral, biomedical, social, and spiritual components of our makeup that interact on a continuing basis in health and disease.” He further noted that the broad discipline overlaps partially with NCCAM’s mission, adding that the CAM community does not consider it a priority for his agency to study mind-body approaches that have well-documented theoretical and evidence bases, such as: patient education, biofeedback, and cognitive-behavioral approaches. These, he said, are all addressed extensively by other ICs working in concert with OBSSR.

This distinction is important because in FY 1999 the Congress provided \$10 million in funding to the OBSSR to establish five mind-body research centers. A request for applications to fund the centers was issued in January 1999. In September awards were made to the University of Michigan, the University of Pittsburgh Medical Center/Carnegie Mellon, University of Miami, University of Wisconsin and Ohio State University. The awards are being administered by the National Cancer Institute, the National Heart, Lung and Blood Institute, the National Institute Child Health and Human Development, the National Institute of Mental Health, and National Institute of Dental and Craniofacial Research. The first results are expected in about two years (See *UPDATE*, October 25, 1999, Number 19).

### **Mind/Body Medicine Is Not Alternative and Complementary Medicine**

Herbert Benson of the Mind/Body Medical Institute at Harvard Medical School proposed that “mind/body medicine, with its self-care and belief-related approaches, holds great promise for the nation’s health and cost of healthcare.” Benson told the Subcommittee that “mind/body medicine is different from what is called alternative and complementary medicine. Mind/body medicine is evidence-based whereas alternative medicine is not.” He further stressed that the “full integration of mind/body, spirituality-related, self-care medicine is completely compatible with existing health care approaches.”

Benson proposed that the Health Care Financing Administration (HCFA) establish large demonstration projects to definitively test the clinical efficacy of mind-body and belief-related interventions and to assess the cost-savings afforded by such approaches. The projects, he said, should start with medical conditions that are prevalent and expensive, such as: the prevention and treatment of coronary artery disease, the treatment of chronic pain, and the treatment of women's disorders including infertility.

Andrew Weil, from the University of Arizona, said that he is "encouraged by the level of interest Congress has shown in behavioral, alternative, and mind/body medicine." Dean Ornish, of the Preventive Medicine Research Institute at the University of California, San Francisco and a recent appointee to the Presidential White House Commission on Complementary and Alternative Medicine Policy, also applauded "Congress for establishing the Office of Alternative Medicine and elevating its status and funding."

Ornish told the Subcommittee that "although at least 50 percent of the determinants of our health are behaviors such as diet and lifestyle, only 1.4 percent of the national health expenditures and only 7 percent of the NIH budget is devoted to these areas." When we treat these underlying causes of diet and lifestyle, continued Ornish, "we find that the body often has a remarkable capacity to begin healing itself, and much more quickly than once been though possible." He, like Benson, advocated that HCFA cover alternative medicine and mind/body programs that have demonstrated medical effectiveness in randomized controlled trials published in peer-reviewed medical journals.

### **NIH Spends \$1.6 Billion on Social and Behavioral Science Research**

In his testimony to the Subcommittee, Acting OBSSR Director Peter Kaufmann noted that "currently, NIH supports approximately \$1.6 billion in behavioral and social science research across the NIH Institutes and Centers." Kaufmann noted that "one example of the kind of behavioral and social sciences research that OBSSR promotes across all of the Institutes and Centers (ICs) is mind/body research." Funding for mind/body research is significant and broad at NIH, he continued, pointing to the fact that 14 of the NIH ICs will fund an estimated \$125.3 million in mind/body research in FY 2001. Approximately 50 percent of the OBSSR's budget is devoted for this type of research.

Kaufmann informed the Subcommittee that mind/body research "encompasses behavioral, social, and biomedical research on the interrelationships among cognition, emotion, biological functioning, and physical health." Examples of the mind/body research being supported by the ICs include the:

- \* National Institute of Mental Health's support of research that examines the psychological and physiological effects of a group psychotherapy intervention for women with metastatic breast cancer, as well as the Institute's ongoing investigation of the link between social environment, psychological states (positive and negative affect, personal control, self-esteem), and vulnerability to upper respiratory infections;
- \* National Institute of Dental and Craniofacial Research's examination of how stress affects the ability to heal;

- \* National Cancer Institute's research assessing the effect of a stress reduction intervention program on the quality of life and immunologic function of women diagnosed with breast cancer; and
- \* The National Heart, Lung and Blood Institute's examination of pathways through which mental stress influences heart function in health and illness.

## **OBSSR TO SPONSOR UPCOMING SOCIO-CULTURAL CONFERENCE**

*April 3, 2000, Number 6*

On June 27-28, the National Institutes of Health (NIH) Office of Behavioral and Social Sciences Research (OBSSR) will sponsor a national conference, *Toward Higher Levels of Analysis: Progress and promise in Research on Social and Cultural Dimensions of Health*. The conference is designed "to highlight the contributions of social and cultural factors to health and illness in order to achieve a better understanding of the interdependence of social, behavioral, and biological levels of analysis in health research."

The conference will address:

- \* Sociocultural constructs such as race, ethnicity, socioeconomic status, and gender;
- \* Sociocultural linkages between demographic factors and health;
- \* Social/cultural factors in prevention, treatment, and health services;
- \* Interpersonal, neighborhood, and community influences on health;
- \* Health justice and ethical issues; and
- \* Global perspectives on health.

### **Travel Stipends Available**

OBSSR is providing a limited number of travel stipends to predoctoral students to attend the conference. Completed applications must be received by April 30, 2000. Recipients will be notified of awards by May 15, 2000. For more information see the OBSSR's web site: [www1.od.nih.gov/obssr/events/conference.html](http://www1.od.nih.gov/obssr/events/conference.html). Questions may be directed to Paula Skedsvold, at [skedvop@od.nih.gov](mailto:skedvop@od.nih.gov).

## **OBSSR SEEKS MORE MINORITY SCIENTISTS**

*April 17, 2000, Number 7*

The National Institutes of Health's (NIH) Office of Behavioral and Social Sciences Research (OBSSR) has launched a web-based project to increase the number of minority scientists in the behavioral and social sciences. NIH grantees who are interested in mentoring minority students are encouraged to visit the web site and add their name and information about their research program to OBSSR's database. Once there is an adequate number of principle investigators (PIs) in the database, OBSSR will invite minority students to search the site for potential mentors. Applicants will then have an opportunity to submit an application directly to a mentor via the site. PIs will then contact the NIH Institute awarding their grant to see if an administrative supplement is available. Working through the 25

Institutes and Centers, OBSSR will use an established NIH grant mechanism - the Research Supplements for Underrepresented Minorities program. For more information, see OBSSR'S website: [www4.od.nih.gov/research/](http://www4.od.nih.gov/research/).

## **HEALTH DISPARITIES DISCUSSED AT NIH COUNCIL OF PUBLIC REPRESENTATIVES MEETING**

*April 17, 2000, Number 7*

Health disparities was among the topics discussed at the April 6 meeting of the National Institutes of Health (NIH) Council of Public Representatives (COPR). Acting Deputy Director Yvonne Maddox gave COPR members an overview of NIH's current efforts. Former NIH Director Harold Varmus initiated the health disparities discussion at the inaugural meeting of the group April 21, 1999 (See *UPDATE*, May 3, 1999, Number 8).

According to Maddox, the NIH is looking at areas other than those identified by the Department of Health and Human Services (HHS) in response to the President's Race Initiative. The Health Disparities Initiative includes a five-step plan that sets as a national goal the elimination of health disparities in six areas by the year 2010. The six areas — infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV/AIDS, and immunizations — were chosen because they are the areas in which racial and ethnic minorities experience "serious disparities in health access and outcomes." These areas were chosen not only because they represent significant disparities, and any improvement would have a significant impact in terms of overall health status of the affected communities, but also because good baseline data is now available that will allow for monitoring the progress being made.

Assistant Secretary for Health and Surgeon General David Satcher and Assistant Secretary for Planning and Evaluation Margaret Hamburg are leading HHS' campaign which has been reaching out to local communities, churches, nurses, physicians, community-based programs, and experts in minority health. The goals are included in Healthy People 2010, which sets the Nation's health goals to be accomplished by that year. The Department acknowledges that advances in medicine and increased access to care can only partially address the difficult, complex, and often controversial issues surrounding racial and ethnic disparities in health status.

In response to the Secretary's HHS Initiative, Varmus established a trans-NIH Working Group on Health Disparities in September 1999. Subsequent to the creation of the Working Group, Varmus directed each Institute, as well as Offices within the Office of the Director (OD), to participate in the establishment of a strategic plan for health disparities research. Acting NIH Director Ruth Kirchstein charged the group to come up with a strategic plan for each of the individual Institutes, with all plans due by April 3, 2000. The NIH will take parts of each of the Institutes' plans and come up with a single NIH-wide strategic plan. The Advisory Committee to the Office of Research on Minority Health (ORMH) will review the completed NIH plan and submit it to Kirchstein for discussion at the NIH's Fiscal Year 2002 annual budget retreat scheduled for June. The trans-NIH plan-of-action will be tied to the agency's budget planning process.

Maddox, along with National Institute of Allergy and Infectious Disease Anthony Fauci, have been appointed by Kirchstein to chair the NIH's strategic planning group. The group's goals include: developing a five-year strategic research agenda; recruiting, training, and career development opportunities for minority investigators both in the extramural community and at NIH; advancing community outreach activities; bridging and forming partnerships; defining, coding, tracking, analyzing and evaluating progress; and enhancing public awareness. The NIH-wide plan will also focus on expanding the recruitment of minority participants in clinical research and clinical trials, and calls for "establishing new partnerships with industry, foundations, and other Federal agencies." Initially, said Maddox, the NIH will focus on racial/ethnic minority populations (African Americans, Asians, Pacific Islanders, Hispanics and Latinos, Native Americans, and Native Alaskans).

One of the most difficult tasks the planning group has faced has been defining "health disparities" for the purposes of NIH, said Maddox. It is in the middle of many issues, she continued. Accordingly, it has been difficult to described what NIH is doing. So the group worked not only on defining health disparities, but on how to code, track, analyze, and evaluate the data. According to Maddox, the NIH definition of health disparities is : "*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.*" Research on health disparities related to socioeconomic status is also included in the NIH definition. NIH must be able to say what the health disparities are and how much is being spent Maddox emphasized. All of this information will eventually be available on the NIH's web site, said Maddox.

Maddox apprised COPR members of the congressional interest in this topic. She referred to three bills that are currently awaiting committee hearings: H.R. 2391, the National Center for Research on Domestic Health Disparities Act, introduced by Representatives Jesse Jackson Jr. (D-IL); H.R. 3250, the Health Care Fairness Act of 1999, introduced by Representatives John Lewis (D-GA) and Bennie Thompson (D-MS); and S. 1880, the Health Care Fairness Act of 1999, introduced by Senator Ted Kennedy (D-MA). In addition to these pieces of legislation, Maddox also noted that the NIH had included in this year's budget submission to Congress a \$20 million request to create an "administrative center to jump start this initiative."

Maddox concluded that the NIH will hold a trans-NIH health fair June 2 -3, 2000 on the NIH campus; Surgeon General David Satcher has been invited. The fair will focus on children, for it is in childhood that one finds indicators of adult disease, concluded Maddox.

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*April 17, 2000, Number 7*

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opportunity to submit an application directly to a mentor via the site. PIs will then contact the NIH Institute awarding their grant to see if an administrative supplement is available. Working through the 25 Institutes and Centers, OBSSR will use an established NIH grant mechanism - the Research Supplements for Underrepresented Minorities program. For more information, see OBSSR'S website: [www4.od.nih.gov/research/](http://www4.od.nih.gov/research/).

## **HEALTH DISPARITIES: A CALL FOR SOCIAL SCIENCE RESEARCH**

*May 1, 2000, Number 8*

Equality, the benchmark of the United States, has not always been met when it comes to minority health, said Donna Shalala, Secretary of Health and Human Services (HHS). Shalala, speaking to more than 1,000 participants at the National Institutes of Health's (NIH) Office of Research on Minority Health (ORMH) conference, *Challenges in Health Disparity In the New Millennium: A Call To Action*, explained the Department's efforts to combat the disparities in health among racial and ethnic minorities (See *UPDATE*, April 17, 2000, Number 7). The conference, held April 17-19 to examine the many issues of health disparities, featured many officials from the HHS, the National Institutes of Health (NIH), and the health care field calling for more social science research.

HHS, said Shalala, has proposed spending \$5 billion in FY 2001 on programs designed to improve minority health, including \$20 million to establish a coordinating center for health disparities within ORMH that will integrate the various research resources of the NIH Institutes and Centers; and \$60 million in funding by the National Cancer Institute to set up Special Population Networks for cancer control and research. (See *UPDATE*, March 20, 1999, Number 5) The NIH is currently seeking legislative authority to allow the new center to award grants for minority health research under exceptional circumstances, when Institutes and Centers are unable to fund research that has been identified as a priority.

If we really want to remove the disparities in health, stressed Shalala, we have to focus on three things: (1) prevention, (2) promotion of access, and (3) increasing cultural sensitivity in the health care profession. We also have to address economic structure, social customs and human behavior, she said.

The Secretary called for more research to examine health risk factors and determine how to modify unhealthy behaviors. We cannot wait until we have universal health care. She called for "culturally sensitive" care, and exclaimed that cannot wait until every person has health insurance. Quoting Martin Luther King, Jr., Shalala said, "I can walk to freedom only if I have a healthy body."

Director John Ruffin, head of ORMH since its inception, noted that his office serves as a catalyst. Health disparities, he said, is a complex problem resulting from a combination of forces: heredity, environmental insults, infectious diseases, personal habits, and inadequate social support. These factors, said Ruffin, also play a role in the lack of participation by racial and ethnic minorities in biomedical research.

### **Race Is Not a Biological Construct**

Otis Brawley, Director of the National Cancer Institute Office of Special Populations, told the group that race, as defined by the Office of Management and Budget's Directive 15, is a sociopolitical construct. Anthropologists, however, reject it, said Brawley. The explanation of race as a biological causation factor is a misconception, he stated. This false idea dates back to infamous Tuskegee experiments, when researchers wanted to determine whether syphilis was a different disease in blacks versus whites, he continued.

He emphasized a need to move away from this construct. Migration studies show the effect of culture and environment, Brawley noted, citing evidence that reveals increased cancer rates among Chinese and Japanese immigrants to America, and whites who migrate from East to West. Diet, cultural habits, and poverty all play a role in the biological behaviors of genes, he told the group. Thus, there is a need to increase the attention to SES (socioeconomic status) and risk analysis of behavior and patterns of care.

The questions are, said Brawley, How do you get better care for all? How can we improve the quality of care? and What interventions can we do to improve the quality of care? Equal treatment would yield equal outcomes, race is not a factor in outcomes, he said.

Echoing many of the conference participants, Brawley called for research that examined how to influence healthful habits and how to convey accurate information in a culturally sensitive manner. We need to understand the role of social factors, he declared. Anthropologists, sociologists, and psychologists must be involved in the research.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Director Allen Spiegel said that the ethical and social implications surrounding health disparities in diabetes must be examined. Spiegel said many individuals with diabetes are admonished to "just lose weight" or "just stop eating." If only it was that easy, he bemoaned. Instead, Spiegel called for culturally and linguistically appropriate messages. Further, he emphasized the need for research on how to prevent or delay diabetes and on lifestyle (i.e., behavioral and sociocultural factors). Spiegel said there is also a need for research on how to prevent or reverse obesity, a key risk factor for Type 2 diabetes which affects 90 to 95 percent of the 16 million Americans with diabetes.

### **Behavioral and Social Science Research Is Clearly Required" to Fight AIDS**

HIV/AIDS is a social, cultural, and political problem as much as it is a scientific problem, Office of AIDS Research (OAR) Director Neal Nathanson told conference participants. AIDS is totally preventable and need not occur at all, said Nathanson. The OAR, he said, is supporting increased numbers of research projects on how to control AIDS. AIDS, he continued, is a major public health failure, citing the fact that there have been 40,000 new infections per year over the last 10 years.

There are 800,000 people living with AIDS in the United States. While AIDS cases in the Nation's white population have gone down, they have been steadily increasing in the black population. It is an "extraordinarily urgent problem," said Nathanson, and "behavioral and social science research is clearly required." Nathanson's comments came only days before the White House officially declared increasing world-wide AIDS' cases as an official threat to national security.

### **“Serious Mental Illness Is an Equal Opportunity Affliction”**

National Institute of Mental Health (NIMH) Director Steven Hyman told conference participants that “serious mental illness is an equal opportunity affliction.” Yet, because there is a difference in understanding mental disorders, access to treatment, and treatment of mental disorders, there will be an additional folio to the first-ever *Surgeon General’s Report on Mental Health* (See *UPDATE*, January 10, 2000, Number 1). The folio, titled “Culture, Race, and Ethnicity” to be released later this year, will increase awareness and access within minority communities, said Hyman.

NIMH, said Hyman, is very interested in cultural changes, SES, and the migration influence on the prevalence of depression. For example, Hyman noted that NIMH-supported research is examining what it means to go from being a majority in a majority population to a minority in a minority population.

Hyman also suggested that the increased sensitivity to disparities in health are causing a revolution in the way NIMH thinks about health services research, citing the Report of the National Advisory Mental Health Council’s Behavioral Science Workgroup as an example of the Institute’s efforts (See *UPDATE*, February 7, 2000, Number 3). NIMH, said Hyman, looks forward to funding its behavioral and translational centers. He emphasized that he hoped to focus the centers on disparities in the recognition of mental disorders.

Echoing Nathanson, Hyman said that there is an “extraordinary disparity in new incidents of HIV cases.” As the nature of the epidemic has changed, said Hyman, so has NIMH’s portfolio. Hyman indicated that NIMH has a \$100 million HIV/AIDS-focused research portfolio.

### **Equal Access to Equal Health Care**

Providing equal access to equal health care and forcing the research community to focus its efforts on areas of concern to minorities and the poor are keys to eliminating health disparities, says former Surgeon General Antonia Novello, now Commissioner of New York State’s Department of Health. Health promotion has not narrowed the health disparities gap, she said. We need to look at the root causes of the problem including: poverty, inadequate housing, education, lack of social support, no jobs, racism, and political naivete, she said.

Novello called for access to comprehensive, family-based, available, and affordable health care. Social and economic costs alone do not account for health disparities, she said. The health care system, she continued, has to be sensitive to the language and culture of the community. To eliminate health disparities, Novello stressed that we must have a good education system, one that fits the needs of minorities. We cannot recruit professionals, if we do not invest in them. Minorities, she said, do not choose medical school because it is not accessible to them. There are no role models and no money, said Novello.

She also called for better data collection, noting that until 1989 Hispanics were characterized as “other.” The lack of comprehensive data, she said, is the biggest barrier to assessing the true status of the need, she continued. She asked: “How can policy makers make good decisions without adequate data?”

### **Time To Think Outside of the Box?**

David Burgess, a member of the ORMH’s advisory committee noted that the past decade has seen unprecedented funding increases for NIH and health promotion. Despite this, “we have failed,” said Burgess.

“Incrementalism has not worked, it is time for a new direction,” he said. Supporters in Congress are leading the way, said Burgess, citing the introduction of legislation (H.R. 2391, the National Center for Research on Domestic Health Disparities Act) by Representative Jesse Jackson Jr (See *UPDATE*, July 12, 1999, Number 13). He further argued that we will not close the gap in racial and ethnic health disparities until we close the training gap. There is a tremendous amount of untapped potential. He hoped that the conference’s recommendations will be radical, since what we have been doing has failed us and our children.

On the final day of the conference, participants expressed their desire for the NIH to support research that address the behavioral, social, and cultural influences on health, and the issue of minority training. Other recommendations included:

- \* The establishment of Centers of Research Excellence in behavioral science, nutrition science and metabolism, genome science, and biotechnology;
- \* Longitudinal studies focused on minorities, particularly the heterogeneity of African-Americans;
- \* The translation of research findings into tangible benefits for minority communities;
- \* Partnerships with minority communities based on trust and mutual respect; and
- \* The elevation of minority health as an academic discipline.

The ORMH will publish the proceedings of the conference later this year. For more information contact ORMH at: <http://www1.od.nih.gov/ORMH/main.html>.

### **APPOINTMENTS . . .**

*May 1, 2000, Number 8*

**Julie Samuels** has been named the Acting Director of the National Institute of Justice, the Department of Justice’s (DOJ) lead research and development agency. Replacing long-time NIJ head Jeremy Travis, who departed for the Urban Institute, Samuels has a long history with the Department of Justice. After graduating from the University of California at Berkeley’s Graduate School of Public Policy, she joined the Office of Policy and Management Analysis (OPMA), within DOJ’s Criminal Division, as a Presidential Management Intern in 1979. Samuels became Director of OPMA in 1986, and — with a couple of intervening details and special projects — served in that position until being named NIJ’s Acting Director.

### **RESIGNATIONS . . .**

**Eve Blither**, Executive Director of the National Education Research Policy and Priorities Board (NERPPB), has resigned from her post, effective June 1. The NERPPB is charged by Congress to advise the United States on the federal educational research and development effort, and works with the Assistant Secretary of Education for the Office of Educational Research and Improvement (OERI) to forge a national consensus with respect to a long-term agenda for educational research, development, and dissemination. Blither oversaw the Board's development and publication of peer review standards to govern research conducted and supported by OERI. The Board is currently seeking a replacement for Blither. All interested persons should contact NERPPB Chair Kenji Hakuta in writing at 80 F Street, NW, Washington, DC 20208.

### **AND A NO GO FOR THE NIH**

Gerald Fischbach, head of the National Institute of Neurological Disorders and Stroke, will likely not be nominated by the Clinton Administration to head the National Institutes of Health (NIH). The administration and officials of the Department of Health and Human Services have apparently decided that the Senate would not be able to confirm him quickly enough to allow for a meaningful tenure. NIH deputy director Ruth Kirschstein will continue as acting director.

### **CONGRESS MOVES APPROPRIATIONS BILLS**

*May 15, 2000, Number 9*

With time short in this election year-Congress the Republican leadership has begun an ambitious schedule of considering the Fiscal Year (FY) 2001 appropriations bills. Both the House and Senate hope to have all the bills through the committee process, with many completing floor action, before July 4. This fast-track-scenario may get stuck over disagreements with the Democrats on spending priorities and threatened vetoes from the White House (see other story).

In the first week of action, the Military Construction and Agriculture bills made it through the full appropriations committees in the House and Senate. The huge Labor, Health and Human Services, and Education bill, usually one of the last to be considered, came early in the process this year, and has passed the full committee in the Senate and the subcommittee in the House. The Transportation and Legislative Branch bills have emerged from their House subcommittees, while the Foreign Operations bill has been sent forward by the Senate subcommittee. The VA, HUD, Independent Agencies bill, which includes the National Science Foundation, and the Commerce, State, Justice bill are expected to see action commencing in late May.

### **Labor, Health and Human Services, and Education**

Since the Senate subcommittee had a significantly higher allocation to work with than the House subcommittee, the **National Institutes of Health (NIH)** received \$20.5 billion from the Senate committee, but only \$18.8 billion from the House committee. The Senate number reflects a \$2.7 billion increase over last year. The House number is the same as the President's request, \$1 billion more than the FY 2000 level. However, in reporting the FY 2001 numbers for the individual Institutes the House

subcommittee assumed that when the process is over, NIH will get its \$20.5 billion and NIH's goal to double its budget in five years will have its third down payment.

The **Centers for Disease Control and Prevention (CDC)** received \$3.29 billion from the House committee and \$3.205 billion from the Senate for FY 2001, up from \$2.964 billion in FY 2000 and slightly larger than the President's request of \$3.134 billion. The **Agency for Health Research and Quality (AHRQ)** received a boost from last year's \$198.8 million from the House committee to \$223.6 million, but not quite the President's request of \$249.9 million. The Senate was much more generous in providing \$269.9 million. **Policy Research** at HHS, supported by the **Office of the Assistant Secretary for Planning and Evaluation (ASPE)**, received \$16.7 million from the House and Senate committees, same as last year and same as the President's request. In addition, another \$20.6 million is provided to policy research through the Public Health Service's one percent evaluation set-aside.

## **BILLS WOULD CREATE HEALTH DISPARITIES CENTER**

*May 15, 2000, Number 9*

The discussion of how to eliminate racial and ethnic health disparities and how best to facilitate the promotion of research in this area at the National Institutes of Health (NIH) moved back to Capitol Hill this week. On May 11, House Subcommittee on Health and Environment Chair Michael Bilirakis (R-FL) held a hearing on H.R. 3250, the Health Care Fairness Act, introduced by Representatives John Lewis (D-GA) and Bennie Thompson (D-MS). The bill would, among other things, create a "National Center for Research on Domestic Health Disparities." Such a center would "conduct and support basic and clinical research, training, the dissemination of health information, and other programs with respect to minority health."

According to the Chairman it was his hope that the hearing would "provide a clear picture of the Administration's perspective on the Health Care Fairness Act and proposals related to the Office of Minority Health in particular." The administration has not publically endorsed the bill, but in the President's FY 2001 budget request the NIH seeks legislative authority to allow a coordination center for health disparities within the NIH Office of Research on Minority Health (ORMH) along with \$20 million in funding.

Assistant Secretary for Health and Surgeon General David Satcher informed the Subcommittee that the administration does not yet have a position on the bill, but is "strongly supportive of strategies and research targeted to disparities in health." ORMH Director John Ruffin and Kermit Smith of the Indian Health Service accompanied Satcher as "technical experts from the HHS agencies." Ruffin noted that Acting NIH Director Ruth Kirchstein has not indicated in their conversations opposition to the elevation of the Office to Center status. Bilirakis indicated, however, that he would like to hear "these things" from the NIH Director.

"We particularly appreciate the acknowledgment of the importance of research into the behavioral and social factors underlying health disparities, and support programs which increase educational attainment and employment opportunities," stressed Satcher in his testimony. He noted that

the legislation “addresses several key elements that the Department has identified as essential to a comprehensive approach toward eliminating disparities,” including:

- \* development of a balanced and comprehensive research agenda that addresses the unequal burden of morbidity and mortality in racial and ethnic minorities;
- \* supporting efforts to improve the quality and outcomes of health care services and addressing the social determinants of health, including but not limited to, access to health care;
- \* strengthening the data collection infrastructure of HHS;
- \* support for graduate health care education curriculum development, continuing medical education efforts to reduce disparity in health and health outcomes, and increasing the knowledge base with respect to cultural competency; and
- \* recognition of the important role of the Office of Civil Rights.

Several members of Congress testified in support of the legislation and urged the Subcommittee to mark up the bill next week. Aside from the bill’s sponsors, Jesse Jackson, Jr. (D-IL), Ciro D. Rodriguez (D-TX), J.D. Hayworth (R-AZ), Dale Kildee (D-MI), Robert Underwood, (D-GUAM), and J. C. Watts (R-OK) voiced support for the bill. Representative John Dingell (D-MI) issued a statement in support of the legislation and urged the Subcommittee to “move forward” with the bill.

Earlier in the 106<sup>th</sup> Congress, Jackson introduced health disparities legislation (H.R. 2391) following the release of the Institute of Medicine Report: *Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and Medically Underserved*. The report stated that “NIH should expand its effort to understand why poor Americans and some ethnic minorities are more likely to develop and die from certain types of cancer.” H.R. 2391 has been incorporated in Lewis’ and Thompson’s H.R. 3250. Jackson is seen by many as filling the void left by former Congressman and Labor-HHS Subcommittee member Louis Stokes (D-OH) who was instrumental in establishing the current Office for Research on Minority Health at NIH. Stokes now serves in an advisory capacity to Acting NIH Director Ruth Kirchstein in the creation of a NIH-wide strategic plan on health disparities.

At the hearing, Jackson noted his disappointment that the “health status gap among blacks and other underserved populations is getting worse, not better” despite “national economic prosperity, and double digit growth” for the NIH. He said that he became convinced of the need to elevate the ORMH to “Center” status “after asking scores of questions to the NIH Director and the Directors of the Institutes and Centers during last year’s hearings about these disparities.” Currently “the [ORMH] director can’t spend his own budget unless an Institute director allows him to fund a grant through his or her Institute,” he emphasized.

### **A Change of Heart**

When he was NIH Director, Harold Varmus found the creation of a Center/Institute “problematic” and stressed that the NIH has a vast set of initiatives that address health disparities. At the hearing, however, Bilirakis said he had received a letter from the former director suggesting that Varmus now supported the development of the center. As NIH director, Varmus indicated that he understood the motivation behind the legislation, but felt that the targeted population would be poorly served with the

Center's creation. Varmus believed then that a new Center could not "possibly have the kinds of expertise currently available across all of the NIH."

### **The Senate's Companion Bill**

In October 1999, Senators Edward Kennedy (D-MA), Daniel Akaka (D-HI), Daniel Inouye (D-HI), Blanche Lincoln (D-AR), and Paul Wellstone (D-MN) introduced S.1880. This legislation, called the Health Care Fairness Act of 1999, is similar to Jackson's, though more comprehensive with regard to the Federal government's role. Title III of the bill strengthens the federal commitment to the "social science aspects of health disparities." It directs the Agency for Healthcare Research and Quality (AHRQ) to conduct and support research on barriers to care, poor quality health services, and the lack of useful outcome measures. The bill also directs the National Academy of Sciences to conduct a study on the data collection and reporting systems within the Department of Health and Human Services. Senator Bill Frist (R-TN) chair of the Senate Health, Education, Labor and Pensions Subcommittee on Public Health has indicated that he will hold hearings on S. 1880.

Kennedy's bill, like H.R. 3250, would establish a "Center for Research on Minority Health and Health Disparities." The Center Director would be appointed by the Secretary of Health and Human Services and report to the NIH Director. A significant difference between the two measures is that in S.1880, the Center would provide funds to NIH Institutes for "high priority areas of minority health research not adequately addressed by the Institutes and Centers."

### **NIH STRATEGIC PLANS AVAILABLE FOR COMMENTS**

*May 15, 2000, Number 9*

Several National Institutes of Health (NIH) Institutes and Centers have posted their individual strategic plans on-line. The plans can be viewed at the following web addresses:

**National Institute on Drug Abuse (NIDA):**

[www.nida.nih.gov/StrategicPlan/HealthStratPlan.html](http://www.nida.nih.gov/StrategicPlan/HealthStratPlan.html)

**National Institute on Diabetes and Digestive and Kidney Diseases (NIDDK):**

[www.niddk.nih.gov/federal/strategicplan.htm](http://www.niddk.nih.gov/federal/strategicplan.htm)

**National Institute of Mental Health (NIMH):**

[www.nimh.nih.gov/strategic/strategicdisparity.cfm](http://www.nimh.nih.gov/strategic/strategicdisparity.cfm)

**National Heart, Lung, and Blood Institute (NHLBI):**

[www.nhlbi.nih.gov/funding/fromdir/plandisp.htm](http://www.nhlbi.nih.gov/funding/fromdir/plandisp.htm)

### **"MUCH REMAINS TO BE DONE" AT THE NIH**

*May 29, 2000, Number 10*

"Investing in NIH [National Institutes of Health] is the single most important action our Nation can take to overcome the challenges of cancer, heart disease, HIV/AIDS, and other diseases and disorders," stressed the appropriators in the Senate Appropriations Committee report accompanying the

Labor, Health and Human Services, and Education Appropriation Bill for Fiscal Year (FY) 2001. Accordingly, the Committee recommended \$20.51 billion for NIH, an increase of \$2.7 billion, which maintains the goal of doubling NIH funding by 2003.

### **NIH Urged to Incorporate Behavioral Research as Part of its Core Public Health Mission**

The Committee noted the “growing public awareness of the behavioral underpinnings of disease and urged the NIH to incorporate behavioral research as part of its core public health mission.” The Committee also recognized that heart disease, lung cancer, liver disease, AIDS, suicide, developmental disabilities, and many neurological and cognitive disorders can be “attributed directly or indirectly to unhealthy behavior.” The Committee requested a detailed description of NIH’s ongoing work in the behavioral sciences, including research and training activities within NIH’s behavioral and social science portfolio.

Emphasizing its concern regarding the disproportionately high incidence and/or mortality rates of cancer in ethnic minority, rural poor, and other medically underserved populations, the Committee urged the Institutes, Centers, and Offices with cancer-directed research agendas to work together to: **1)** develop and proceed with a five-year strategic plan to implement the recommendations in the 1999 Institute of Medicine study, *The Unequal Burden of Cancer*; **2)** establish benchmarks, program evaluations, and accountability procedures; **3)** allocate the necessary resources to address IOM-identified priorities; and **4)** substantially increase funding for **(a)** population, behavioral, socio-cultural, communications, and community-based research; **(b)** recruiting and training efforts to attract more candidates from ethnic minority and medically underserved populations in all areas of cancer research; and **(c)** cancer data collection, management, and interagency coordination of data collection.

**National Institute on Aging.** The Committee recommended \$794.6 million for NIA, \$68.6 million more than the budget request and \$106.7 million more than FY 2000. The Committee encouraged NIA to use the forthcoming Institute of Medicine recommendations of future directions for behavioral, cognitive, and neuroscience research as a guide for expanding its portfolio in this area. Observing that the Institute’s research program on Demography and Economics of Aging and the Office of Demography are vital to the mission of the Institute, the Committee encouraged NIA to consider increasing its support for the ten population Demography of Aging Centers which were competitively renewed last year.

**National Institute on Alcohol Abuse and Alcoholism.** The Committee provided \$336.8 million for NIAAA, \$28.2 million more than the requested level and \$42.6 million above FY 2000. The Committee noted its support of NIAAA’s efforts to understand the relationships between alcohol use and violence. It also encouraged NIAAA to consider supporting more research in this area, particularly to understand the individual characteristics and environmental conditions, situations, and circumstances under which alcohol use and violent behavior are connected.

**National Institute on Drug Abuse.** The Committee recommended \$790 million for NIDA, \$64.6 million more than the budget request and \$102.6 million above FY 2000. Noting its understanding that behavioral interventions are a critical, and sometimes only, component of drug addiction prevention, the Committee stated that it will continue to support NIDA’s expansion of its behavioral science portfolio. NIDA, according to the Committee, is a model of how to approach behavioral science and public health

responsibilities. Likewise, NIDA was commended for its children and adolescent research initiative and urged to continue to support its research portfolio in areas of co-occurring mental disorders, developmental consequences, prenatal exposure, genetic vulnerability, and environmental risk factors.

**National Institute of Child Health and Human Development.** The Committee provided \$986.1 million for NICHD, \$81.3 million more than the budget request and \$126.8 million above FY 2000. NICHD was praised for its initiatives to increase the understanding of the behavioral and cognitive aspects of child development.

The Committee commended NICHD for its aggressive support of research on the causes of demographic trends and their impact on our society. The Committee stressed that NICHD should place a high priority on providing objective information on such topics as teen childbearing, declining marriage rates, fatherhood, health disparities, racial and ethnic diversity, and migration within and across our borders. The Institute was further commended for its collaborative projects with other Federal agencies – the Immigration and Naturalization Service, the National Center for Health Statistics, and the Department of Education, among others – which have created innovative data sets.

Expressing its increasing concern regarding youth and health behaviors and their impact on society, the Committee noted that issues related to school violence, school failure, drug and tobacco use, and other behavioral issues have become public health priorities. The Committee lauded NICHD for its impending collaborations with the CDC, the Substance Abuse and Mental Health Services Administration, and the Health Resources and Services Administration to develop a collaborative program to examine these issues. The Committee requested that the agencies involved focus a portion of their efforts which utilize molecular neuroscience, brain mapping, and behavioral analysis on discovering approaches to intervene and prevent complex behavior problems in children and youth.

**National Institute of Mental Health.** The Committee provided \$1.118 billion to NIMH, \$86.6 million more than the budget request and \$143.3 million above FY 2000. The Committee noted NIMH's efforts to address major issues of concern through a balanced approach that includes basic neuroscience, behavioral research, health services research, and clinical research.

The Committee stated its support of NIMH's efforts to encourage researchers to collaborate with basic social and behavioral scientists, noting that this collaboration will increase our understanding of how characteristics of individuals, families, and social and cultural environments affect decisions about using services and adherence to treatment, as well as the efficacy of treatment and services.

The Committee commended NIMH for developing research knowledge essential for understanding and preventing HIV transmission, particularly among people at high risk for infection (e.g., the mentally ill, minority women, youth, and rural populations) where the epidemic is spreading most rapidly.

Noting that the suicide rate has diminished only slightly despite the availability of highly effective treatments for mental disorders, NIMH was encouraged:

\* to support research to address this issue as well as whether those who need treatment are not receiving effective treatments, and if current treatments are effective in reducing suicide; and

\* to consider supporting additional research on protective factors to better understand phenomena such as why African American women have the lowest suicide rates but have mental disorders at rates comparable to those of white women.

Observing that mental disorders in children must be considered within the context of the family and peers, school, home, and community, the Committee supported NIMH's efforts to increase research on children's mental disorders and to increase the number of trained scientists available to do this crucial research. The Committee encouraged the Institute to continue to support research on multi-year, multi-component interventions at the family, school, and community levels. The Committee also urged NIMH to develop further research on early interventions in children.

The Committee commended NIMH for its new initiative in translational research to close the gap between basic and clinical research in behavioral science. It was also encouraged to consider centers to support collaboration between behavioral and clinical investigators, and to train new investigators.

**John E. Fogarty International Center.** The Committee recommended \$61.3 million for FIC, \$13.2 million more than the administration's request and \$17.9 million above FY 2000. The Committee noted its appreciation of the steps FIC has taken to address the relationship between health on demographic status and economic development, and to forge linkages with other organizations such as the World Bank. The Committee encouraged FIC to consider making additional investments in this program, in as much as the results could impact on many sources of disparities in health globally.

The Committee commended FIC for addressing the global burden of noncommunicable diseases, in particular smoking prevention and cessation and the burden of mental illness. Additionally, in the area of genomics/genetics, the Committee encouraged the support of transcultural studies on the ethical, legal, and social implications of genome research and the effect of the diet and environment on gene expression.

**National Cancer Institute.** The Committee recommended \$3.804 billion for NCI, \$299 million more than the request, and an increase of \$492.3 million above FY 2000. The Committee commended NCI for expanding its infrastructure to fund behavioral and population research in cancer prevention, treatment, and control. It also encouraged NCI to expand its investigation of the effective provision of mental health services to improve the course of cancer treatment and to aid in the adjustment to cancer survivorship. The Committee noted its interest in expanding health promotion research focused on children and youth, and interdisciplinary research on tobacco addiction and cessation. NCI was also urged to expand its research on adherence to treatment regimens and to health-promoting behaviors such as physical activity and healthy diet.

**National Institute of Diabetes and Digestive and Kidney Diseases.** The Committee provided \$1.318 billion in funding for NIDDK, \$108.9 million more than the budget request and \$ 176.7 million above FY 2000. The Committee noted its interest in learning more about NIDDK's plans for setting a behavioral and social sciences research agenda for diabetes. NIDDK was encouraged to continue to partner with the Office of Behavioral and Social Sciences Research and other Institutes to support basic and applied research on the prevention and treatment of diabetes and obesity. The Committee further encouraged NIDDK to explore partnerships with other Institutes on health services delivery research that

can improve communication among health providers, and between health providers and their patients, to enhance treatment for diabetes.

**National Heart, Lung, and Blood Institute.** The Committee recommended \$2.328 billion for NHLBI, \$191.3 million more than the budget request, and \$301.6 million above FY 2000. Noting that an estimated 106 million Americans age 20 and older are overweight or obese, a condition that increases the risks of heart attacks, stroke, high blood pressure, and diabetes, the Committee urged NHLBI to launch studies to improve understanding of weight loss maintenance and to examine behaviors that influence obesity, weight loss, and weight loss maintenance. The Committee also urged NHLBI to expand its research on innovative theories about behavioral, cultural, social, psychological, and environmental methods to increase adherence to lifestyle and medical regimen.

**National Institute of Dental and Craniofacial Research.** The Committee recommended \$309.9 million for NIDCR, \$25.7 million more than the budget request and \$40.7 million above FY 2000. NIDCR was commended for its multi-disciplinary approach to oral health promotion, particularly its comprehensive Dental Health Centers. The Institute was encouraged to expand its behavioral research on reducing health disparities among minority populations. In particular, the Committee encouraged NIDCR to expand its investigation of effective dental care and oral cancer prevention programs in minority populations.

**National Institute of Nursing Research.** The Committee recommended an appropriation of \$106.8 million for NINR, \$14.3 million more than the budget request and \$17.3 million above FY 2000. The Committee encouraged NINR to take advantage of significant new research opportunities in the following areas: enhancing adherence to diabetes management behaviors; biobehavioral research for effective sleep in health and illness; prevention of low birth weight in minorities; and expanded opportunities for pre- and post-doctoral training in nursing research at schools of nursing.

**National Institute of Arthritis and Musculoskeletal and Skin Diseases.** For NIAMS, the Committee recommended \$401.2 million, \$32.4 million more than the budget request and \$51.7 million above the FY 2000 funding level. Observing that the portion of the NIAMS research portfolio devoted to behavioral and social sciences research is significantly lower than the NIH average, the Committee encouraged NIAMS to foster promising behavioral and social science research.

## **SENATE APPROPRIATIONS APPROVES MULTI-BILLION DOLLAR YOUTH VIOLENCE INITIATIVE**

*June 12, 2000, Number 11*

The massive funding bill for the Departments of Labor, Health and Human Services, and Education (Labor-HHS-Education) has passed both the House and Senate Appropriations Committees and awaits floor action. As it did in last year's bill, the Senate Appropriations Committee approved funding for the Youth Violence Prevention Initiative, a collaborative effort of several Federal agencies and the White House.

Last year, the Senate Appropriations Committee provided nearly \$900 million for the initiative. This year, the Committee provided \$1.2 billion which, according to the panel, “will improve research, prevention, education, and treatment strategies to address youth violence.”

Noting that youth violence is a public health problem, and that “many familial, psychological, biological, and environmental factors contribute to youths’ propensity toward violence,” the initiative is a collaborative and coordinated approach to “eliminate the conditions which cultivate violence.” The funds, reallocated from existing programs, come largely from the National Institutes of Health, particularly the National Institute of Mental Health (NIMH), National Institute of Drug Abuse (NIDA), and the National Institute of Alcohol Abuse and Alcoholism (NIAAA), and the Department of Education.

Given its collaborative approach, the Initiative has several research foci. The Committee calls on individual agencies to support and conduct research on various issues related to youth violence. For instance, the NIMH is called upon to undertake research on child abuse and neglect, both of which, claims the Committee, contribute to youth’s violent behaviors. NIMH is also requested to support research to determine the most cost-effective features of proven programs for resource-poor communities. The NIAAA is requested to support research on the link between alcohol abuse and violence as well as research on prevention efforts, while NIDA is requested to undertake similar studies on drug abuse and youth violence. The Committee report accompanying the funding bill also identifies four cross-cutting areas in need of further research, including: 1) community interventions, 2) media and its impact on youth violence, 3) health provider training, and 4) information dissemination.

### **Education as a Key Component**

A running theme in the report language is the importance of education. Therefore, the Committee devotes a lot of attention and resources to research on education and how it can be used to prevent the violent behavior of some youth. The Committee points to sociological and scientific studies which suggest that the “first three years of a child’s cognitive development sets the foundation for life-long learning and can determine an individual’s emotional capabilities.” Citing the importance of parents to a child’s cognitive development and educational attainment, the Committee provides funds for the Education Department’s parent information and resource centers program. It also provides funds for the 21<sup>st</sup> Century Community Learning Centers. The Committee decided to provide funds for this program based on Justice Department research that shows that 50 percent of all juvenile crime occurs between the hours of 2 pm and 8 pm. The 21<sup>st</sup> Century Centers provide after-school programs for youths that emphasize safety, crime awareness, and drug prevention. Finally, in the area of education, the Youth Violence Initiative directs resources to youth literacy programs since “studies show that literacy is one tool to prevent youth violence.”

## **HOUSE APPROPRIATIONS COMMITTEE CALLS FOR MORE SOCIAL AND BEHAVIORAL SCIENCE RESEARCH**

*June 12, 2000, Number 11*

On Thursday, June 8, the House began consideration of the Fiscal Year (FY) 2001 Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill (H.R. 4577). To allow debate

on other legislation, discussion of the funding bill, annually one of the most contentious appropriations bills, was tabled. Consideration of the bill is expected to resume the week of June 12, 2000. However, because of lack of funds for his education and job training initiatives, President Clinton has indicated that he will veto the bill.

Like the Senate, the House urged the agencies under its jurisdiction to increase funding for the social and behavioral sciences. The Committee also emphasized that the spending levels in its version of the bill reflect its attempt to establish priorities within very stringent budgetary limitations.

The Committee provided \$3.29 billion for the Centers for Disease Control and Prevention (CDC), \$326.4 million above the FY 2000 funding level and \$156.7 million above the President's budget request. Included in the Committee-approved figure is \$125 million for a National Campaign to Change Children's Health Behaviors. The Committee noted its belief that if the Federal government wants to have a positive impact on the future health of the American population, we must change the behaviors of our children and young adults by reaching them with important health messages. The Committee directed the CDC, in collaboration with the Health Resources and Services Administration (HRSA), the National Institute of Child Health and Human Development (NICHD), and the Substance Abuse and Mental Health Services Administration (SAMHSA) to plan, implement, and evaluate a campaign designed to clearly communicate messages that will help kids develop habits that foster good health over a lifetime, including diet, physical activity, and avoidance of illicit drugs, tobacco, and alcohol.

The Committee agreed with the CDC's assessment that obesity is an important public health issue because of its correlation with a wide range of debilitating and chronic health conditions, including cardiovascular disease, diabetes, arthritis, and cancer. Accordingly, the CDC was urged to continue its efforts to promote healthy eating and physical activity and thereby prevent obesity.

The Committee provided \$90.1 million for CDC's injury control program, the same as the FY 2000 funding level and \$4.9 million below the President's request. The bill retains the limitation included in previous appropriations acts to prohibit the National Center for Injury Prevention and Control from engaging in any activities to advocate or promote gun control. The panel encouraged the CDC to extend the development and implementation of Best Practices for the Prevention of Youth Violence to include culturally sensitive social-cognitive, mentoring, parenting, and nurse home visits programs. The Committee noted that culturally responsive interventions and programs should be developed through evaluation research and demonstrations to address the disparities in morbidity among racial and ethnic minorities that is attributable to violence. (See related story on the Youth Violence Prevention Initiative).

### **Funding for the National Institutes of Health**

For the National Institutes of Health (NIH), the House noted that because of "limited funding within the allocation, funding increases in the bill are constrained to the amount proposed by the President." The House provided the NIH a \$1 billion increase (a 5.6 percent increase) bringing its total to \$18.8 billion. The House, which believes that decisions about appropriate levels of funding and appropriate avenues of research are best left to the scientific managers at NIH, was much more restrained than the Senate in the amount of report language directing the agency. The funding levels in the House bill for each of the Institutes and Centers reflect what the Committee "would have provided if it were able to provide a 15 percent increase for NIH, the third year installment of the doubling effort."

The Committee noted its concern with the disproportionately high incidence and/or mortality rates of many cancers in ethnic minorities, rural poor, and other medically underserved populations. The House panel encouraged the NIH to develop a strategic plan to address the recommendations in the Institute of Medicine's *The Unequal Burden of Cancer* report (See related story). In addition, the Committee encouraged NIH to enhance funding for population, behavioral, sociocultural, communications, and community-based research. Recognizing that "economic status may also have an impact on health outcomes," the Committee urged the National Cancer Institute (NCI) to include the rural population in its efforts to eliminate health disparities.

The Committee urged the NIH, in coordination with the Office of AIDS Research, National Institute of Allergy and Infectious Diseases (NIAID), NICHD, National Institute of Mental Health (NIMH), National Institute on Drug Abuse (NIDA), and the Office of Research on Women's Health, to expand its behavioral research on use, acceptability, and compliance with microbicides through all available mechanisms. The Committee requested the NIH Director to be prepared to testify on the progress of this effort at the FY 2002 appropriations hearings.

The Committee encouraged the NIH to support more research on "religiousness and health." The Committee emphasized that the research may prove helpful in reducing health care costs, increasing longevity, improving the quality of life for chronically and seriously ill patients, and reducing risky lifestyles.

The National Heart, Lung and Blood Institute (NHLBI) was urged to enhance research on innovative theories about behavioral, cultural, social, psychological, and environmental methods to increase adherence to lifestyle and medical regimens. The Committee also encouraged the Institute to examine behaviors that influence obesity, weight loss, and weight loss maintenance.

Like the Senate, the House commended NICHD for its support of research examining the causes of demographic trends and their impact on society, and encouraged NICHD to enhance its efforts in training and developing new demographic scientists.

The Committee lauded the National Institute on Aging (NIA) for its research program on demography and economics of aging which provides insights into changing risk factors for chronic disease, including socio-economic health inequalities, and disease processes at the population level.

Similarly, the panel commended the National Institute of Dental and Cranofacial Research (NIDCR) for its collaboration with other NIH Institutes and Centers, including the Office of Behavioral and Social Sciences Research (OBSSR), and Federal agencies in developing centers for research to reduce oral health disparities. NIDCR was encouraged to implement the initiative to the fullest scientific extent possible.

## **NCI's RESPONSE TO IOM REPORT: FUNDING IS INADEQUATE**

*June 12, 2000, Number 11*

In its response to the Institute of Medicine (IOM) report, *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*, the National Cancer Institute (NCI) concurs “with the view that overall funding to address the needs of ethnic minority and medically underserved populations is inadequate.” Consequently, the Institute will seek input from its various advisory committees and working groups to determine the appropriate level of funding for minority and underserved populations and how current resources might be redirected to meet these needs.

According to the response, “the disagreement between NCI and IOM over the allocation of funds to special populations research is based, in part, on the complexity of coding issues in a large organization such as the NCI, the lack of uniformly applied definitions and different organizational units within NCI and the National Institutes of Health carrying out coding and funding allocation procedures.”

The NCI agrees with the IOM report’s conclusion that research and research funding on ethnic minority and medically underserved populations should be increased. Citing the IOM committee’s position that NCI alone will not solve the questions, NCI suggests that it is important to remember that the root of the unequal burden of cancer is, in part, a reflection of unequal resources, access, power and opportunities in our society. Ultimately, this unequal burden will only be redressed by taking responsibility to correct both historic and persistent inequities.

NCI acknowledges that “there is a critical need to improve the ability to address the needs of the underserved, and this need pervades all aspects of the health care delivery system, many social services, and in research to improve the knowledge of the special needs of these individuals.” Many of the issues go well beyond the “scope of a single Institute at NIH,” the NCI, therefore, maintains that it is committed to joining forces with colleagues at NIH as well as other federal and nonfederal groups to initiate discussion and develop strategies to attack “some of these seemingly intractable issues at the highest levels of organizational leadership.”

Noting that “OMB-mandated racial and ethnic classification system is not scientifically based, and does not reflect the sole variables important to the cancer burden,” NCI emphasizes that it has “gone well beyond” the OMB standards in attempting to monitor the burden of cancer, with the categorization of societally underserved people by their socioeconomic class, insurance, or cultural background, a subject for research.

Major priorities for NCI in the coming years include, “developing a national consensus on critical definitions (such as for “medically underserved” and “special populations”) and creating systems to monitor and track the burden of cancer on populations identified on the basis of ethnic, cultural, and socioeconomic characteristics rather than by the OMB Standard classification system.” The highest priority is being placed on asking questions about unequal cancer burden in surveillance, epidemiology, prevention, detection, treatment, survivorship, training, and communications.

The Institute also agrees with the IOM report that the newly structured Division of Cancer Control and Population Sciences (DCCPS) and the Division of Cancer Prevention “offer great promise in addressing behavioral and social science research within diverse populations. . . DCCPS is committed to increasing funding to develop strategies to encourage behavioral changes conducive to health through culturally sensitive interventions.”

The recent formation of the Applied Sociocultural Research Branch within DCCPS, notes the report, will support research that complements existing behavioral, etiologic and surveillance research activities in the rest of NCI. Activities of the branch include planning and conducting a program of grant supported research aimed at populations underserved due to excess cancer incidence and/or mortality rates or who are underserved due to the lack of inadequate cancer prevention and control services.

## **NIMH DIRECTOR: IT'S BEEN A GOOD YEAR**

*June 26, 2000, Number 12*

“It’s been a good year” for attention to mental health issues and research noted National Institute of Mental Health (NIMH) Director Steven Hyman at the Institute’s *Fourth Annual Research Roundtable*. He highlighted the fact that public interest in mental health issues has increased since last June’s Roundtable meeting and the December 1999 release of the first-ever Surgeon General’s *Report on Mental Health*. The media and public response to the Report, authored by Surgeon General David Satcher, has been “phenomenally positive.” This report, he continued, has had an “enormous impact,” particularly outside of the mental health specialities. The Surgeon General, according to Hyman, plans to initiate follow-up reports to address the particular mental illness and health concerns of racial and ethnic minorities and youth violence. He also noted that the Surgeon General designated the prevention of suicide – a lethal outcome of mental illness – as a public health priority.

Chronic noncommunicable diseases create enormous burden of disease and obstacles to economic development, said Hyman. He observed that the general director of the World Health Organization (WHO), Gro Harlem Brundtland, is also very interested in mental health issues. Each year the WHO dedicates a world health day. Hyman noted that mental health will be the focus in 2001. The effort by WHO, said Hyman, will extend the awareness and recognition that life depressions are real disorders worthy of treatment and help build capacity to identify and treat these illnesses. The world, he noted, is beginning to recognize that these disorders are real and addressable.

At the same time of the increased attention to mental health issues and research, noted Hyman, the NIMH has been fortunate, through its staff and advisory committee, to move the Institute’s portfolio into “a position to capitalize on the cutting edge of science.” Hyman said that the NIMH is making a new commitment to determine the service needs of those suffering from the many forms of mental illness. The NIMH, he continued, has launched a major effort to determine the extent of mental illness in America, with certain projects focusing specifically on youth and ethnic and racial minorities. In a time when there are important disparities — gender, race, and ethnicity — the NIMH is interested in understanding the full picture of mental illness and risk factors for all Americans, said Hyman.

Hyman also stressed that it is very important for NIMH to combine basic behavioral science with public health issues. “It is clear to me, and the National Advisory Mental Health Council workgroup, that the field of behavioral science has much to offer in mental health.” The workgroup’s report, *Translating Behavioral Science Into Action*, said Hyman, offers recommendations for translating scientific achievement in behavioral research into clinical relevant advances, including an action plan for a practical strategy for enhancing the clinical contributions of behavioral science in the area of mental health. The

report can be found on the NIMH web site: [www.nimh.nih.gov](http://www.nimh.nih.gov) (See *UPDATE*, February 7, 2000, No. 3).

He also emphasized that it was important to bring together behavioral science, clinical trials, and services research to address several unanswered questions: Why people don't come to treatment? Is it because they can't pay for it? Is it personal behavior, stigma, shame? Do parents fear being blamed?

He also addressed the problem of nonadherence (a topic of a 1999 COSSA congressional briefing). NIMH is seeking to understand how to build commitment and adherence to psychotherapy regimens, said Hyman. The Institute is also seeking to create a change in the system so that the practitioner understands the factors associated with adherence. It is a very rich area for all of medicine, he continued. In the so-called "molecular revolution" without adherence medicine stays in the bottle. Hyman also noted that adherence is a factor in maintaining a good diet and getting enough exercise. The NIMH is looking to fund "very interesting ideas" in this area, said Hyman.

Hyman further called for research on how we can alter the behavior of providers to ensure that there is a decrease in the number of inappropriate diagnoses, citing as an example the use of computer-based screening tools.

Noting that suicide is the ninth leading cause of death in the U.S. and, as the Centers for Disease Control and Prevention (CDC) reports, the third leading cause of death among 15 to 24 year old, Hyman stressed that NIMH continues to encourage researchers to submit applications to study suicide. Researchers, he said, should keep in mind that suicide is most meaningfully studied in the context of other psychopathological processes, including comorbid psychiatric and substance abuse disorders. We need, said Hyman, to delineate the relationship between clinical disorders and psychopathology, and suicidal behaviors in children and adolescents, as well as in elderly people, whom epidemiologic data show are at the highest risk for suicide.

The Institute, said Hyman, has targeted a significant portion of its funding to initiatives that have been deemed by the public as health emergencies, including: research on the use of medications in children; youth violence in schools and community, and suicide prevention. To address the issue of youth violence the Institute is focusing resources on understanding risk factors, experiences, and processes that are related to the development of aggressive, antisocial, and violent behavior.

## **BETTER DATA NEEDED ON CHILDREN**

*June 26, 2000, Number 12*

Major gaps remain in the Federal statistical system that must be filled if we are to have a complete picture of the quality of our children's lives, according to the Department of Health and Human Services' (HHS) fourth annual report on trends in the well-being of our Nation's children and youth. The report, *Trends in the Well-Being of America's Children & Youth 1999*, contains the most recent and reliable estimates on more than 90 indicators of well-being.

The indicators are organized into five broad areas: 1) population, family, and neighborhood; 2) economic security; 3) health conditions and health care; 4) social development, behavioral health, and teen fertility; and 5) education and achievement.

The report is intended to provide a sense of how children and youth are faring overall. Recent findings include:

- \* Youth violence has been decreasing, with homicide rates down from 20.7 to 12.8 per thousand youth ages 15 to 19 between 1993 and 1997, and reported weapon carrying among 9<sup>th</sup> - 12<sup>th</sup> grade students declined from 26 percent in 1991 to 18 percent in 1997.
- \* There were 965,623 child victims of maltreatment in 1997. Of those cases 25 percent were classified as physical abuse, 12 percent as sexual abuse, 55 percent as neglect, 2 percent as medical neglect, 6 percent as emotional maltreatment, and 12 percent as “other” or “unknown” types of maltreatment.
- \* Median income for families with children increased between 1996 and 1997, from \$41,925 to \$43,545.

The 1999 report includes additional indicators based on the work of researchers from the Family and Child Well-Being Research Network, funded by the National Institute of Child Health and Human Development (NICHD). The new indicators are developed from existing data sources.

### **Gaps in Knowledge**

There are, however, gaps in the Federal statistical system. For example, the report notes that there are “few measures of social development and health-related behaviors for very young and pre-teenage children that are measured on a regular basis.” Other gaps cited in the report include:

- \* A lack of mental health measures for all ages of children;
- \* Positive measures of social development and related behaviors;
- \* Indicators that reflect the positive development desired for children and youth;
- \* Measures of parent-child interactions, critical to the social and intellectual development of children;
- \* An annual measure of whether both biological parents of a child are living in the household; and
- \* Reliable indicators of child homelessness.

According to the report, other areas in need of measurement development or improvements in the quality, consistency, and frequency of available data include child abuse and neglect, youth violent crime, day care quality, learning disabilities, and measures of children in institutionalized care.

The Federal Interagency Forum on Child and Family Statistics is an interagency group of leaders of Federal agency and departments responsible for collecting data on children and youth. Member agencies play crucial roles in the production of the report, providing data and reviewing relevant text. The forum, created in 1995, will continue to develop strategies for improving the Federal statistical system in ways that preserve existing data while also filling in the gaps.

## **PROGRESS ON CONGRESSIONAL SPENDING BILLS ILLUSORY? VETO THREATS ABOUND**

*July 10, 2000, Number 13*

With a month to go before the recess for the national nominating conventions and the traditional August break, Congressional action on federal spending for Fiscal Year 2001, has moved along at a surprisingly brisk pace in the House, and much more slowly in the Senate.

Set to return after a week long Independence Day break, the House has four of the 13 appropriation bills left to pass. The Senate, however, has passed only four. Perhaps, the biggest surprise is that the huge Labor, Health and Human Services, Education appropriations bill has made it through both Houses (for details see the chart on page 7). Unfortunately, as with many of the bills passed by the House, as it currently stands, the Labor bill would be vetoed by the President. Neither the House nor the Senate gave the President much of what he asked for in education. The Senate did add an amendment sponsored by Senator Bill Frist (R-TN) to fully fund, at \$20 million, the Interagency Education Research Initiative (IERI). The House provided no funding specifically for IERI. (See related story on page 2 for additional information.)

One bill has made it entirely through the process, the non-controversial Military Construction appropriations and the President has indicated he will approve this one. The Defense bill, which has also made it through both Houses, but not a conference yet, is also “signable,” since there was a general consensus on spending levels for national security. The House began debate on the Agriculture spending bill right before adjourning for the Fourth of July recess. The debate will resume when Congress reconvenes on July 10. The Senate version of the bill has made it through full Committee, but has yet to see floor action.

Thus, some observers see the House’s flurry of activity on the rest of the spending bills as an exercise in futility that awaits correction by the Senate or by White House-Congress negotiations. This appears the case with the VA, HUD, Independent Agencies appropriation, which includes the National Science Foundation. The Senate has not taken any action on the bill yet. Indications from the Subcommittee suggest that restoring its allocation, doled out to pass other spending bills, will have to occur before it can begin thinking about a markup. Similar problems exist for the Commerce, Justice, State appropriation.

In the meantime, Congress reached agreement on a \$11.2 billion FY 2000 supplemental appropriation to fund military needs, anti-drug efforts in Colombia, disaster relief, and other items sponsored by individual members. In addition, the Office of Management and Budget issued a report indicating that the budget surplus over the next ten years will be \$1.9 trillion, exacerbating the debate on whether and how to spend these additional government revenues.

With three busy weeks before the break, the Republican-led Congress will spend the rest of July trying to present a picture of accomplishment to the country. Whether that will avoid a hectic September of high-stakes negotiations with a lame-duck, but still determined President, is doubtful.

## **NIH CONFERENCE HIGHLIGHTS IMPORTANCE OF SOCIAL AND BEHAVIORAL INFLUENCES ON HEALTH**

*July 10, 2000, Number 13*

"Social and cultural factors play a central role in preventing illness, maintaining good health, and treating disease," observed Acting National Institutes of Health (NIH) Director Ruth Kirchstein, welcoming more than 1,000 participants to the groundbreaking NIH-sponsored conference, "Toward Higher Levels of Analysis: Progress and Promise in Research on Social and Cultural Dimensions of Health," held June 28 - 29 on the NIH campus. Kirchstein expressed her "delight" at being the keynote speaker at a conference centered around social and behavioral factors and their impact on health.

The conference, sponsored by NIH's Office of Behavioral and Social Sciences Research (OBSSR), was designed to: 1) highlight the contributions of social and cultural factors to health and illness to achieve a better understanding of the interdependence of social, behavioral, and biological levels of analysis in health research; 2) examine the state of science in the area of sociocultural constructs such as race, ethnicity, socioeconomic status (SES), and gender; 3) examine the influences of social and cultural factors as well as interpersonal, neighborhood, and community influences on prevention, treatment, and use of health services; 4) examine the current status of issues related to health justice/ethics and perspectives for global health; and 5) provide recommendations for future research directions.

### **"There Is More to Health and Life than the Genome"**

Kirchstein noted that the timing of the conference was "particularly apt" given the announcement the previous day of the completion of the mapping of the human genome. "There is more to health and life than the genome," she said. The OBSSR conference puts the entire activities of the NIH – biomedical, behavioral, and social science – into context, allowing for a more complete picture. Kirchstein commended the Conference's co- chairs: Christine Bachrach of the National Institute of Child Health and Human Development, and David Takeuchi of Indiana University, along with the planning committee which included representatives from eleven NIH Institutes and three outside social and behavioral science organizations: COSSA, the American Anthropological Association, and the American Sociological Association.

Kirchstein emphasized that research has shown that individuals' social environment, their family, neighborhood, schools and workplaces, have a "profound impact on health." She added that individuals' socioeconomic status (SES), regardless of their economic condition, as well as their gender, race and ethnicity, have been consistently linked to health outcomes. We know that a person's social ties, the quality of social relationships, and social resources can "mediate the effect of stress on health," said Kirchstein. Further, as a result of social and behavioral science research, she continued, "we know that cultural factors influence how we view, diagnose, and treat both physical and mental illnesses."

She observed that by examining the contributions of social and cultural factors to health, "including the influence of social structures and social processes, we can attain a better understanding of how to prevent illness and treat disease." By analyzing these two factors along with behavioral and biological factors allows for a more complete picture of the total person and what contributes to positive health outcomes, she added. This multifaceted effort, said Kirchstein, will allow the Nation to better attack the most difficult health problems it faces.

Highlighting her anticipation of achieving the administration's goal of eliminating health disparities, Kirchstein underscored that "research on social and cultural factors is a vital part of [NIH's] efforts to

understand health disparities, and critical to understanding the etiology of health and illness in general.” She further observed that NIH’s commitment to improving health for all Americans requires 1) a better understanding of the influences of the social and cultural environment on health, 2) an examination of the social processes and social structures that affect health, and 3) support of the development of an integrated understanding of how social, cultural, behavioral, and biological factors combine to produce health and illness. She concluded by calling for the preparation of more scientists for research careers in the behavioral and social sciences; the facilitation of interdisciplinary training among scientists to allow for the understanding of the different methods, procedures, and theoretical frameworks; and improving the dissemination of research to “our immensely diverse world.”

### **Social and Behavioral Science Research: "Our Time Is Now"**

“Our time is now,” exclaimed the former and first OBSSR Director Norman B. Anderson. Now at Harvard University, Anderson stressed a need to galvanize the field. He reflected that upon his arrival at the NIH five years ago as OBSSR’s first director many NIH leaders did not understand how social and behavioral science related to the overall mission of the agency. Basic and applied research in the social sciences, he continued, and its integration with other fields of health science, is critical to the mission of the NIH, emphasized Anderson. Although health science disciplines may be separate conceptually, methodologically, and administratively, the processes about which they are concerned are inextricably linked, he continued.

Echoing Kirchstein, Anderson underscored that social science research, and the interdisciplinary research among social, behavioral, and biomedical scientists will accelerate the progress toward understanding and improving health while ameliorating health disparities. Anderson presented what he termed the “level of analysis” framework, which would allow for such interdisciplinary research. The levels of analysis — social/cultural/environmental, behavioral and psychological, organ systems, cellular, and molecular — is an attempt to get beyond those artificial distinctions, said Anderson. Emphasizing that the five levels are interdependent, he stressed that an integrated multilevel approach to research may be essential to accelerating advances in understanding health.

The majority of today’s research in the health sciences, however, occurs within a single level of analysis and is closely tied to specific disciplines, he continued. According to Anderson, scientists have “reified the distinction” between disciplines as if those differences reflect a true framework. Even when scientists from the different fields collaborate on the same research question, maintained Anderson, it is not always multilevel research. He observed that integrating the levels of analysis has not been completely overlooked in the health sciences, citing cognitive and behavioral neuroscience as examples where the levels of analysis has been applied quite productively.

### **Coming Back To the Social and Behavioral Sciences**

“Ironically and paradoxically,” said Anderson, the completion of the mapping of the human genome provides “incredible opportunities for the behavioral and social sciences.” Ultimately, he continued, we will have to answer the question, what turns a particular gene on or off? It will become increasingly clear that the other levels affect the organ and cellular levels. The social and behavioral science community, therefore, has to be ready, “they are coming back to us,” cautioned Anderson. He concluded that the conference is timely given that several factors are coming together: the Department of

Health and Human Service's Healthy People 2010 initiative, the creation of strategic plans on eliminating health disparities by all of the NIH Institutes and Centers, as well as an NIH-wide strategic plan on health disparities and the Congress' call for the creation of a National Center on Health Disparities at the NIH (See *UPDATE*, May 15, 2000, #9).

### **Understanding the Social Context: The Promise and the Challenges**

David R. Williams of the University of Michigan provided an overview of select findings that suggest that factors related to the social environment such as socioeconomic status, race, gender, and place are closely related to the distribution of disease and death. Several of the findings presented by Williams were counterintuitive and paradoxical, highlighting the limited understanding of the mechanisms and processes by which social structures affect health.

According to Williams, the gap in death rates between African-Americans and whites was as large five years ago as it was 50 years ago. Comparing the 1995 leading causes of death among blacks and whites to 1950 rates, Williams observed that in 1950 the death rates for African Americans was 1.6 times higher than the rate for whites — identical to what it was in 1995. While the overall death rates have declined for both groups, the racial gap is wider today than in 1950 for several leading causes of death, including diabetes, cardiovascular disease, cancer, and cirrhosis of the liver.

Williams explained that racial differences in economic status play a large part of the black- white health differences. Men and women with higher household incomes have better health than those with lower incomes, explained Williams. “Moreover, the differences in health between high income and low income persons of each race are often larger than the overall differences between blacks and whites,” Williams continued. He added, however, that at the same time, at every level of income, blacks tend to have higher death rates than whites. This could reflect the added effect of racism and discrimination. According to Williams “racism can affect health indirectly through institutional policies that reduce employment and educational opportunities for minorities.” He also stressed that racism can affect health directly in multiple ways. The stress of experiencing discrimination, and residing in poor neighborhoods, said Williams, can also have negative effects on health, said Williams.

Williams also noted that Asian Americans, 70 percent of whom are foreign-born, have lower death rates for all 10 of the leading causes of death in the United States. He also noted that immigrants of all racial groups tend to have better health than their native-born counterparts, adding that unfortunately the health of immigrants also declines as length of stay in the United States increases.

“Advancing our understanding of the role of the social environment and health,” emphasized Williams, “will require careful, theoretical, and empirical work that seeks to (1) characterize the multiple dimensions of the social context, and (2) comprehensively assess potential consequences for physical and mental health.” There is a need, said Williams, for multidisciplinary research that identifies and evaluates plausible biological mechanisms for observed social processes. “This comprehensive approach is necessary to facilitate identification of the conditions under which various components of social structure are more or less consequential in predicting specific health outcomes,” he concluded.

### **The Challenge Ahead For NIH**

A long-standing commitment prevented the current Acting OBSSR Director Peter Kaufmann from participating in the two-day conference. In a statement read by Christine Bachrach to conference participants, Kaufmann called the NIH-sponsored conference "visionary" for its attention to the social and cultural dimensions of health. "This conference," said Kaufmann, "is a natural outgrowth of the growing recognition, among biomedical and behavioral scientists alike, that what happens inside our bodies is the result of a unique series of interactions among genetic, biological, psychological, and environmental influences. The social and cultural milieu plays a critical, and increasingly appreciated role in this equation."

"The challenge," according to Kaufmann, "is for the NIH to move beyond appreciating the importance of social and cultural influences on health to fully developing the science that elucidates them, explain how they operate, and translate this knowledge into interventions that can reduce health disparities and improve the health of all people." This, said Kaufmann, requires the development of better methods and models for understanding how social and cultural factors combine with other health determinants to produce health and disease. Biomedical scientists and social and behavioral scientists need to collaborate to develop truly integrated models of health. The work of this conference is an important step toward meeting these objectives, said Kaufmann.

In the months to come, according to Kaufmann, the OBSSR will develop a research agenda to build on the "recommendations and vision" of conference participants. Noting that a draft of the research agenda will be posted on the NIH/OBSSR website ([www1.od.nih.gov/obssr/obssr.asp](http://www1.od.nih.gov/obssr/obssr.asp)) in the Fall for public comment, Kaufmann encouraged the social and behavioral science community to provide additional comments.

*This is part one of a two part article that will continue next issue.*

## **NIH SOCIAL AND BEHAVIORAL SCIENCE RESEARCH CONFERENCE: PART TWO** *July 24, 2000, Number 14*

The National Institutes of Health (NIH) held the first ever conference "Toward Higher Levels of Analysis: Progress and Promise in Research on Social and Cultural Dimensions of Health," June 28 and 29 on the NIH campus. The two-day conference covered the full range of social and behavioral sciences, and provided participants with a wealth of information. The following is a sample of the presentations given at the conference. (This is the second of a two part series. See *UPDATE*, July 10, Number 13, for the first story.)

### **Race and Health**

Robert Hahn of the Centers for Disease Control and Prevention discussed the use of race and ethnicity and social science in Federal policy. To illustrate, he noted that a goal of the U.S. Public Health Service in its Healthy People 2010 initiative is the elimination of health disparities based on race and ethnicity. Hahn noted that there are a number of problems associated with the way the Federal government collects racial and ethnic information, including: categories that are not well defined and not

used consistently among Federal agencies, the possibility that categories are not well understood by many respondents, response rates and miscounts that differ substantially among racial and ethnic groups, and persons who report different racial and ethnic identities in different surveys at different times (See *UPDATE*, 6/2/97, 7/1/97, 9/29/97, 11/10/97).

He stressed that despite substantial Federal effort and some advances in the collection of racial and ethnic information, fundamental problems remain unresolved which hinder efforts to understand and monitor health equity. He concluded that, notwithstanding the difficulty of collecting this information, many anthropologists question the use of race.

Anthropologist Janis F. Hutchinson, University of Houston, explained that the definition of “race” and the identification of different races has been problematic since the inception of the concept. Although discrete biological races cannot be identified, everyone identifies with race, said Hutchinson. Social meanings are articulated through racial identities. Power is also embedded in the construction of racial identities, said Hutchinson.

She observed that racial identities are constructed in five ways: 1) the intersection of race, class, gender, and nationality; 2) the construction of racial identities by those in power; 3) the formation of racial identities in opposition to those in power — a form of resistance; 4) sociality, creates a comradery among people; and 5) everyday experiences. She further noted that since colonial days, racial variation in health has been dominated by a genetic model that views race as a function of biological homogeneity and black-white differences in health as mainly genetically determined. There are no qualitative differences between populations, she argued. Ninety-nine percent of the human genome is common to all people. Further, the definition and meaning of race are not the same everywhere, stressed Hutchinson.

### **Socioeconomic Status (SES) and Health**

“SES is a pervasive and consistent predictor of health,” emphasized Ichiro Kawachi, Harvard University. While the socioeconomic distribution of illnesses can sometimes change directions, and various risk factors come and go in the population, the poor have always suffered higher rates of premature mortality and morbidity, said Kawachi. The SES/health relationship, he continued, “occurs as a gradient, and is not confined to poverty.” The lower one’s position on the socioeconomic hierarchy, the worse one’s health status, he said. Adding that there has always been a health gradient, Kawachi emphasized that SES is a neglected dimension in official sources of health statistics. Even when the data is collected, observed Kawachi, it tends to be underreported.

According to Kawachi, there are many different pathways through which socioeconomic advantage “confers better health.” Both material and psychosocial factors play a role in giving rise to the SES gradient, he underscored. New advances in biology, he concluded, have contributed to a better understanding of how socioeconomic conditions “get under the skin” to produce health disparities.

### **Gender and Health**

We are born with a biological sex, said Paula England, Department of Sociology and Population Studies Center, University of Pennsylvania. Gender, she continued, arises in part because of social

interaction and because people are treated differently because of their sex. This “gender system,” said England, operates at many levels, from the micro to the macro. At the micro level, one’s sex is transformed into gender because it affects the expectations one encounters throughout the lifecycle. The flow of information and opportunities received across the lifecycle are affected by sex-segregated social networks. Cultural meanings, England continued, about what is valued in men and women appear in jokes, stories, and the mass media. At the macro level, said England, corporate, military, and social welfare policies are affected by gendered assumptions. As an example, England noted that the schedules and demands of many jobs were devised on the assumption that the worker had a full-time homemaker at home.

According to England, links between gender and health defy simple summary. Women suffer from some physical illnesses and from depression, yet they live longer than men and suffer less from other types of ill health. “These seemingly contradictory patterns make sense, given the gendered patterning of opportunities and social structural roles,” she said. For example, said England, sex discrimination in labor markets, as well as childcare responsibilities, lead women to have lower earnings and be under-represented in positions of authority. For single mothers, this often means household poverty. For married women, it lowers their bargaining power in marriage. Low power and resources can often lead to stress, depression, and physical ill health.

Socially approved notions of masculinity as “power” and “daring,” said England, encourage men to engage in risky behaviors such as violence and substance abuse. This risky behavior, she said, leads to men’s higher mortality. On the other hand, England noted that women’s embeddedness in networks of emotional support is health-inducing and is a buffer to many stressors.

### **Culture and Health**

Culture, stressed W. Penn Handwerker, University of Connecticut, consists of the knowledge people use to live their lives and the way in which they do so. It is what is in one’s head and influences what one does. What is in our head is unique to us. It is shared in specific ways with specific people. Culture makes up a major component of the behavioral ecosystems in which we live our lives. Handwerker said that unfortunately he could not say how this happens. Consciousness comes after behavior, he said.

A “culture,” in contrast with culture, said Handwerker, consists of the intersection of sets of labels, definitions, and meanings that we “variously share” with other people. The emotional tone to experience comes from the danger and opportunity signaled by our stress response. Stress thus shapes cultural meaning and induces specific choices that generate cultural replication or evolution. Childhood experiences, said Handwerker, may induce specific forms of adult brain structure and function. Stress-induced “morbidity” may consist of adaptive responses to ecosystems in which children find themselves subject to predation and denial of access to resources. “Resilient” children, he stressed, may exhibit high mortality.

Further research, said Handwerker, is needed to identify and characterize 1) the stressor dimensions and specific health effects of social relations and interaction predicated on power inequalities between and among individuals and social groups; and 2) the effect of various forms of stressors and social supports on children’s brains and behavior, particularly their relation to the familiar litany of

depression, substance use and abuse, suicide and other forms of violence, sexually transmitted diseases, HIV/AIDS, and teen pregnancy.

### **Social Capital and Health**

According to John Hagan, Northwestern University and American Bar Foundation, “individuals acquire at birth and accumulate through their lives unequal shares of human and social capital that incrementally alter and determine their life chances.” Hagan explained that these shares of human and social capital are acquired through the resources of surrounding social institutions — families, schools, and neighborhoods. Because individuals vary in their access to these resources, they must adapt themselves to the institutional and structural circumstances they inherit and inhabit. In less advantaged community and family settings, without abundant institutional resources, parents are less able to supply or transmit opportunities to their children. Using violence as an example, Hagan noted that young people who come from disrupted families or who are failing in educational settings have increased risk of exposure to various kinds of violence — not only neighborhood or street violence, but also self-destructive violence (e.g., suicidal behavior) and intimate partner violence (e.g., romantic relationships).

Gary Sandefur, University of Wisconsin, discussed families, social capital and health, and said that social relationships can provide resources that lead to the enhancement of the well-being of individuals. These relationships — parent-child, spousal, friends, neighbors, coworkers, teachers, among others — provide resources to individuals, including social support and encouragement, access to larger social networks, role modeling, and opportunities to learn and develop. Sandefur also noted that the availability of data, such as the National Longitudinal Survey of Adolescent Health (Add Health), creates opportunities to look at the effects of social capital and parental investments in social capital on the physical and mental well-being of adolescents, as well as other social and behavioral outcomes.

“It is widely recognized that social relationships, social integration, and affiliation have powerful effects on physical and mental health,” echoed Lisa Berkman, Harvard School of Public Health. People who are isolated, she said, are at increased risk from dying from many causes of death, she continued. Berkman further explained that social networks and the degree to which individuals are embedded in supportive social relationships are related to many different outcomes, most likely for many different reasons, that need examination.

### **Religion, Spirituality, and Health**

“A large and growing research base indicates that religious involvement typically has beneficial effects on physical health, mental health, and survival itself,” noted Linda K. George, Duke University. George observed that currently the most important research in this area is focused on identifying the mechanism by which religious involvement affects health. The search to do so is important for a number of reasons, she emphasized. First, from the perspective of basic science, the search for mechanisms is a hallmark of causal inference. Second, from a public health perspective, if we can identify the mechanisms that account for the relationships between religion and health, it may be possible to “package” those mechanisms in forms other than religion — an important goal because not everyone finds religious involvement palatable, said George.

## Neighborhoods and Health

The short term consequences of urban renewal in the second half of the 20<sup>th</sup> century, said Mindy Thompson Fullilove, New York State Psychiatric Institute, were dire and included the loss of money, loss of social organization, and psychological trauma. The long term consequences, continued Fullilove, “flow from the social paralysis of dispossession and, most importantly, a collapse of political action.” This has important implications for the well being of African-Americans. Blacks, as a people, believe themselves to be a group and because of segregation were only able to live in certain areas, she said.

The structure of a city provides the substrate of individuals lives. The issue is to understand what happens socio-geographically during urban renewal. Where do the people go and what happened to them? The bulldozing that accompanies urban renewal, continued Fullilove, displaces people and destabilizes the ecosystem. Showing before and after slides of renewal of such cities as Memphis (Tennessee) St. Louis, (Missouri), and Pittsburgh (Pennsylvania), Fullilove underscored that urban renovation causes destabilizing events, including confusion, disorder, and nonsense. With the tearing apart of the structure you weaken the group. What does this have to do with health?, asked Fullilove. The bulldozing of communities destroys health because individuals are not able to go it alone, she answered.

Robert Sampson, University of Chicago, emphasized the need to study the effects of environment on health. Social characteristics of neighborhoods vary widely by family structure, lifestyle, stability, and SES, said Sampson. Research suggests that multiple dimensions of poor health are ecologically concentrated in disadvantaged neighborhoods. Sampson discussed research that depicts the spatial clustering of health-related outcomes such as violence, infant mortality, and low birth weight. There seems to be a direct link between moving to better neighborhoods and health outcomes. The research, he said, is fairly consistent — inequality in neighborhood is reflected in health outcomes.

Sampson posed the question that if there is clustering, what is it about neighborhoods, above and beyond the attributes of the individuals who inhabit them, that might contribute to various health outcomes? Current research seeks to identify both the individual selection and social causation processes hypothesized by theory to account for why community disadvantages and poor health are seemingly intertwined, said Sampson.

## Sociocultural Process and Prevention

There is consistent evidence that social norms affect health-related behaviors such as violence and drug use, noted J. David Hawkins, University of Washington. There is also evidence that broad social norms among adolescents change significantly over relatively short periods of time, and that such changes are accompanied by changes in the prevalence of relevant health behaviors. Further, there is consistent evidence, he continued, that interventions in schools and communities can have beneficial effects in changing norms regarding alcohol and other drug use among middle school students and in preventing drug use during adolescence across a wide range of racial, cultural, and socioeconomic groups.

Noting that obesity, physical inactivity, negative body image, and disordered eating are on the increase among American youth, Mimi Nichter, University of Arizona, emphasized that in order to design appropriate prevention and intervention programs to address these important public health concerns, it is necessary to understand the social and cultural contexts in which these problems arise. Ethnographic

studies of adolescents attentive to notions of culturally appropriate body size, patterns of consumption, and attitudes to physical activity, said Nichter, have provided important insights into the experiences of teens. According to Nichter, prevention programs need to heighten girls' awareness of unrealistic body images and discuss the possibilities for more realistic body shapes. She further observed that considering the diversity that exists across cultures, there is much that can be learned by bringing girls of different ethnic groups together to articulate cultural differences and reflect upon the cultural underpinnings of how girls and women feel about their bodies.

### **Culture Change and Health**

Immigrants to the United States, even those from very destitute origins, exhibit superior morbidity and mortality outcomes compared to U.S. minorities, noted William A. Vega, University of Medicine and Dentistry of New Jersey. According to Vega, immigrants' frequency of practicing various risky health behaviors (e.g. criminal, domestic abuse, and substance abuse) are lower as well. This is "especially paradoxical," said Vega, "because their children will become U.S. minorities."

"Regrettably," he continued, these "positive outcomes deteriorate the longer they are in the U.S." Their rates "normalize" to the U.S. population rate in subsequent generations. The evidence for this "immigrant adjustment" effect is widespread. The primary mechanisms responsible for this adjustment, however, are not known, said Vega.

Questions for further research, said Vega, include: How do we explain the superior immigrant health profile? How do income and education interact with culture? What can we learn about social structure and health?

In the Fall, the Office of Behavioral and Social Science Research (OBSSR) will develop a research agenda based on the conference's presentations and recommendations. A draft of the agenda will be posted on the NIH/OBSSR website ([www1.od.nih.gov/obssr/obssr.asp](http://www1.od.nih.gov/obssr/obssr.asp)), to allow the social and behavioral science community to provide comments and suggestions.

### **CONTINUED FOCUS ON HEALTH DISPARITIES**

*August 7, 2000, Number 15*

Congress and the social and behavioral science community continue to focus on differences in health outcomes for different racial and ethnic populations.

### **Legislation Marked Up**

On July 26, the House Commerce Committee approved by voice vote H.R. 3250, a measure to establish a National Center for Research on Minority Health and Health Disparities. The Center is "to conduct and support basic and clinical research, training, the dissemination of health information, and other programs with respect to the health of racial and ethnic minority groups and other health disparity populations."

H.R. 3250 would: 1) require the Center to carry out a program to facilitate research on minority health by providing for research endowments at Centers of Excellence, 2) establish an advisory council, including a representative of the Office of Behavioral and Social Sciences Research, to advise, assist, consult with, and make recommendations to the Center Director, 3) establish a loan repayment program for qualified health professionals such that not less than 50 percent of the contracts are with individuals who are from disadvantaged backgrounds, and 4) require that an evaluation report be submitted to the Senate Committee on Health, Education, Labor, and Pensions, and the House Committee on Commerce. The bill also authorizes \$100 million for the Center in FY 2001, and "such sums as may be necessary" for FY 2002 - 2005.

(Continued next page)

### **Senate Hearing**

"The recent mapping of the human genome has shown that, in genetic terms, all human beings, regardless of race or gender, are more than 99.9 percent the same. However, despite this fact, serious and tragic disparities in health outcomes exist that are specific to race and gender," observed Chairman of the Senate Health, Education, Labor and Pensions Subcommittee on Public Health Senator Bill Frist (R-TN). Speaking at a Committee hearing on July 26, Frist noted that recent studies have demonstrated that ethnic minority populations, in addition to having lower rates of health care access, exhibit poorer health outcomes, and have higher rates of death from cancer and heart disease, HIV/AIDS, diabetes, infant mortality, and other health problems.

Embracing a "renewed focus on how to address minority health disparities," Frist stressed his interest in examining how the National Institutes of Health's (NIH) administrative process to elevate the current NIH Office of Research on Minority Health (ORMH) to that of center status was fairing. The hearing also addressed the health care disparities between women and the rural underserved populations, and the actions of NIH to address these disparities as well as to review relevant legislation (S. 1880, the Health Care Fairness Act of 2000) designed to address the issue of health disparities.

The evidence of health disparities in the United States is striking and beyond dispute, testified Acting NIH Director Ruth Kirchstein. The causes are multiple and include: "poverty, level of education, inadequate access to health care, lack of health insurance, societal discrimination, and lack of knowledge about the causes, treatment, and prevention of serious diseases disproportionately affecting differing populations." The causes are not genetic, except in rare cases such as sickle cell disease, emphasized Kirchstein. Echoing Frist, she stressed that "all of us, regardless of race, have basically the same genetic construction."

The Federal government is engaged in multifaceted initiatives designed to address health disparities in Americans including, Healthy People 2010, a national program to promote wellness and disease prevention, has the elimination of health disparities as one of its primary goals. In addition, the Department of Health and Human Services' Initiative to Eliminate Racial and Ethnic Disparities in Health targets six health disparities for elimination: infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV/AIDS, and immunization (See *UPDATE*, April 17, Number 7).

### **New Approaches Needed**

Scientific research, emphasized Kirchstein, "is all about trying new approaches when current ideas do not achieve expected results." This philosophy applies to health disparities, she said. While the NIH has made strides in some areas, "it is clear that we need a different approach," said Kirchstein. Noting the Administration has proposed the creation of a coordinating center in the fiscal year (FY) 2001 budget and legislative authority for the ORMH to award grants in certain circumstances, Kirchstein said that the NIH also supports the creation of a national center for research on minority health and health disparities as proposed in both House and Senate legislation.

According to Kirchstein, the NIH envisions authority for the center to award grants to fill in research gaps and build capacity at research institutions. The major role of the center would be to coordinate the efforts of all NIH Centers and Institutes. However, she believes "the primary research on disease that result in health disparities must remain at the Institutes and Centers with expertise in disease specific research," stressed Kirchstein.

Kirchstein informed the Senate Subcommittee that for the past six months, the NIH has been developing a comprehensive "Strategic Plan to Reduce and Ultimately Eliminate Health Disparities." The plan, which for the first time coordinates the research resources of the NIH Institutes and Centers, reported Kirchstein, is currently in draft form and is under review by the ORMH advisory committee. The goal, said Kirchstein, is to ready the Strategic Plan to submit as part of the NIH's FY 2002 budget as an outline of the agency's priorities and commitment to research on health disparities. According to Kirchstein, the Plan is focused on three major areas: 1) research; 2) research infrastructure; and 3) public information, outreach, and education.

### **Varmus, Evolved?**

Noting that in the past former NIH Director Harold Varmus, currently President of Memorial Sloan-Kettering Cancer Center, expressed reservations regarding the creation of such a center, Frist asked Kirchstein to comment on those reservations. What has changed? asked Frist. Kirchstein stressed that Varmus' perspective evolved over time and just before leaving the NIH he supported the legislation. Former Health and Human Services Secretary Louis Sullivan, also testifying before the Subcommittee, further observed that in a recent commencement address to the Washington University School of Medicine, Varmus focused his remarks solely on the issue of health disparities.

In those remarks, Varmus emphasized that the NIH "must take an active role in addressing these issues." Varmus noted that NIH has "tried to do so, but the progress has been slow, policies have been contentious." Emphasizing that "greater burdens of disease are carried by people in certain locations [environment], in lower socioeconomic groups, or in minority ethnic and racial groups," Varmus underscored "that not all of these differences can be ascribed to deficiencies in medical care or even in access to care. "Educational levels and cultural and economic factors play important parts," he noted. Varmus also stressed the need for health workers to "become more sensitive to their own perhaps even unconscious prejudices." He also stressed that schools must review their curricula to prevent the transmission of stereotyping. Quoting Harold Freeman, who recently joined the National Cancer Institute, Varmus said that "physicians . . . must learn to see people not through the lens of race," because race is a social construct, without basis in biology "but instead as the individual persons they are."

Sponsors of the House companion bill, H.R. 3250, Representatives John Lewis (D-GA) and Jesse Jackson Jr (D-IL), and J.C. Watts (R-OK), testifying on behalf of S. 1880, urged the Senate to consider the measure before the 106<sup>th</sup> Congress adjourns. "It's a good bill, a necessary bill, and the right thing to do. Mark up and do what you can to pass the bill," urged Lewis.

### **NIH Creates Health Disparities Website**

Twelve of NIH's 25 Institutes and Centers have posted their health disparities strategic plans on the web. The site also includes NIH's definition of health disparities, information regarding opportunities for scientists to apply for NIH grants and contracts targeted to reducing health disparities, along with recruitment and retention information for increasing the minority scientists. The website address is: (<http://.healthdisparities.nih.gov>)

### **BRIEFING HELD**

*August 7, 2000, Number 15*

On June 26, 2000, COSSA, the American Psychological Association, the Society for the Psychological Study of Social Issues, the National Association of Social Work, and the American Sociological Association held a joint congressional briefing, "*How SES, Race and Ethnicity Effect Health Outcomes and What to Do About It: Research on Minority Health Disparities,*" on Capitol Hill.

Addressing a standing room only audience, social and behavioral scientists addressed the ways in which health outcomes can be improved for racial and ethnic minorities by including social and behavioral science research in federal health research initiatives. They included: **Brian Smedley**, study director of the Institute of Medicine's report "Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and Medically Underserved;" **Norman B. Anderson**, the former and first director of the National Institutes of Health (NIH) Office of Behavioral and Social Sciences Research (OBSSR); **Hector Myers**, Professor, Department of Psychology, University of California Los Angeles; **David R. Williams**, Professor of Sociology and a senior research scientist at the Institute for Social Research, University of Michigan, and a faculty associate in the African American Mental Health Research Center and the Center for AfroAmerican and African Studies, Michigan; and **Jeanne Miranda**, Associate Professor of Psychiatry, Georgetown University Medical Center and Senior Scientific Editor of the Supplement to the Surgeon General's Report on Mental Health on Culture, Race, and Ethnicity.

### **The Real Promise for Reducing Health Disparities Lies Not in Genetics Alone**

Smedley commented on that morning's announcement that the mapping of the human genome was completed. He noted that, "ironically, . . . we are also increasingly coming to understand that breakthroughs in medical genetics are not going to result in the overall population health improvements

that have been the goal of public health for decades." The greatest improvements in the Nation's health, said Smedley, will "result from a better understanding of social and better factors that affect health."

It is "critical," he said, "to support research that will examine differences in behavioral and social factors," such as "cultural variations in health attitudes and practices; ethnically appropriate interventions to improve diet and reduce risk behaviors such as smoking; and social and environmental conditions, such as a lack of access to appropriate cancer screening and prevention information, that may contribute to disparities."

Anderson, now at Harvard, noted that the timing of the briefing was particularly auspicious, given that "there have never been greater interest and determination, both in Congress and the Administration, to take action to eliminate the health disparities that exists between minority and majority populations in this country." He expressed his belief that the NIH is moving toward an expanded view of health: that the physiology we are born with, and the social and physical environments in which live, and the choice we make about our lifestyles all interact to make us sick or keep us well. The NIH is approaching an increasing number of health conditions from a multidisciplinary perspective, which increases the odds that the multiple influences on health can be sorted out and understood, Anderson concluded.

### **"These Are Not Acts of God"**

Williams provided congressional staffers with an overview of "what we know" regarding trends and social determinants of health. Focusing his remarks mainly on the black/white differences, Williams presented data similar to those he described at the National Institutes of Health's conference "*Toward Higher Levels of Analysis: Progress and Promise in Research on Social and Cultural Dimensions of Health*" held June 27 -28 on the NIH campus. (See *UPDATE*, July 10, Number 13).

How do we make sense of the data? he asked. "These are not acts of God," he continued. The answer, said Williams, lies in the systematic implementation of policy, the legacy of racism (skin color is one of the mechanisms not readily recognized), residential segregation, schools, and jobs. These factors are all driving forces in determining the health status of blacks, said Williams.

Myers discussed the "Biobehavioral Contributions to Ethnic Health Disparities: The case of Hypertension and Birth Outcomes." Myers stressed that "health and disease are products of the interaction of psychosocial, behavioral, and biological processes." The effects, he continued, may be direct via biological changes that parallel, precede, or are part of emotional reactions or behavioral patterns in response to chronic life stresses.

Using hypertension as an example, Myers expanded on the usefulness of the biobehavioral model in understanding ethnic health disparities. Hypertension, he said, results from the dysregulation of blood pressure control mechanisms. He listed the risk factors for hypertension including: family history, low socioeconomic status, excess weight, African American ethnicity, older age, male, high sodium intake and low intake of calcium, potassium and magnesium, high fat diet, sedentary lifestyle, smoking, excessive alcohol consumption, and high chronic stress. Noting that most of the research has been on black/white differences, Myers said the studies suggest that hypertension has a different pathogenesis in blacks and

whites. In blacks, noted Myers, high blood pressure develops earlier, is more likely to be undiagnosed and uncontrolled, has a faster disease course, and earlier mortality.

### **Sociocultural Aspects of Psychotherapy**

Miranda focused her presentation on the “Sociocultural Aspects of Psychotherapy: Disseminating Effective Care.” She began by expressing her amazement that there are not disparities in the need for mental health care. However, she observed that there are huge disparities regarding access and use of mental health care. Miranda also highlighted new evidence that reports as minorities use mental health care, they get poorer quality care than their white counterparts. Blacks, said Miranda, have the potential to have worse outcomes. They are over-represented in homeless populations and the criminal justice system, she noted. She emphasized that it is also possible that their mental health problems lead to worse outcomes.

She noted, however, that African-American, Latino, and poor patients differ from middle class whites in their responses to therapists and to mental health settings. They are less likely to participate in care than middle class white patients, and they tend to underuse services or discontinue using services prematurely, she continued. On the other hand, African American and Latino patients respond similarly to quality care as white patients, noted Miranda.

### **KINGTON NAMED NEW OBSSR DIRECTOR**

*September 11, 2000, Number 16*

Raynard S. Kington has been appointed the National Institutes of Health’s (NIH) new Associate Director and Director of the Office of Behavioral and Social Sciences Research (OBSSR) by Acting NIH Director Ruth Kirchstein. Kington, who will be the OBSSR’s second director, is scheduled to begin his tenure at OBSSR on October 8, 2000. “His broad medical, scientific, and administrative background will serve him well as he directs OBSSR in exploring the role of behavior, lifestyle, and social factors in health promotion and disease prevention,” notes Kirchstein in a memo to the NIH Institute and Centers Directors.

A speaker for COSSA’s 1996 Congressional Seminar *Aging Well: Health, Wealth, and Retirement*, Kington is currently the Director of the Division of Health Examination Statistics in the Center for Disease Control and Prevention’s (CDC) National Center for Health Statistics (NCHS) where he leads the National Health and Nutrition Survey (NHANES).

Before joining the CDC, Kington was a Senior Natural Scientist at the RAND Corporation and an Assistant Professor of Geriatric Medicine at the University of California, Los Angeles. A Robert Wood Johnson Clinical Scholar at the University of Pennsylvania, he completed his M.B.A. and Ph.D. in health policy and economics at the Wharton School. He received his M.D. from the University of Michigan. He was a co-director of the Drew/RAND Center on Health and Aging, a National Institute of Aging Exploratory Minority Aging Center. His research interests have included the economics of aging, health economics, the evaluation of preventive interventions in elderly populations, and the relationships among race, socioeconomic status, and health.

In reaction to the announcement, Norman B. Anderson, the OBSSR's first director, said, "I think Raynard is an excellent choice to lead OBSSR. His broad training, coupled with his diverse research and administrative experiences, make him ideally suited to help NIH move vigorously forward in the social and behavioral sciences. I also know that the [social science community] will embrace and encourage him as it did me." Anderson left the agency earlier this year after five years of successfully working to integrate the social and behavioral sciences throughout the NIH health research enterprise to join Harvard University's School of Public Health as a Professor of Health and Social Behavior.

## **NRC REPORT ASSESSES NATION'S NEED FOR SCIENTISTS**

*September 11, 2000, Number 16*

The National Institutes of Health (NIH) should increase its emphasis on interdisciplinary research training in the behavioral and social sciences, according to the recently released National Research Council (NRC) report *Addressing the Nation's Changing Needs for Biomedical and Behavioral Scientists*. The congressionally-mandated report, the eleventh in a series that began in 1975, reviews the recent production and current supply of scientists.

The report is the result of the NIH's request to the Committee on National Needs for Biomedical and Behavioral Scientists to assess the need for National Research Service Award (NRSA) training grants and fellowships, and the need for new research personnel in biomedical, behavioral, and clinical sciences.

Noting that the report "appears at a time of contradictions," the Committee observes that on one hand, improvements in health resulting from biomedical and behavioral research are increasingly apparent. On the other hand, it is "increasingly difficult for new scientists to establish independent research careers." The report further notes, that "the composition of the research workforce and the focus of its work do not adequately address some of the Nation's needs." The rapidly increasing medically underserved minority populations, and the lack of commensurate growth of the number of research personnel who seek to address their health problems are cited as examples.

### **We Have Enough Ph. Ds. . .**

As requested by NIH, the NRC Committee focused on the three broad fields of biomedical, behavioral, and clinical research. The Committee found that "the number of new Ph.D.s awarded annually in the basic biomedical sciences is well above that needed to keep pace with growth in the U.S. economy and to replace those leaving the workforce as a result of retirement and death." Accordingly, the Committee concluded that research training in these fields should not be increased.

Likewise, the Committee recommended that "there should be no growth in the aggregate number of Ph.D.s awarded annually in the behavioral and social sciences." The Committee notes that "given the current employment opportunities for behavioral and social scientists and the continuing growth forecast in the workforce, the present number of approximately 2,600 new behavioral and social science Ph.D.s per year is sufficient to fulfill anticipated national needs in the near future (until at least 2005)." In the area of clinical research, the Committee recommend that "Ph.D. production in the clinical science fields

not be increased but that efforts to train and retain physicians be intensified until the decline in the numbers has been reversed and the clinical research workforce includes substantially more M.D.s than is now the case.”

### **Behavioral and Social Sciences**

The report emphasizes that “[r]esearch training in the behavioral and social sciences related to health should be expanded beyond traditional disciplinary boundaries and provide opportunities for participating students and fellows to integrate their knowledge of the behavioral and social sciences with advances in the brain sciences (and related fields such as brain imaging, biochemistry, and pharmacology), public health, and medicine.”

To transform behavioral and social science research into a more interdisciplinary activity “is likely to require a concerted effort by the NIH and changes in several facets of its research training programs.” The NRC report recommended several options for the NIH to consider:

- \* Gradually shift the focus of its predoctoral programs from single discipline to interdisciplinary training.
- \* Increase the opportunities for postdoctoral training through interdisciplinary training grants.
- \* Involve more NIH Institutes in behavioral and social science research training, either independently or in joint activities with the Institutes that already support the bulk of this training — National Institute of Child Health and Human Development, National Institute on Aging, National Institute on Drug Abuse, National Institute on Alcohol Abuse and Alcoholism, and the National Institute of Mental Health.
- \* Monitor more closely the implementation of the 1997 policy change for M.D.-Ph.D. programs, to ensure that more students are provided opportunities to pursue studies in the behavioral and social sciences related to medicine.

Noting that Ph.D.s trained in behavioral and social sciences pursue a broader research agenda, much of which is unrelated to health and medicine, the report recommends that the NIH and the National Science Foundation take steps to improve data on the behavioral and social sciences workforces, so that those conducting health-related research can be specifically identified in national surveys of the scientific workforces.

According to the report, African Americans, Hispanics, and Native Americans are “greatly underrepresented among Ph.D.s and health professionals in the research workforce. Meanwhile, the health problems of the nation’s growing underrepresented minority populations are not receiving adequate attention.” While the Committee acknowledges that the number of underrepresented minority individuals earning Ph.D.s in behavioral and social sciences has increased substantially in recent years, the Committee recommends that the NIH continue its effort to identify and support programs that encourage and prepare underrepresented minority students for careers in behavioral and social science research.

In discussing crosscutting issues in research training, the Committee further recommends that “[l]ed by the NIH, the agencies with responsibility for health research training should strengthen their efforts to ensure diversity in the research work force.” NIH, the Agency for Healthcare Quality and Research, and the Health Resources and Services Administration are urged to focus their attention on improvements in opportunities for minorities at the secondary school level (or earlier), seeking legislative authority to do so, if necessary. The report notes that although “these agencies have not traditionally

played a role in secondary education, we believe that their responsibility for ensuring diversity in the research workforce necessitates that they do so.”

### **Dissenting View Provided**

John F. Kihlstrom, from the University of California, Berkeley and a member of the NRC Committee, provided a personal statement regarding research training in the behavioral and social sciences, which is included in the Appendix of the report. Kihlstrom notes that while he generally agrees with the findings, conclusions, and recommendations of the Committee, he believes “that the Committee has not fully considered the actual and potential contributions that the behavioral and social sciences can make to health and health care, and the implications of these contributions for the National Research Service Award training program and related training activities sponsored by NIH, AHRQ, and HRSA.”

In his statement, Kihlstrom outlines contributions of the behavioral and social sciences to health and health care. He uses the role of behavioral and social sciences in combating HIV/AIDS as an example. “Almost two decades after identification of AIDS (in 1981) and the isolation of the HIV virus (in 1983) and extensive biomedical research, there is still no cure and no vaccine. Nevertheless, psychosocial interventions, taking account of both the determinants of individual behavior and the wider sociocultural context in which individual behavior takes place, have effectively reduced the incidence of HIV-related sexual risk behaviors.” Kihlstrom further emphasizes that “altering behavior” through targeted education, peer influence and community action, advertising, and marketing remains “the primary way to control the epidemic of HIV/AIDS.”

He also declares that “across a wide variety of chronic and life-threatening diseases, from asthma and hypertension to epilepsy and renal disease, compliance with prescribed medical regimens is universally acknowledged to be a central problem for health care professionals.” He also notes that the “situation is just as bad, if not worse, for compliance with such disease prevention regimes as diet and exercise. The problem of compliance underscores the fact that developing a pill is only one step toward effective treatment or prevention. . . . This is a behavioral problem that must be addressed at the individual and sociocultural levels of analysis,” stresses Kihlstrom.

Disagreeing with the Committee’s decision “not to repeat or reinforce its predecessors’ calls for increases in NRSA awards in the behavioral and social sciences,” Kihlstrom notes that with the establishment of the Office of Behavioral and Social Sciences Research, “NIH has taken an important step forward in recognizing the contributions of the behavioral and social sciences to health and health care and in promoting these fields within the institutes.” The agency and the Department of Health and Human Services (HHS), says Kihlstrom, “can and should do more.”

### **IOM REPORT CALLS FOR MORE INTERDISCIPLINARY RESEARCH**

*September 25, 2000, Number 17*

“To achieve the health goals of the 21<sup>st</sup> century, scientific training and research must bring together many scientific fields that offer different insights and technologies,” emphasizes a recently released Institute of Medicine (IOM) report, *Bridging Disciplines in the Brain, Behavioral, and Clinical Science*. The report, released by the Division of Neuroscience and Behavioral Health of the

Committee on Building Bridges in the Brain, Behavioral, and Clinical Services, highlights that “[i]nterdisciplinary efforts need to be facilitated at all levels of teaching and research.” The report further underscores that “[n]ever before have there been such opportunities to understand the human brain and behavior.”

The report, commissioned by the National Institute of Health’s (NIH) Office of Behavioral and Social Sciences Research, National Institute of Mental Health, National Institute on Nursing Research, and National Institute on Aging, offers recommendations “to delineate, enhance and accelerate a process that is already reflected in many training and research programs.”

According to the Committee, both single disciplinary and interdisciplinary research are needed to develop methods for prevention, diagnosis, and treatment of disease and to understand the basic mechanisms of brain and behavior. *Interdisciplinary research* is defined by the Committee “as a cooperative effort by a team of investigators, each expert in the use of different methods and concepts, who have joined in an organized program to attack a challenging problem. Ongoing communication and reexamination of postulates among team members promote broadening of concepts and enrichment of understanding. Although each member is primarily responsible for the efforts of his or her own discipline, all share responsibility for the final product.”

Observing that the need for interdisciplinary research appears to be increasing, the Committee explains that “many of the chronic conditions that challenge us today do not respond well to the single investigator, single discipline model that worked well in the past, as in the paradigm of infectious disease.” The report warns, however, that “interdisciplinary research is an approach, not an end and should arise out of a response to a problem that cannot be embraced by a single discipline.”

### **Barriers to Interdisciplinary Research**

The “Bridging Disciplines” report also highlights the “traditional and persistent barriers to interdisciplinary research,” including disciplinary jargon, cultural differences, perceptions of interdisciplinary science as second rate, and a “sense of superiority within each discipline and the view that other disciplines are less rigorous or important also present barriers.” Concerns that interdisciplinary fields will not prepare graduates for a career are observed. Despite these barriers, the report recognizes that interdisciplinary programs are growing at academic institutions.

In recognition of the need for MDs to understand the behavioral and sociological aspects of disease, to address the important issues of behavior change and adherence, and to “think globally about population and environmental factors in disease,” the report “strongly encourages” training in these nontraditional fields.

### **Translational Research Needed**

The IOM report underscores the need to translate the findings of research to the clinic or from the clinic back to the laboratory. According to the report, translating findings is considered an important aspect of interdisciplinary research, although sometimes difficult to achieve.

Federal funding agencies, including NIH, are encouraged to identify areas that can be most effectively investigated with interdisciplinary approaches and to remove the barriers to interdisciplinary research and training. These would include MD/Ph.D. programs in the social and behavioral, as well as biomedical sciences. Although existing program language permits such graduate study, training in social and behavioral science (e.g., anthropology, economics, psychology, and sociology) is undertaken infrequently. NIH can highlight the need for such graduates and encourage grantees to recruit them.

### **NIH AND NSF GRANTS SUPPORTED THE 2000 NOBEL PRIZEWINNERS IN ECONOMICS**

*October 23, 2000, Number 19*

On October 11, 2000, two American economists, James J. Heckman of the University of Chicago, and Daniel L. McFadden of the University of California, Berkeley, were awarded the Nobel prize in Economics. Heckman and McFadden received the coveted prize for their work in micro-econometrics, which is widely applied in the analysis of individual and household behavior in economics and other social sciences.

Principal Deputy Director Ruth Kirchstein of the National Institutes of Health (NIH) expressed her satisfaction that the “two longtime NIH grantee scientists have made such significant advances in the social sciences.” Noting that most of the 100 Nobel Laureates who have been funded by NIH to advance scientific knowledge won their prizes in physiology, medicine, or chemistry, Kirchstein expressed her delight “to see that honor has been extended to NIH-supported work in economics.”

“Theoretical and methodological advances in economics are becoming increasingly valuable in a wide range of areas in health research. It is gratifying to see two economists whose work has been supported by NIH receive this recognition,” said newly appointed Director Raynard Kington of the Office of Behavioral and Social Sciences Research. I hope that this will provide an even greater incentive to economists as well as scientists from other social science disciplines to think about how their disciplines can be applied to help us study and ultimately improve the health of all people, and I hope this will also encourage more social scientists to apply to NIH for funding support.”

Heckman and McFadden are also current grantees of the National Science Foundation’s (NSF) Economics Program, and Heckman also receives support from the agency’s Methodology, Measurement and Statistics Program. Both have been supported by the NSF “nearly continuously since the 1970s,” explained NSF Director Rita Colwell. “This is always exciting news for scientists,” Colwell continued, “because we know what led up to this milestone — the long hours, hard work, and simple love of science. It’s especially exciting for the National Science Foundation because we so often play a significant role in the Nobelists’ careers.”

Heckman's recognition stems from his pioneering work in accounting for unknown factors affecting statistical samples. Much of this work has been applied to understanding how early life events contribute to individuals' later earnings potential and economic standing. Specifically, his work has provided researchers with the methods to determine the effects of poverty and other environmental factors on the life choices individuals make.

According to National Institute of Child Health and Human Development (NICHD) Director Duane Alexander, Heckman's "microeconomic models have provided the standard for researchers the world over . . . His research also points to the critical nature of the first five years of life as predictive of such later life events as dropping out of high school, teenage pregnancy and early divorce." Heckman is currently funded by the NICHD to examine the implications of earning a high school equivalency diploma, or G.E.D., for an individual's later economic prospects.

McFadden earned the honor for his work involving a new theory of "discrete choice," a way to measure how an individual's decisions regarding occupation or housing, for example, reflect choices among a limited number of alternatives. According to the head of the Behavioral and Social Research Program, Richard Suzman at the National Institute on Aging (NIA), "application of these theories has broad implications for understanding the economics and other social behavior of individuals approaching and in retirement."

McFadden, who has received support for his work from NIA since 1986, has performed significant work related to understanding economic behavior and its consequences. This includes:

- Extensive methodological work on the measurement of wealth of the elderly.
- Development of methods to determine the effects of a declining birth rate and aging population on the housing market. McFadden's work is part of a larger project on the economics of aging, led by David Wise of Harvard and the National Bureau for Economic Research (NBER). This work showed that the large gains of the housing market in the 1960s and 1970s will not extend to the baby boomer generation and that changes in this market could have a detrimental effect on the wealth and well-being of future elderly.
- Study of the relationship between how long a person expects to live and how much they save. This work, with Michael Hurd of The RAND Corp. and NBER, will allow scientists to better understand how people use subjective information in making choices. This research involves the use of the NIA-sponsored Health and Retirement Study, the largest survey to date looking at the health and well-being of people as they age.

## **NIH-WIDE HEALTH DISPARITIES PLAN RELEASED FOR COMMENT**

*October 23, 2000, Number 19*

The National Institutes of Health (NIH) recently released its draft five-year trans-NIH strategic research plan on health disparities, *NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities*. The Plan, developed by a trans-NIH working group co-chaired by NIH Acting

Deputy Director Yvonne Maddox and National Institute of Allergy and Infectious Diseases Director Anthony Fauci, describes the activities underway and plans to “bring the full strength of NIH’s research and training programs to bear on the challenge of eliminating domestic health disparities.” (See *UPDATE*, August 7, 2000).

NIH welcomes comments and suggestions on the draft plan through December 1, 2000

“Our aim at the NIH is to promote the development and transfer of research-based information from biomedical, behavioral, and social sciences for use by health professionals, communities, and others working toward the elimination of health disparities,” notes Principal Deputy Director Ruth Kirchstein and Office of Research on Minority Health Director John Ruffin.

The Plan draws on the health disparities plans of the NIH Institutes and Centers and relevant offices within the Office of the Director, including the Office of Behavioral and Social Sciences Research (OBSSR). The Plan emphasizes that health disparities are “believed to be the result of the complex interaction among biological factors, the environment, and specific health behaviors. Inequalities in income and education also appear to underlie many health disparities in the United States. Disparities in income and education levels are associated with differences in the occurrence of illness and death, including heart disease, diabetes, obesity, elevated blood lead level, and low birth weight.”

The NIH plan focuses on three areas: research, research infrastructure, and public information and community outreach. The agency is focusing its initial attention on the health status and socioeconomic factors of specific racial and ethnic minority populations. According to the Plan, research efforts will be directed to the role of the environment and socioeconomic status (SES) in health disparities. New or improved approaches to preventing or delaying the onset or progression of disease and disabilities in minority populations will be explored as they relate to diseases such as diabetes, obesity, dental caries, asthma and HIV vaccine development, among others.

The following is a sample of social and behavioral science research directives included in the Plan:

**Sexual Behaviors:** A proposal to expand the understanding of factors that contribute to high-risk sexual behaviors is included in the Plan. Part of the study will measure the magnitude of risk reduction in the context of monthly support groups.

**Youth Violence:** The NIH Youth Violence Consortium will develop a collaborative effort to understand the antecedents, social and neurobiological causes, and outcomes of violent youth behavior. The agency will also support a collaborative effort across racial and ethnic lines to study the short- and long-term effects of domestic violence during pregnancy and the effects of domestic and community violence on children.

**Environment and Socioeconomic Status:** The NIH Plan acknowledges that research seeking to better understand the effects of social and physical environments on human health and disease is an important contribution towards ameliorating the health disparities suffered by the economically disadvantaged. NIH expects that the Science and Ecology of Early Development Project, which

examines the relationship of poverty to other factors that affect the development of children, will be extended.

**Cognitive:** The NIH will coordinate demographic and epidemiological studies on the racial, ethnic, geographic, socioeconomic, educational, and health factors affecting cognitive, sensory, and motor health and the development of mild cognitive impairment, Alzheimer's disease and other neurodegenerative disease of aging.

**Language Disorders:** The Plan notes that as the United States becomes more culturally, racially and linguistically diverse, it is becoming increasingly difficult to discriminate between language disorders and languages differences in children. The NIH is supporting research to develop language tests for non-standard English.

**Mental Health:** NIH will support research to determine why recruitment and retention of minority group members in clinical trials of mental health treatments is so difficult; to determine the most culturally relevant, appropriate, and acceptable outcomes regarding symptoms and functioning; to see if there are different outcomes for minority groups when treatment interventions are provided in the community and if so, why; to determine whether providers use different interventions for various minority groups and if so, why; and to determine the impact of cultural competence training on the quality of care and treatment outcome for minority patients.

The Plan can be found on the NIH website: [www.nih.gov/about/hd/strategicplan.pdf](http://www.nih.gov/about/hd/strategicplan.pdf).

## **CONGRESS CREATES NEW NIH CENTER ON HEALTH DISPARITIES**

*November 6, 2000, Number20*

Despite its inability to come to an agreement on the remaining appropriations measures, the Congress cleared for the President S. 1880, the Minority Health and Health Disparities Research and Education Act (see *Update*, August 7, 2000). The legislation, which the President is expected to sign, won approval after Senate leaders modified language to address concerns raised by the Department of Justice.

“The Minority Health and Health Disparities Research and Education Act will expand research and education for the biomedical, behavioral, economic, institutional, and environmental factors contributing to health disparities in minority and medically underserved populations,” said Senator Bill Frist (R-TN), who introduced the amended version of the legislation in the Senate with Senators Edward Kennedy (D-MA) and Jim Jeffords (R-VT). Frist emphasized that “health disparities may be the result of many factors, including limited access to prevention and treatment services, poverty and socio-economic factors, exposure to environmental toxins, and even cultural factors.”

Kennedy, the original sponsor of the Senate legislation, stressed that “the reality of poverty clearly affects the nation's health” (see *Update*, May 15, 2000 ). S. 1880 provides “the needed resources for research, data collection, medical education, and public awareness in order to understand the root causes of diseases and poor health outcomes and to develop the strategies to meet the health needs of these

vulnerable communities.” Each of these aspects, Kennedy declared, has an important role to play in the reduction and eventual elimination of the unacceptable disparities in health outcomes that now exist.

### **ORMH Elevated to Center Status**

As passed, S.1880 amends the Public Health Service Act to expand federal research and education efforts to address health disparities. Additionally, the measure elevates the current National Institutes of Health (NIH) Office of Research on Minority Health, established in 1990, to the National Center on Minority Health and Health Disparities. The newly established Center would fund research not already supported by one of NIH’s other 25 Institutes and Centers. The measure also requires NIH to report to Congress the amount of money it spends on minority health research. S. 1880 also allows the federal government to repay up to \$35,000 of the educational loans of researchers, regardless of their race, for each year they conduct studies of the disparities that exist in health outcomes. For fiscal year 2001, the measure authorizes \$100 million in funding.

Anticipating the bill’s requirement of a trans-NIH plan for health disparities research, the agency recently posted such a plan on its website seeking public comment through December 1 (See *Update*, October 23, 2000). Each of the Institutes and Centers (ICs) (including the Office of Behavioral and Social Sciences Research) were also required by Principal Deputy Director Ruth Kirchstein to come up with individual health disparities strategic plans (see related story on page 5). Most of the ICs have posted these plans on their individual websites or they may be viewed at: [www.nih.gov](http://www.nih.gov).

### **AHRQ**

S. 1880 requires the Agency for Healthcare Policy and Research (AHRQ) to conduct research on the causes and barriers to reducing health disparities, taking into consideration such factors as “socioeconomic status, attitudes toward health, language spoken, the extent of formal education, the area or community in which the population resides, and other factors the Director determines appropriate.” AHRQ is also directed to conduct and support research and demonstration projects to identify, test, and evaluate strategies for reducing or eliminating health disparities.

### **National Academy of Sciences Study Required**

The bill mandates the National Academy of Sciences to conduct a “comprehensive study of the Department of Health and Human Services’ (HHS) data collection systems and practices and any data collection or reporting systems required under any of the programs or activities of the Department relating to the collection of data on race or ethnicity, including other Federal data collection systems (such as the Social Security Administration) with which the Department interacts to collect relevant data on race and ethnicity.” The report is due one year after the enactment of the legislation.

### **Cultural Competency Addressed**

The Secretary of HHS, acting through the Health Resources and Services Administration (HRSA), is authorized to award grants, contracts, or cooperative agreements to public or nonprofit entities to carry out research and demonstration projects (including research and demonstration for continuing health

profession education), training, and education for the reduction of disparities in health care outcomes and the provision of culturally-competent health care. HRSA is also required to convene a national conference on health professions education as a method for reducing disparities in health outcomes.

The bill also requires the HHS Secretary to conduct a national campaign to inform the public and health care professionals about health disparities in minority and underserved populations.

COSSA joined nearly 40 organizations in a letter organized by the National Medical Association and sent to the House and Senate leadership urging passage of the bill.

## **OBSSR'S HEALTH DISPARITIES STRATEGIC PLAN ON THE WEB**

*November 6, 2000, Number20*

The National Institutes of Health's Office of Behavioral and Social Sciences Research (OBSSR) has posted its strategic plan for health disparities research on the agency's website (<http://obsr.od.nih.gov>).

The OBSSR's plan emphasizes that the projects it describes are the result of discussions with the extramural research community and the NIH Behavioral and Social Sciences Research Coordinating Committee and represents important areas of investigation or development which may not be highlighted in the rest of the Institutes and Centers' (ICs) strategic plans."

According to OBSSR, the project represents directions that the Office would like to pursue in the next five years as funding allows. These projects "fall into broad categories of background risk factors, intervention research, and training and communications and are not listed in priority order." It is noted that the OBSSR may also pursue projects not identified in the plan if opportunities for collaboration with the ICs arise.

The OBSSR's plan includes four areas of focus: 1) racial bias and health; 2) racial/ethnic and socioeconomic inequalities in health; 3) behavioral change interventions to diminish racial/ethnic health disparities; and 4) health disparities and health care systems.

**Racial Bias and Health** — The OBSSR plans to assess the state-of-the-science on racial bias and health and stimulate research on areas identified as gaps in knowledge. Initiatives designed to stimulate research on racial/ethnic and socioeconomic inequalities in health will follow the assessment. The plan emphasizes that the influence of racial bias is not limited to access to health care. "Discrimination can restrict the educational, employment, economic, residential, and partner choices of individuals, affecting health through pathways linked with what psychosocial scientists refer to as human capital." An insufficient focus on the impact of societal forces has hindered the ability to understand and effectively address the influence of racial biases on health disparities.

**Racial/Ethnic and Socioeconomic Inequalities in Health** —The OBSSR plans to assess the state-of-the-science in measuring SES (socioeconomic status) and race/ethnicity and plans to examine current research on SES and race as they affect health. SES and race/ethnicity have been found to relate to a variety of health outcomes. "While it is well known that minority groups are dis-proportionately represented in low socioeconomic strata in the United States, less recognized is that at most levels of SES, morbidity and mortality rates are higher for blacks than for whites." Study is needed on the roles of

environment, family, workplace, and community contexts as they interact with SES, race/ethnicity, and health. The report notes that another largely unexplored topic is the way that psychosocial, biological, familial, community, and environmental risk factors can be utilized as potential targets for interventions designed to disrupt the negative effects of low SES or race/ethnicity on health.

**Behavioral Change Interventions to Diminish Racial/Ethnic Health Disparities** — OBSSR will examine current research on the availability, delivery, and effectiveness of barriers to intervention as a function of racial/ethnic group membership, as well as the mechanisms of intervention which best manage the health outcomes of particular ethnic or racial groups. OBSSR will develop initiatives to stimulate research on behavioral interventions for different ethnic/racial groups.

**Health Disparities and Health Care Systems** — Increased conceptual and empirical efforts are needed to identify and understand the processes leading to differential health care and to develop intervention strategies. The OBSSR plans to assess the state-of-the-science and develop an agenda for research on racial/ethnic group health differences and health care systems. The research initiatives arising from this assessment are likely to address gaps in both basic and intervention research on racial/ethnic group interactions with health care systems.

The OBSSR's plan also addresses the need for training and developing scientists. The office will increase its activities to expand the pipeline of minority researchers in behavioral and social sciences, especially students interested in research on health disparities. OBSSR is establishing goals to increase the number of scientists who study health disparities from a multidisciplinary perspective.

The plan also aims to improve NIH Public Health Messages. OBSSR will assess the state-of-the-science in communicating health information to diverse racial and ethnic populations. Working in collaboration with the ICs, OBSSR will organize a task force to review relevant communication theory and research and identify knowledge gaps in developing health communications for specific populations. If significant gaps are identified, the OBSSR, in collaboration with the Institutes and Centers, will develop an initiative to stimulate research in needed areas.

## **NIH PUBLIC REPS DISCUSS HUMAN SUBJECTS PROTECTIONS**

*November 6, 2000, Number20*

Human subjects research protections was the focus of the fourth meeting of the National Institutes of Health (NIH) Council of Public Representatives (COPR) held on the Bethesda campus October 31 through November 1, 2000. National Bioethics Advisory Commission (NBAC) representative Tom Murray, President of the Hastings Center, and the Department of Health and Human Services' new Office of Human Research Protection (OHRP) Director Greg Koski presented recommendations and directions for protecting human subjects in research.

## **HUMAN GENOME RESEARCH YIELDS OPPORTUNITIES FOR STUDY**

*November 20, 2000, Number21*

The National Human Genome Research Institute (NHGRI) “needs the social and behavioral science community,” according to Francis Collins, Director of the Institute. Speaking at the American Psychological Association’s annual meeting this summer, Collins said that NHGRI has not made the connection between the ethical, legal, and social implications (ELSI) surrounding human genetics and genomics research as vigorously as it needs to.

Acknowledging a role for social and behavioral scientists in genome research, Collins explained that human beings are 99.9 percent alike. The human species is “very young” and can be traced back to 10,000 folks in Africa, he added.

How are we going to get ready to practice genome medicine?, asked Collins. It is a huge challenge. He stressed that there are opportunities for the social and behavioral science community in human genetics and genomics research. He specifically highlighted the need for investigation into how people will react to genetic information in making medical decisions. Although some conditions revealed by genome medicine will require no action, others will prompt a lifestyle change or pharmaceutical intervention, Collins underscored.

All of us are at risk for something, explained Collins. We each have approximately 40 to 50 glitches in our DNA that put us at risk for disease. Although, many of these glitches may not be revealed, Collins argued that scientists do not know how people will react to the genetic information that is revealed about themselves or others. This presents an opportunity to do some interesting research, he emphasized.

Referring to the difficult and complex problem of information exchange between patients and their doctors, Collins emphasized that many physicians are not skilled at conveying such information. Similarly, many individuals receiving the information will not be able to “translate it into a quantitative schema,” he said. And the more we know, declared Collins, the more complicated things will become. On the other hand, he noted, genetic tests do not always give you bad news.

Collins explained that NHGRI has five percent of its budget (a major commitment on the part of the Institute) set aside to fund this kind of research. Social scientists, ethicists, biologists, chemists, engineers, and theologians all have a role to play in this enterprise. The potential is enormous, Collins concluded.

### **NHGRI’s ELSI Program**

Within NHGRI’s Division of Extramural Research resides the Ethical, Legal, and Social Implications (ELSI) Research Program. The program supports basic and applied research that identifies and analyzes the ethical, legal, and social issues surrounding human genetics research. The ELSI Research Program, established in 1990, is currently the largest federal supporter of bioethics research, with an annual budget of more than \$12 million.

Since 1990, the ELSI program has supported nearly 200 research and education projects and conferences. Activities supported by the project have ranged from relatively small historical, philosophical, and theoretical research projects and legal analyses of specific ELSI issues to large clinical studies designed to examine the efficacy of particular genetic testing or educational interventions. Principal investigators have come from a variety of disciplines, including philosophy, nursing, behavioral sciences, anthropology, history, law, genetic counseling, education, and consumer advocacy.

NHGRI's ELSI program has been organized around four research areas: (1) privacy and fairness in the use and interpretation of genetic information; (2) clinical integration of new genetic technologies; (3) issues surrounding genetics research; and (4) public and professional education.

In 1998, the ELSI Research Planning and Evaluation Group (ERPEG), the ELSI programs at the Department of Energy, and the NIH identified five new goals for the ELSI Research Program for 1998-2003. They are:

- 1) Examine the issues surrounding the completion of the human DNA sequence and the study of human genetic variation. This research will raise a number of unique ethical, legal, and social issues, many of which may be of special concern to individuals from diverse communities. According to NHGRI, these issues will become more acute if genetic variation research reveals data on the interactions between genotype, disease, and traditional, socially-constructed concepts of race, ethnicity, and culture.
- 2) Examine issues raised by the integration of genetic technologies and information into health care and public health activities.
- 3) Examine the issues raised by the integration of knowledge about genomics and gene-environment interactions into non-clinical settings.
- 4) Explore the ways in which new genetic knowledge may interact with a variety of philosophical, theological, and ethnic perspectives.
- 5) Explore how socioeconomic factors, gender, and concepts of race, ethnicity, and culture influence the use and interpretation of genetic information, the utilization of genetic services, and the development of policy.

For more information on NHGRI's new goals for the Human Genome Project (1998-2003), see the website: [www.nhgri.nih.gov/98plan/elsi](http://www.nhgri.nih.gov/98plan/elsi).

### **Research Gaps in ELSI Program**

Earlier this year, ERPEG released its report, "A Review and Analysis of the ELSI Research Programs at the National Institutes of Health and the Department of Energy," in which ERPEG identifies a number of areas requiring additional attention.

Regarding the issue of genetic discrimination, the group notes that the small amount of "rigorous empirical work on genetic discrimination in the ELSI research portfolio may turn out primarily to be a consequence of the fact there have been relatively few documented cases of genetic discrimination to date." Nevertheless, states ERPEG, "much more work needs to be pursued in this area." Additionally, more *empirical* work is needed surrounding the experiences of consumers and the attitudes of the general public with respect to "stigmatization" based on genetic status.

While the genetic research portion of the ELSI portfolio has generally been well balanced, the group notes, gaps exist in that area as well. The impact of economic and commercial interests on genomic

research and on the development of genetic tests has been largely overlooked. Other topics requiring additional attention, ERPEG states, extend to the ethical problems involved in the design of genomic research studies, how cultural factors influence the way genetic and genomic researchers design and carry out their studies, and how the genetic research enterprise is shaping cultural perceptions of genetics.

The group also identified a number of deficiencies in the education and resources portion of the portfolio. Despite the considerable efforts in ELSI-related education, the report notes that a lack of consensus remains regarding the basic question of what constitutes adequate knowledge of genetics. A major gap in the education and resources portion of the portfolio “is the absence of studies that examine such fundamental issues as what each audience (such as students, teachers, nurses, judges, and the lay public) actually needs to *know* about ELSI.” Additionally, the report recognizes that no research has been done to address other basic education issues, such as how various audiences learn genome-related content most effectively.

The report then considers genetic issues in a broader context, drawing attention to the lack of studies in the ELSI program that focus on the interactions between genetic issues and other aspects of the health care environment and society at large. The report emphasizes the under-representation of investigators from certain disciplines such as economics, cultural and physical anthropology, and religious and moral philosophy. The report states that “while some research topics . . . do not lend themselves as easily to broad, theoretical studies, a need still exists for greater cross-fertilization among ELSI researchers and for more involvement in ELSI projects by persons in disciplines that have traditionally been under-represented in ELSI research.”

ERPEG’S report highlighted another weakness of the ELSI research portfolio: very few of the principle investigators in funded projects have been members of minority racial or ethnic communities. While this is not unique to ELSI research, the report states, given the significant cultural and societal impact that genetic research and technologies may have on individuals and groups, it is important that the ELSI research programs strive for broader representation in the planning and implementation of their projects.

### **Solicitations for Research Applications**

To facilitate accomplishing the goals set for ELSI research, the NIH recently released three program announcements (PAs) encouraging research applications pertaining to ELSI. In the first program announcement, NHGRI, with eight of the NIH Institutes (Drug Abuse, Aging, Child Health and Human Development, Deafness and Other Communication Disorders, Environmental Health Sciences, General Medical Sciences, Mental Health, Nursing, and Neurological Disorders and Stroke), has reissued the program announcement (PA-00-133) seeking applications that “anticipate, analyze, and address the ethical, legal, and social implications of the discovery of new genetic technologies and availability and use of genetic information resulting from human genetics and genomics research.”

The second program announcement (PA-00-132) is supported by NHGRI and the Institutes of Aging, Drug Abuse, Deafness and Other Communication Disorders, and Mental Health. The announcement is designed to solicit small research programs that anticipate, analyze, and address the ethical, legal, and social implications surrounding the human genome project.

The third PA (PA-00-134) is aimed at “developing innovative educational approaches that increase knowledge and understanding of genetics and genomics research and its ethical, legal, and social implications.” Applications to the program are expected to focus on developing and evaluating new and innovative interventions that are designed to reach a large and diverse audience or that can be successfully exported to other institutions or learning environments.

NHGRI encourages inquires regarding these PAs. For general inquiries regarding program issues contact: The ELSI Research Program, NHGRI, Building 31, Room B2B07, 31 Center Drive, MSC 2033, NIH, Bethesda, MD 20892-2033; Tel: 301/402-4997; Fax: 301/402-1950; e-mail: [elsi@nhgri.nih.gov](mailto:elsi@nhgri.nih.gov); or see the NIH guide at: <http://grants.nih.gov/grants/guide>.

### **Postdoctoral Fellowships**

To develop the cadre of scientists needed to accomplish the goals of the Human Genome Project (HGP) and to use the knowledge, resources, and data that will be generated for further research, NHGRI is providing individual postdoctoral fellowships. The fellowships are designed to train scientists who will have multidisciplinary skills that will allow them to engage in research to accomplish the short- and long-term objectives of the HGP and similar genomic projects. Such training would allow these scientists to take advantage of the resulting genomic data and resources to solve biomedical and bioethical problems.

NIH encourages scientists and scholars at all career levels to apply for the fellowships. Individuals who have already completed one postdoctoral fellowship in another scientific discipline may be eligible for a waiver of the three-year limit on NRSA (National Research Service Award) support to allow the awarding of a postdoctoral fellowship in genomic or ELSI research if the additional training can be justified in the context of the individual’s future commitment to pursuing a career in genomic or ELSI research.

For more information regarding the fellowships, contact NHGRI staff: Joy Boyer ([joy\\_boyer@nih.gov](mailto:joy_boyer@nih.gov)), Elizabeth Thomson ([elizabeth\\_thomson@nih.gov](mailto:elizabeth_thomson@nih.gov)), or Jean McEwen ([jean\\_mcewen@nih.gov](mailto:jean_mcewen@nih.gov)).

### **“Decade of ELSI Research” Conference**

Finally, the NIH and the Department of Energy will hold a conference on January 16 -17, 2001 to celebrate a decade of ethical, legal, and social implications research. The conference is designed to provide an opportunity to reflect on the past, present, and future of ELSI research and consider its impact on research, health, and public policies and practices. For more information on the conference see: [www.tech-res-intl.com/ELSI/index.asp](http://www.tech-res-intl.com/ELSI/index.asp).

The Common Rule (the Federal Policy for the Protection of Human Subjects adhered to by 17 federal agencies and departments) is an albatross to change under an exceedingly difficult set of circumstances, said Murray. The Common Rule, he stressed, is “unsupple,” exemplified by the fact that it took many years for all of the agencies and departments involved to ratify it through a consensus process. To make even minor changes, he continued, is extremely cumbersome.

Murray told COPR members that while the Commission's recommendations regarding human subjects protections are still in draft form, they are the most ambitious recommendations NBAC has made to date. The Commission has released four other reports that discuss ethical challenges and make recommendations concerning specific issues. (see *Update*, October 9).

NBAC has tried to work around changing the common rule, explained Murray. The forthcoming NBAC report, "Ethical and Policy Issues in the Oversight of Human Participants Research," takes the Common Rule head on, he said. In part, he said, the report recommends establishing an independent office with jurisdiction over all research — public and private — that involves human subjects.

The major issues in the oversight project, Murray contends, are the adequacy of the current regulatory framework (including the Common Rule) and the adequacy of the local oversight system of IRBs.

According to Murray, the Commission is considering other specific issues, including analysis of risk and potential benefit, informed consent, privacy and confidentiality, vulnerability, education, monitoring, cooperative research review, accountability mechanisms, and resources.

Some of the key features of the oversight system NBAC is proposing include: a new framework for analysis of "vulnerability;" compensation for research injuries (an issue that has been unresolved for the last 25 years); education of IRB members and investigators in the ethics of human subjects research; increased representation of non-experts and unaffiliated members on IRBs; accreditation of institutions; and greater scrutiny of protocols with high or unknown risk.

Although much of human subjects research is innocuous, Murray explained, educational, social, and behavioral science research is subject to the same intensity of protocol and attention from IRBs.

### **HHS: The Appropriate Home for OHRP?**

Koski differed with NBAC's recommendation for the creation of a new entity outside the Department of Health and Human Services, noting that "HHS is the appropriate home for such an office." He added that there is not a lot of enthusiasm for the creation of a new federal agency. Koski emphasized that OHRP's jurisdiction is broader than many realize and would apply to the private sector.

Echoing many of the comments he made in his presentation before NBAC, Koski explained that the system of funding research has changed significantly since the system was set up 30 years ago (see *Update*, September 25, 2000). Then, most of the research was done by the NIH. The system has not evolved to keep up with change, stressed Koski. The largest sponsor of research now, he continued, is the pharmaceutical industry. That is not bad, he added — just different.

The current system, Koski remarked, was built on respect, benevolence, and justice. Unfortunately, in an environment of limited resources, one gives only what is necessary to meet the minimum obligation. We do not want to provide only the minimum required protection to human subjects, Koski declared, but it is an artifact of the system.

Koski again emphasized the need for a conceptual change, where everyone is engaged and embraces the system. The current system is based on compliance and confrontation. IRBs have been placed in the role of the “worthy adversary.” We provide a mechanism that allows the parties involved to say it is not my problem, he remarked. Furthermore, the system is based on impartiality, assuming that the members of the IRBs will forget that their background can color their discussions. We need to reconsider how we construct the process, said Koski.

### **What Is the OHRP Doing?**

Koski told COPR members that the key to changing the system is to remove the IRBs from their position between the subjects and the investigators. He questioned the way that IRBs are constituted and whether the system for forming IRBs was adequate. Human subjects protection needs to mimic that of the medical research system, he claimed, with apprenticeship and proper training. Koski applauded NIH for its initiation of specific training in bioethics as a step in the right direction.

OHRP, with the support of the NIH, the Food and Drug Administration, the Centers for Disease Control and Prevention, and the Agency for Healthcare Research and Quality, will engage the Institute of Medicine (IOM) to recommend uniform, performance-, and resource-based standards for private, voluntary accreditation of human research review boards, said Koski.

The IOM is expected to complete the report by April 1, 2001. After the accreditation standards have been created, the IOM will also be asked to conduct a study of the human research system to determine the extent to which the issues raised by the Department of Health and Human Services Office of the Inspector General and the recommendations of the forthcoming NBAC report are addressed. The IOM will also be asked to develop objective criteria for measuring the effectiveness of the system for protection of human subjects in research. These criteria will then be used on an ongoing basis for continuing assessment of the system.

Koski concluded his remarks by informing the COPR that his office is in the final stage of selecting the individuals to serve on the newly established National Human Research Protection Advisory Committee (NHRPAC) which will hold its inaugural meeting in December.

NBAC has held a number of public meetings to discuss the issue and receive input from the public. Transcripts of all of its meetings can be found on the NBAC website: [www.bioethics.gov](http://www.bioethics.gov). Information regarding OHRP can be found at [www.hhs.gov](http://www.hhs.gov).

### **LAME DUCK, POST-ELECTION WRANGLING CONTINUE**

*December 11, 2000, Number 22*

On December 8, Congress passed and the President signed the 18<sup>th</sup> Continuing Resolution to keep the government operating for three more days in the now over two-month-old Fiscal Year 2001. On December 11, the same ritual will result in the 19<sup>th</sup> Continuing Resolution. All hope it will be the last.

With the Republicans anticipating a George W. Bush presidency, they have emboldened themselves to challenge some of the waning Clinton administration's prerogatives on the four remaining appropriations bills that need enactment before the 106<sup>th</sup> Congress becomes history. Most prominent is the GOP's attempt to reduce the Labor, Health and Human Services, Education spending bill by \$6 billion from the level nearly agreed to by both parties before the election. The various schemes for achieving this cut could impact the National Institutes of Health's (NIH) presumed 15 percent increase and reduce appropriations for Clinton's education initiatives.

The Commerce, Justice, State and the Judiciary spending bill remains under discussion while the administration and Congress try to agree on provisions affecting immigration. Once again, emboldened Republicans are forcing the lame-duck administration to reconsider its earlier positions. Once these two bills are worked out, the Legislative Branch and Treasury, Postal Service bills will be signed by the President and, perhaps, Congress will adjourn. A tax bill and changes in Medicare and Medicaid are also in the works as the lame-duck session enters its second week.

At the same time the 106<sup>th</sup> Congress tries to finish up, preparations for the 107<sup>th</sup> Congress are underway. Senate leaders Trent Lott (R-MS) and Tom Daschle (D-SD) continue to meet and try to figure out how a Senate divided 50-50 will work (once again assuming a Bush presidency). The Democrats want power-sharing. At the moment, they are calling for co-chairmanships, equal representation, equal staffs on committees, and certain privileges regarding floor scheduling and activity. The Republicans, assuming a Cheney Vice Presidency, proclaim that, as tiebreaker, he gives them majority status and thus power sharing should be limited at best.

In the House, barring any changes in recounts or party-switching, the lineup will be 221 Republicans and one Republican-leaning Independent, and 212 Democrats and one Democratic-leaning Independent. In addition to keeping their majority for the fourth straight Congress, the Republicans maintained their rule, instituted in 1995, to limit Committee and Subcommittee Chairs to three terms. Thus, the "musical chairs" reorganization of leadership positions will create new power centers and shift old relationships. In addition, the resulting contests for committee chairmanships on the GOP side could leave a bitter taste in the losers' mouths that may have policy implications.

This unique situation is spurring calls for bipartisanship. A number of members of both the House and Senate, mostly those who call themselves "moderates," are meeting to form groups that proclaim the need for bipartisan solutions to problems. They hope to forge working relationships that will transcend any partisan bitterness left from the presidential contest and the close divisions in the party makeup of the two Houses. Their chances of success may depend on their ability to isolate the ideologues in both parties, including House Majority Whip Tom DeLay (R-TX), who has spent the last few weeks declaring the dominance of the GOP in America and his desire to enact a Continuing Resolution to last the rest of the fiscal year, which would keep many agencies, including NIH, at last year's funding levels.

## **PORTER HONORED BY HEALTH AND EDUCATION COMMUNITY**

*December 11, 2000, Number 22*

Representative John Edward Porter (R-IL), chair of the House Labor, Health and Human Services and Education Appropriations Subcommittee (Labor-HHS) urged the research community to push

Congress and the White House towards resolution of the Labor-HHS appropriations bill. Porter made the appeal at a December 1 reception held in his honor. Porter, an ardent and consistent supporter of biomedical and behavioral research and an instrumental force in the drive to double the budget of the National Institutes of Health (NIH) over a five-year period, strongly encouraged the packed room of advocates, legislative staff, and federal agency staff to “impact this process as we have never before.”

After two decades in Congress, Porter is leaving Capitol Hill (see *Update*, October 25, 1999). Porter informed the crowd that he “does not intend to retire,” but to remain very much involved. His goal, he announced, is to continue work on issues important to America — health, research, and education. He emphasized that he is seeking to move to a place where he can continue to work with the research community. There are so many important issues that remain on the table, Porter observed. This is not the time to let the guard down or slack off, he remarked.

The conference report on the Labor-HHS bill, explained Porter, was completed in July. He expressed his “great worry” that the bill will “continue to drift.” It would be a “disaster for our country”; we cannot allow that to happen, Porter declared. Porter noted his meeting with the chair of the Senate Appropriations Committee, Ted Stevens (R-AK), who said he shares his commitment to see that Congress passes the Labor-HHS bill.

Concluding his remarks, Porter emphasized that while there are good people coming to the 107<sup>th</sup> Congress, they do not necessarily know the things they need to know about health policy; they need to be educated, said Porter. He urged the science community to reach out to them.

## UPCOMING EVENTS . . .

On January 29 - 30, the National Institutes of Health (the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute of Mental Health, and the Office of Behavioral and Social Sciences Research) are sponsoring a conference, *Depression and Mental Disorders in Patients with Diabetes, Renal Disease, and Obesity/Eating Disorders*, to highlight the fact that major depression and mental disorders are more common in patients with chronic diseases than in the general population. The conference will address gaps in current knowledge and develop recommendations for future research. For more information, contact Maria Smith of TASCOS, Inc. at 301/315-9000 or msmith@tascon.com.