

**FORMER COSSA PRESIDENT NAMED  
MEDAL OF SCIENCE WINNER** HS

William Julius Wilson, Malcolm Wiener Professor of Social Policy at the John F. Kennedy School of Government, Harvard University and a former President of COSSA and the American Sociological Association, was named by President Clinton on December 8 as one of nine winners of this year's National Medal of Science. Wilson was cited for his "pioneering methods of interdisciplinary social science research that have advanced understanding of the interaction between the macroeconomic, social structural, cultural, and behavioral forces that cause and reproduce inner city poverty." In announcing the awards President Clinton said, "By sustaining our investments in science and technology, we ensure that America remains at the forefront of scientific capability, thereby enhancing our ability to build a better America for the twenty-first century."

**OMB PONDERES DATA SHARING RULES**

The Congress has given the Office of Management and Budget (OMB) the task of revising data sharing policies on federal grants. The Omnibus Appropriations bill approved in October included a provision that orders OMB to revise Circular A-110 "to require federal awarding agencies to ensure that all data produced under an award will be made available to the public through the procedures established under the Freedom of Information Act (FOIA)." OMB is expected to issue a Notice of Proposed Rule Making in early January that will be open to public comment before a final rule is issued.

Circular A-110 sets rules and regulations governing grants and agreements with institutions of higher education, hospitals, and other non-profit agencies. The Freedom of Information Act provides procedures for individuals to gain access to federal agency information. It grants nine exemptions that

allow agencies to protect information including: national security, trade secrets and commercial or financial information, "personnel and medical files and similar files the disclosure of which would constitute a clearly unwarranted invasion of personal privacy." A whole body of case law has been built up interpreting these exemptions.

The provision in the Omnibus bill culminated an effort by Congressional Republicans, concerned about scientific studies used to promulgate regulations by federal agencies, to gain access to the data from these studies. In 1997, Republicans in the House led by Representative Robert Aderholt (R-AL) tried to insert a provision into the Treasury, Postal Service Appropriations bill to require most researchers with government grants or contracts to make public their raw data. His amendment was defeated. Aderholt's proposal arose after a strong debate over new EPA air pollution rules. Industry groups had been denied access to raw data from a study conducted by Harvard University scientists that helped EPA determine the new rules. EPA claimed it did not have the data. Harvard refused to turn them over to the agency based on the claim that subjects' medical histories and lifestyle habits, as well as death records from state and local agencies were collected

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and thus protected by confidentiality. In another case, the National Rifle Association sought data from a federally funded study on the risk of death in homes with guns from the Centers for Disease Control and Prevention.

Under Aderholt's proposal data would have been released "not later than 90 days after the date of the first public use of the research." Exceptions would have included proprietary information and the portion of the information that would constitute a clearly unwarranted invasion of personal privacy, as well as a national security exclusion for the Department of Defense and defense-related Department of Energy research. The Aderholt proposal was opposed by scientists concerned about the possible political misuses of their data.

In this year's discussion, Senate Republicans pointed out that Circular A-110 already states that unless specifically waived, federal agencies "have the right to obtain, reproduce, publish or otherwise use the data produced under an award." Senator Richard Shelby (R-AL) complained that these policy directives are not being implemented on a systematic basis and sponsored the new provision calling for the extension of FOIA. The Senate Committee report did note that NASA, the Public Health Service, and NSF currently implement data sharing policies in order to permit wider assessment of the validity of the

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The Consortium of Social Science Associations (COSSA), an advocacy organization for federal support for the social and behavioral sciences, was founded in 1981 and stands alone in Washington in representing the full range of social and behavioral sciences. *UPDATE* is published 22 times per year. Individual subscriptions are available from COSSA for \$65; institutional subscriptions, \$130, overseas mail, \$130. ISSN 0749-4394. Address all inquiries to COSSA, 1522 K Street, NW, Suite 836, Washington, D.C. 20005. Phone: (202) 842-3525, FAX: (202) 842-2788. <http://members.aol.com/socscience/COSSAindex.htm>

research results and to facilitate broader public understanding. The report also noted, however, that other federal agencies do not.

Given the prevalent use of Government research data in developing regulations and federal policy, the Committee declared "it is important that such data be made available to other interested federal agencies and to the public on a routine basis for independent scientific evaluation and confirmation." Majority Leader Trent Lott (R-MS) on the Senate floor said, "This provision represents a critical step forward in assuring that the public has access to the research and underlying data used by the federal government in developing policy and rules."

#### Concerns

The Office of Science and Technology Policy raised a number of issues in a background paper on the new requirements. OSTP expressed concern that "this provision has the practical (if not necessarily legal) effect of transforming all research data produced under a federal grant into federal records." If OMB agrees with this analysis the impacts, according to OSTP, could be significant:

— The provision could impose a significant and expensive burden on NSF, NASA, DOD, and NIH — indeed, every granting agency — by requiring them to process FOIA requests for research data. It will also place unprecedented legal burdens on universities, investigators, and federal agencies to maintain repositories of federally-funded research data.

— It undermines the traditional "right" of scientists to use unique research results or data sets for multiple papers by forcing researchers to make their raw data public. (Note that the bill might even require researchers to make data public before they have published anything, or force the disclosure of on-going clinical trials.) This will have a chilling effect on anyone doing federally-funded research.

— Under federal procurement law, the government does not own the research produced under grants and the results of such research are not considered government records for the purposes of FOIA. This

provision casts legal doubt on the issue of ownership of federally-funded data.

— The history of the provision assumes that research data can easily be made electronically available, but the broad scope of the language could include items which cannot be digitized, such as cultures, mice, tissue samples, etc.

— Finally, some scientists are concerned that the provision can be used as a tool to harass researchers whose work is seen as being threatening by economic or political interests. The history of the provision suggests that the scope is intended to reach to raw, unpublished data — perhaps even down to the level of bench notes and individual records maintained by the principal investigator receiving the grant.

Wendy Baldwin, Deputy Director for Extramural Research at NIH, has also expressed concerns about how OMB might interpret the congressional mandate. Among the questions the new rules will need to address, according to Baldwin, are:

How will data be defined? How will FOIA exemptions for “predecisional” materials and confidential information be construed with respect to research data? What data should be made available? If the event that triggers data release is “publication,” does a poster session or a Power Point presentation constitute “publication?” Does publication of a portion of the data make all the researcher’s data subject to release? If the government has provided only a small portion of the research project’s funding, is the public entitled to disclosure of all the project data? How will grantees be reimbursed for the costs of preparing data for public release? Will there be protections against the use of repeated and burdensome FOIA requests as a method of harassing federal agencies and individual researchers.

### Sharing Research Data

In 1985 the National Academy of Sciences issued a report: *Sharing Research Data*. Its most general recommendation was, “[s]haring data should be a regular practice [because] the advantages of data sharing are sufficient to warrant considerable attention to ways to share data without imperiling privacy or breaching confidentiality promised to data

providers.” The Academy also recommended that “[i]nvestigators should share their data by the time of publication of initial major results of analyses of the data except in compelling circumstances.”

Furthermore, the Academy noted that “[d]ata relevant to public policy should be shared as quickly and widely as possible, [but not] prior to appropriate review.”

Science has operated on the principle that studies should be available for replication and verification. The development of data archives has provided opportunities for secondary analyses of data sets and previous investigations and discoveries. Progress in science is the constant refining and reanalysis of results, sometimes based on old data that leads to new discoveries. What makes this new congressional requirement murky are the practical considerations and difficult questions that must be answered balancing the public’s right to know with various protections for scientists, subjects and respondents, and others involved in creating the information? It is a gray area that scientists, journalists, and decision-makers confront every day. We shall see what OMB produces.

### AGING INSTITUTE NAMES SUZMAN TO HEAD BEHAVIORAL AND SOCIAL RESEARCH; ABELES JOINS OBSSR AS

The National Institute on Aging (NIA) has named Richard M. Suzman, Associate Director for Behavioral and Social Research (BSR). The appointment became effective September 13<sup>th</sup>. Suzman, who has a distinguished career in social and behavioral science, specifically in the demography and economics of aging, most recently served as chief of NIA’s Demography and Population Epidemiology Unit, Director of the Office of the Demography of Aging, and architect of NIA’s Economics of Aging program. Suzman has directed the development of the Health and Retirement Study, the Longitudinal Study of Aging, and the National Long Term Care Survey all of which have improved our understanding of health, demographic, and economic aspects of aging.

Suzman has also served as staff director for the Federal Forum on Aging-Related Statistics, which is charged with ensuring the quality of statistical efforts government-wide. Prior to joining NIA in 1985, he held academic research positions at the University of California at San Francisco and Stanford University. He received his undergraduate degree from Harvard, a diploma in social anthropology from Oxford University and Masters and Doctoral degrees in social psychology from Harvard. He was a postdoctoral fellow at Stanford University.

Former Acting BSR Director Ron Abeles has become a Special Assistant to Norman Anderson, Director of the NIH Office of Behavioral and Social Sciences Research (OBSSR). In this new capacity, Abeles will assist Anderson in "fostering the OBSSR's mission to stimulate and coordinate behavioral and social sciences research throughout the NIH." In addition, Abeles will continue some of his program development activities within the BSR Program at NIA. His efforts will be devoted mostly to the Personality and Social Psychology of Aging Section within the Adult Psychological Development Branch.

#### COURT HEARS CENSUS DISPUTE DH

The Supreme Court on November 30<sup>th</sup> heard arguments for and against the proposed use of statistical sampling in the upcoming census. The Court's decision, not expected for several months, could affect the political composition of the House of Representatives and many state legislatures in the next decade. Until then, the Census Bureau will continue the dual-track planning for both a sampling- and non-sampling census.

United States Solicitor General Seth Waxman, representing the Administration, argued that the Census Bureau's plan to use sampling in 2000 would provide much more accurate information about the nation's population by addressing the persistent undercount. Maureen Mahoney, representing House Republicans opposed to the plan, argued that the Constitution does not provide for the use of sampling, but an "actual enumeration."

Several justices questioned the legal standing of the House of Representatives to bring the lawsuit to Court. If the Court decides that the House does not have legal standing and dismisses the case, an interesting dilemma arises. Will the Census Bureau follow through with its plan to use statistical sampling given the possibility that the numbers could be invalidated if the House of Representatives challenges the use of sampling in a new lawsuit? Will Congress cut off funding for the Census Bureau and the Departments of Commerce, Justice, and State on the June 15<sup>th</sup> deadline stipulated in the omnibus appropriations bill, to prevent the use of sampling in 2000 (See *UPDATE*, October 26)?

#### FORUM ON ADOLESCENCE WORKSHOP AS

On November 9-10, the Forum on Adolescence, a "new cross-cutting activity of the Institute of Medicine and the National Research Council (NRC)," held a workshop, *Research to Improve Intergroup Relations Among Youth*. The event showcased the findings of 16 research projects, funded by the Carnegie Corporation of New York, that have focused on intergroup relations among youth. COSSA President Eleanor Maccoby serves as a liaison to the Forum on Adolescence.

Participants presented findings from their research on cultural values and ethnic identity; racial attitudes, tolerance, and prejudice reduction; and strategies to promote intergroup relations among young people. They also discussed the policy and programmatic implications of their research findings as well as identified gaps in the research knowledge base. Proceedings of the workshop will be available in the coming months and will include a discussion of how the Forum can advance the research.

Established in October 1996, the Forum's "overarching mission is to synthesize, analyze, and evaluate scientific research on critical national issues that relate to youth and their families, and disseminate research and its policy and programmatic implications." For more information contact Michele D. Kipke, Director, Board on Children, Youth and Families at 202/334-1937 or <http://www.nas2.edu/bocyf>.

## NIDA HOLDS 5<sup>TH</sup> ANNUAL CONSTITUENT CONFERENCE

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On December 1 -2, the National Institute of Drug Abuse (NIDA) held its fifth annual constituent conference. The annual conference allows NIDA and these organizations to build upon the relationships developed over the years and "affords an opportunity for constituent groups to discover new ways to collaborate with NIDA and among themselves." NIDA Director Alan Leshner said the conference is a "major mechanism" that allows the Institute to respond to the field. It also provides NIDA with "the opportunity to present its latest science-based research and information."

Each year, NIDA prepares a "Report Card" that "illustrates how the Institute has acted in response to the organizations' recommendations from the preceding year." Several core issues: collaborative efforts, children and adolescents, HIV/AIDS, special populations, treatment, prevention, education and information disseminations are recurring themes. New and additional issues in which the Institute's constituents have expressed an interest include: vulnerability to addictions, basic research and initiatives addressing the Nation's methamphetamine crisis, and nicotine addiction.

Highlights of the 1998 Report Card include:

### Collaborations

•NIDA is a cosponsor with other NIH Institutes of the Program Announcement "Methodology and Measurement in the Behavioral and Social Sciences," issued on June 30, 1998. This announcement is intended to encourage research to improve the quality and scientific power of data collected in the behavioral and social sciences, relevant to the missions of the NIH Institutes and Centers.

### Dissemination of New Materials

•*Drug Abuse Research and the Health of Women* and its companion *Executive Summary* were posted on the NIDA Web site in June. The national conference covered in these volumes brought together leaders in women's health who addressed the issues of drug abuse by women from historical, epidemiological, biological-behavioral, and legal perspectives.

### Children and Adolescents

•The NIDA Child and Adolescent Initiative is an ongoing, comprehensive set of activities designed to strengthen the Institute's child and adolescent research base and at the same time increase the interchange of useful information among researchers, practitioners, and the general public. Specific activities include solicitation and support of needed research, dissemination of electronic and print information, conduct of scientific meetings to advance the field, and promotion of research training. All NIDA Divisions and Offices, as well as several of the NIDA workgroups, are addressing components of the Initiative.

### Improving Behavioral and Pharmacological Addiction Treatments for Adolescents

•Because people are using drugs at younger and younger ages and developing addiction in middle or late adolescence, rather than adulthood, there is a need for development of new treatments focusing specifically on the special circumstances of adolescents patients. Research supported by NIDA includes research on pathways to drug addiction which emphasizes the importance of both risk factors and protective factors that influence a young person's progression from experimentation with drugs to drug abuse and addiction.

### Expanding NIDA's Behavioral Therapies Development Initiative

•NIDA is launching a new initiative to stimulate research, based on emerging basic behavioral/psychological research findings, on the development of creative new therapies for drug use disorders and innovative behavioral approaches to HIV risk reduction in drug-abusing populations. This research ultimately involves translation of ideas from basic behavioral/psychological science into clearly defined behavioral interventions.

### Prevention

•*Cost-Benefit/Cost-Effectiveness Research of Drug Abuse Prevention: Implications for Programming and Policy* (NIH Publication No. 98-4021) is a new NIDA research monograph that presents a practical framework for evaluating cost and benefits of science-based drug abuse prevention programs for school-age youth at risk for drug abuse. The volume is designed to help bridge the gap between prevention

science and practice by providing salient data on the costs of drug abuse to society and the benefits of adopting science-based drug abuse prevention programs at the State and community levels.

#### Basic Research

•NIDA is also part of a trans-NIH initiative in the creation of National Mind/Body Centers of Research. The initiative is led and supported by the OBSSR, per a congressional mandate. Three areas of mind/body research will be emphasized: (1) exploring the impact of beliefs and attitudes on physical health, or biological functioning; (2) determinants or antecedents of health-related beliefs or attitudes; and (3) behavioral or social stress management interventions for physical illness and/or biological functioning.

#### NIH ADVISORY COMMITTEE *AS*

Addressing the 77<sup>th</sup> Meeting of the Advisory Committee to the Director (ACD) of the National Institutes of Health (NIH) held on December 3, NIH Director Harold Varmus noted that the 105<sup>th</sup> Congress had not addressed a number of legislative issues of concern to the NIH. These issues include Circular A-110, "a potential burden or threat" which could possibly extend the Federal Freedom of Information Act to extramural grants. Such an extension, noted Varmus, opens the possibility that scientists might have to turn over "any data at any stage" in response to a request to the agency that funded their work (See story on page 1).

Varmus mentioned several areas that received no Congressional attention, including: NIH reauthorization [NIH was last reauthorized in 1993], confidentiality of medical records, genetic discrimination, tobacco legislation, clinical research, and the issue of loan repayment for extramural scientists in hard to recruit areas.

#### Nominations for NIH Council of Public Representatives

The NIH is seeking nominations for membership on the NIH's Director's Council of Public Representatives (COPR). The search is in response to the Institute of Medicine (IOM) report, *Scientific*

#### *Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health (NIH).*

Anne Thomas, Associate Director for Communications, told the ACD that COPR will "serve as a forum for discussing issues and concerns and exchanging viewpoints important to NIH policies, programs, and research priorities." The new advisory group, said Thomas, is being designed to "help bring to the NIH the concerns and interests of the many external publics that have a stake in the agency's activities, programs, policies, and research."

The COPR will consist of up to 20 individuals and will meet approximately twice a year. Other activities may be suggested by the group, subject to the approval of the NIH Director, who will serve as the Chair of COPR. Members of the first COPR will serve one, two, or three-year terms." Subsequent terms will be three years. Final selections will be made by the NIH Director. The first COPR meeting is planned for late April 1999. For more information contact Anne Thomas or Laura Vazquez at the NIH: 301/496-4461.

#### NIH REVIEWERS NEEDED *AS*

The National Institutes of Health (NIH) Center for Scientific Review (CSR) is urgently seeking scientists with expertise in biobehavioral and social sciences to serve as Scientific Review Administrators (SRA) in the management of NIH's peer review process. Interested individuals with research experience in one or more of the following areas: psychology, sociology, developmental science, cognition and perception, behavioral medicine, language and communication, mental health, substance abuse, demography, anthropology, rehabilitation and prevention, should contact Anita Miller Sostek, National Institutes of Health, Center for Scientific Review, 6701 Rockledge Drive, Room 5202, MSC 7848, Bethesda, MD 20892-7848, Email: scirev@drq.nih.gov.

## NIMH'S CALL FOR REVIEWERS IS A DEPARTURE FROM THE NORM AS

The National Institute of Mental Health (NIMH) is seeking persons "who have had personal experience with mental disorders — as a patient, family member, service provider, policy maker, or educator" — to participate in the review of grant applications for treatment and services research.

A workgroup of the National Advisory Mental Health Council recommended such a modification in the traditional review process to allow public participants in the initial review. In the past, the initial review was conducted by a Scientific Review Group made up of individuals with demonstrated academic or research expertise in the scientific area under consideration. The purpose of the initial review is to address the scientific merit of the review. The call for individuals with personal experiences with mental disorders is a departure from the past procedure of including only researchers or persons with expertise in a particular field.

## GENOME INSTITUTE DEVELOPS 5 YEAR PLAN: SOCIAL SCIENCES EMPHASIZED AS

The National Institutes of Health and the Department of Energy (DOE) have developed a new five-year plan for the U.S. Human Genome Project (HGP). The plan is designed to carry the genome project forward for the next five years, fiscal years 1999-2003.

Included in the plan are five new goals for the ELSI (Ethical, Legal and Social Implications) Research Programs at the National Human Genome Research Institute (NHGRI) and DOE. NHGRI Director Francis Collins emphasized that "[w]hile recognizing that genetics is not the only factor affecting human well-being, NIH and DOE are acutely aware that advances in the understanding of human genetics and genomics will have important implications for individuals and society." Accordingly, the examination of the ethical, legal, and social implications of genome research, he said, is "an integral and essential component" of the human genome project (HGP).

The major ELSI goals for the next five years:

1. Examine the issues surrounding the completion of the human DNA sequence and the study of human genetic variation.
2. Examine the issues raised by the integration of genetic technologies and information into health care and public health activities.
3. Examine issues raised by the integration of knowledge about genomics and gene-environment interactions into nonclinical settings.
4. Explore ways in which new genetic knowledge may interact with a variety of philosophical, theological, and ethical perspectives.
5. Explore how socioeconomic factors and concepts of race and ethnicity influence the use, understanding, and interpretation of genetic information, the utilization of genetic services, and the development of policy.

"The HGP has created the need for new kinds of scientific specialists who can be creative in the interface of biology and other disciplines such as computer science, engineering, mathematics, physics, chemistry, and the social sciences," noted Collins. He also stressed an "urgent need to train more scientists in interdisciplinary areas that can contribute to genomics . . . Another urgent need is for scholars who are trained to undertake studies of the societal impact of genetic discoveries. Such scholars should be knowledgeable in both genomic-related sciences and in the social sciences." For more information, consult the NIH Webpage: <http://www.nih.gov>.

## EDITOR'S NOTE

This is the final issue of *UPDATE* for 1998. The next issue — the first 1999 issue of *UPDATE* — will be published on January 8<sup>th</sup>. COSSA has compiled a comprehensive index of the past year's *UPDATE*. If you are interested in obtaining a copy, please contact us. The staff at COSSA wishes everyone a happy holiday season and a joyous new year.

 Happy Holidays 

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