# COSSA WASHINGTON UPDATE

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## RESEARCH INVOLVING MINORS BILL REVISED

Responding to the concerns of researchers and federal officials, a House panel revised legislation that witnesses at a recent congressional hearing said would have a deleterious effect on social science research. The committee deleted a provision mandating written parental permission for eight categories of research questions involving minors. As the bill moves to the House floor the week of April 3, an amendment may be offered to restore the written permission requirement.

A week after receiving testimony from Lloyd Johnston of the Institute for Social Research at the University of Michigan, Sally Katzen, Administrator of the Office of Information and Regulatory Affairs at the Office of Management and the Budget, and William T. Butz, Associate Director of the Demographic Programs at the Census Bureau, Rep. Steve Horn (R-CA), chairman of the House Subcommittee on Government Management, Information, and Technology unveiled changes to H.R. 11, the "Family Protection Act." Horn, who holds a Ph.D. in political science, drafted a bill with bipartisan support, H.R. 1271, that revised H.R. 11 by:

- · deleting the word "written;"
- clarifying language by replacing "analysis or evaluation" with "questionnaire;"
- · allowing the States to define who a "minor" is;
- providing exceptions to the prior-consent language in matters of criminal investigation or adjudication, health and safety or welfare, customs or immigration and internal revenue, as well as financial assistance and academic performance testing; and
- assuring confidentiality for participants.

The changes were adopted by Horn's subcommittee on March 22 and on the following day by the full Government Reform and Oversight Committee. During discussion of the bill, Rep. Mark

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### WALKER AND BROWN MEET WITH PCAST: DEPARTMENT OF SCIENCE ADVOCATED

The current and former chairs of the House Science Committee met with the President's Committee of Advisers on Science and Technology (PCAST) on March 28. Rep. Robert Walker (R-PA) and Rep. George Brown (D-CA) discussed current issues with the 19 member group, co-chaired by Presidential Science Adviser John Gibbons and former Hewlett-Packard CEO John Young.

Introduced by Gibbons as a "real champion" of science, Walker noted that the drive toward a balanced budget severely limits his ability to aggressively pursue some policy options. As Vice-Chair of the House Budget Committee, Walker is in an important position to consider the ramifications on science of proposed budget reductions. The chairman stated that supporting scientific research will remain a fundamental role of government. Repeating his preference for basic science, he claimed this did not mean he favored the end of government sponsored applied research.

Walker announced that the House Budget Committee will likely recommend the abolition of four Cabinet departments: Energy, Commerce, Education and HUD. With the elimination of the first two, Walker will revive the idea of a Department of Science, something he has favored for a long time. Walker said he and his staff are currently examining

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## **CENSUS BERATED AT HOUSE** HEARING: MERGER OF **AGENCIES ADVOCATED**

Commerce Department officials received a browbeating from the visibly angry chairman of the House panel that oversees funding for the Census Bureau. At the March 16 hearing held by his Commerce, Justice, State Appropriations Subcommittee, Rep. Harold Rogers (R-KY) sharply criticized the cost and content of the decennial survey and also advocated consolidation of federal statistical agencies.

In chiding the 1990 Census, Rogers noted that his state of Kentucky lost a congressional seat "because of the ineptitude of the Census Bureau" and that despite the record cost of that survey, the agency "still can't produce a count two people can agree on." He said that he has "grave concerns" about the 2000 Census, which he said is "heading down the same pike as 1990." Rogers acknowledged the importance of quality data, but said it must be weighed against the cost of collecting it.

The chairman expressed his long-held view that the Census be conducted on the back of a postcard. While mockingly reading questions from the 1990 short form (what time do you leave for work appeared to be a personal favorite), he repeatedly asked Commerce Department Undersecretary for Economic Affairs Everett Ehrlich and Census Bureau Director

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Martha Farnsworth Riche why such questions were on the form. They cited specific statutes for each one, but it was unclear whether the data must be obtained through the decennial census. Both promised a more detailed response in writing for the subcommittee.

Discussing the questions he read aloud, Rogers said that his subcommittee would not provide funding for a survey of that nature and, turning to the Commerce Department officials said, "you're ruining this census." Rogers threatened that his subcommittee would create the 2000 questionnaire if the Census Bureau did not do it properly. He called for a form that was "pure, simple, and patriotic."

Rogers faulted the design of the questionnaire, which he said was at the root of the non-response issue. He termed it the product of "somebody who has a doctoral degree in confusing people" and that Sears or Wal-Mart could do a better job. He repeatedly referred to the census form as "junk mail" and "trash." Holding up a copy of the twenty page long form questionnaire, received by one in six potential respondents, he said, "you couldn't pay me to fill this out."

After being told to "get some simple forms people won't throw in the trash," Riche concurred with the chairman's suggestion to approach an outside marketing firm to redesign the questionnaire for 2000. She added that the Bureau will conduct extensive content research in 1996, but that prior studies have shown that the length of the form was not a significant factor affecting response rates.

Both Ehrlich and Riche expressed understanding of Rogers' concerns and pledged cooperation with the Subcommittee on these issues. In their statements before the panel, each cited specific actions the Census Bureau has taken to address the past concerns of the Subcommittee regarding costs and content as well as fiscal management at the Bureau.

## Merger of Data Agencies Urged

Both Rogers and panel member Rep. Michael Forbes (R-NY) advocated the consolidation of 14 federal statistical agencies into one agency in the hopes of achieving cost savings and efficiency, as well as reducing burden on respondents through bundling multiple topics in surveys. Rogers said that in an age of sweeping technological change, the structure of the

federal statistical system is in the "Model T era."

Forbes commented that the spirit of reinventing government is often offset by bureaucratic turf battles and a lack of coordination and cooperation between agencies.

Ehrlich, while acknowledging some merit to the proposal, declined to take a formal stance, saying that the Office of Management and Budget is currently studying the issue and hopes to reach a decision by the end of the year. He said the benefits of consolidation could be offset by logistical problems in a "significant bureaucratic undertaking."

#### **RESEARCH ON MINORS**

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Souder (R-IN) expressed his strong support for legislation that will protect minors and families from having to answer embarrassing or offensive questions. "I have recently felt this at a personal level--both my daughter and son were asked to respond to a survey, and we received no advance notification, " Souder reported. Without identifying the study, Souder read aloud a list of sexual behavior questions to which he objected because "these questions suggest to minors that it is normal to do the behaviors addressed in the questionnaire." He also cited that "it can be humiliating for students because of peer pressure to opt out of a study unless schools are sensitive to the issue."

While the full committee sent the bill to the House floor without any amendments to the revised legislation, Rep. Gene Green (D-TX) expressed concern regarding the elimination of the word "written." While not opposing H.R. 1271, he stated that "some clarification should be spelled out in report language accompanying the bill." While report language does not have the force of law, as an expression of congressional intent it is weighed heavily when agencies formulate implementation rules.

For more information, see the March 20 issue of Update or contact Susan Persons at COSSA.

## NIH FACES CONGRESSIONAL APPROPRIATORS

The National Institutes of Health recently completed its annual cycle of testimony before the House Labor, Health and Human Services and Education Appropriations Subcommittee chaired by Rep. John Porter (R-IL). Each institute presented its budget request for the upcoming fiscal year as well as an overview of its research accomplishments and goals.

In his testimony before the subcommittee, NIH Director Harold Varmus was asked by freshman Rep. Jay Dickey (R-AR) if NIH devotes too much attention to diseases that are linked to certain behaviors. "It seems like, in the cases of AIDS and lung cancer, we're spending money to allow people to harm themselves. We don't want to spend money to condone these behaviors." In response, Varmus said, "It is difficult to name a disease that does not have a behavioral component associated with it."

What follows is a summary of testimony presented by institutes that have significant social and behavioral research components. The summaries focus on aspects of the testimony describing social and behavioral research.

#### National Institute on Aging

"Research in aging over the last two decades has contributed to the realization that aging should not be equated with inevitable decline and disease," reported Richard Hodes, Director of the National Institute on Aging. Hodes cited progress in Alzheimer's disease, vascular disease, and studies of aging at the cellular level that track the actual mechanisms of aging as strong evidence for his optimism.

In addition to citing advances in biomedical research, Hodes emphasized the importance of the demography of aging, stating that the aging of the population "will become one of the most important social phenomena of the next half century, especially when the now middle-aged baby-boom generation becomes eligible for Social Security and Medicare. How this nation and its institutions accommodate themselves to the dramatic demographic shift will have a significant effect on the quality of life in the twenty-first century."

Findings of NIA's Health and Retirement Study will play a significant role in policy decisions, according to Hodes, as it will be utilized in studying the influence of health and private pensions on retirement, the impact of changing Social Security's age of eligibility provisions, and the impact of the Americans with Disabilities Act. A related study of persons 70 and older will examine the interplay of family and economic resources and late life transitions. To facilitate the use of data from these and other national surveys, and in response to Congressional recommendations, NIA will fund nine new Demographic Centers, Hodes reported.

Other important areas of NIA's social and behavioral research portfolio highlighted by Hodes included: 1) long-term care--preventing institutionalization, enhancing the quality and efficiency, easing the burden, and forecasting the requirements; 2) cognitive functioning--implications for older people's ability to perform daily tasks, such as driving, decision-making, and understanding and following medical instructions; and 3) minority-relevant research projects--disentangling the influence of cultural preferences from the effect of socioeconomic differences.

### National Institute on Alcohol Abuse and Alcoholism

"Alcohol's misuse accounts for more economic and social damage than almost any other public health problem," reported Enoch Gordis, Director of the National Institute of Alcohol Abuse and Alcoholism (NIAAA). "About 14 million Americans--almost 10 per cent of adults--meet diagnostic criteria for alcohol abuse or alcoholism at a cost of \$98.6 billion a year in morbidity, mortality, and economic vitality," he said.

"But are we making any progress on this problem?" Chairman Porter asked. Gordis replied that there is a general change in the public's attitude--that alcoholism is now recognized as a medical problem and not seen as immoral and sinful. "Per capita, alcoholism is down since the early 1980's," he added. Citing NIAAA's discovery that Fetal Alcohol Syndrome (FAS) is caused by alcohol per se, Gordis' written testimony also assured the subcommittee that "NIAAA researchers will continue to develop the scientific basis for prevention and effective intervention for FAS and FAE, with special efforts

made on how best to communicate this message to women whose drinking behavior has not been changed by current efforts."

Regarding the gap between behavioral and biomedical basic science, Gordis stated that it is "rapidly disappearing." "NIAAA scientists continue to explore not only genetic coding for aspects of behavior, but also the role environmental influences play in determining the manifestation of certain behaviors.... 'Environment' includes at least two kinds of influences: influences that affect the actual structure and function of the nervous system, especially in the young, when it is known to be affected by various inputs; and second, influences of home and peers as well as the effect of social and policy decisions regarding access to alcohol and its use."

## National Institute of Child Health and Human Development

Duane Alexander, Director of the National Institute of Child Health and Human Development (NICHD) focused his remarks primarily on the biomedical aspects of NICHD's research, describing progress being made in the prevention of neural tube defects, typhoid fever, whooping cough, Sudden Infant Death Syndrome (SIDS), HIV transmission to infants, cardiovascular disease, and unwanted or unintended pregnancy. With respect to behavioral research, Alexander's written testimony highlighted NICHD's work in developing and evaluating intervention programs to reduce violence and related behaviors in youth.

Regarding the funding of sexual behavior research, Chairman Porter asked Alexander if the release of *The Social Organization of Sexuality* last fall (the National Health and Social Life Survey--see *Update*, October 10, 1994), "proves that the private sector has the ability to fund sexual behavior studies." Alexander replied, "Yes, in some instances, but the private sector is not able to fund large scale studies which ensure high confidence levels."

#### National Institute on Drug Abuse

Illustrating the relevance of both behavioral and biomedical research at the NIH, Alan Leshner began his testimony by saying that "drug abuse is a preventable behavior and addiction is a treatable disease of the brain." Frustrated with the "unique disconnect between what NIDA's research has shown and what too much of the general public thinks about drug abuse and addiction," Leshner explained that "drug addiction is all too frequently viewed as a social problem, to be dealt with only thorough social programs or through the criminal justice system. Drug addicts are too often seen as weak or bad people and, therefore, not deserving of care and treatment. Science has taught us that while the initial act of drug taking is voluntary, drug addiction is a chronic, relapsing disease of the brain. The difference between the perception of a 'bad person' vs., a 'chronic illness sufferer' has tremendous implications."

As drug abuse is the fastest growing transmitter for the spread of HIV/AIDS, Leshner emphasized the importance of NIDA's research demonstrating the efficacy of drug abuse outreach and intervention programs. "CDC findings show that as of June 1994, 3 out of every 8 cases of AIDS were related to injection drug use....not only among drug users, but also among nondrug using populations," Leshner reported. "This is critical not only to the drug abusing population, but to their sexual contacts and to their children....55 per cent of pediatric AIDS cases are among children born to mothers who had been injecting drugs or had sexual contact with an injecting drug user," he said.

Regarding treatment, Leshner stated that "for every one dollar invested in treatment programs, there is an average return of seven dollars in reduced drug-related crime, criminal justice costs, and theft alone." He also reported that "behavioral approaches are among the most successful forms of treatment...with highly structured, multi-component, outpatient 'relapse prevention' regimens documented to be effective, by NIDA researchers, as well as comprehensive interventions to help addicts make the initial transition to abstinence."

Additional social science research priorities for NIDA cited by Leshner include: 1) assessing the effectiveness of drug prevention efforts in primary health care settings; 2) targeting culturally diverse groups for prevention programs; 3) developing more effective approaches for rural areas; and 4) identifying components of prevention programs that seem to have the greatest impact in different population subgroups, developmental stages, and environmental settings.

#### National Institute of Mental Health

"FY 1996 will mark the 50th anniversary of the National Institute of Mental Health (NIMH) as one of the original NIH institutes," announced Acting Director Rex Cowdry as he presented his testimony to the new Republican majority. After citing the extent of the problem, as well as the tremendous cost to the nation of mental illness, Cowdry explained how "demonstrating the biological underpinnings of mental illness and in developing an array of effective treatments--research has reduced the stigma attached to mental illness."

In response to a question regarding social and behavioral aspects of mental health by Rep. Nancy Pelosi (D-CA), Cowdry expressed strong support for basic behavioral science research at the NIMH. A new NIMH report, Basic Behavioral Science Research for Mental Health: A National Investment, will soon be released to Congress, he stated.

A provocative news release distributed at the hearing by Citizens Against Government Waste prompted questions by Republican members of the panel regarding the funding of specific research projects at the NIMH. Chairman Porter asked Cowdry to explain each of the twenty studies cited in the news release. Cowdry stated that the statement was "disinformation misrepresenting the NIMH portfolio." "I believe the Church of Scientology is the source of the misleading information," he added. Rep. Jim Istook (R-OK) did not approve of Cowdry's criticism of the Church of Scientology, and also questioned the "rigor of the review process" at the NIH. Rep. Henry Bonilla (R-TX), also concerned with the charges made by Citizens Against Government Waste, questioned the length of time needed for research projects involving animals, as well as how many grants dealt with sexual behavior.

Porter and other panel members requested that the NIMH provide a written statement explaining each of the twenty grants cited. Porter also said that NIMH may need to return in May to answer any further inquiries by the subcommittee.

#### National Institute of Nursing Research

"A dominant theme of the NINR is to link biological and behavioral research," reported Acting Director of the National Institute of Nursing Research

### AMERICAN INSTITUTES FOR RESEARCH JOINS COSSA

COSSA is pleased to announce that the American Institutes for Research has joined the Consortium as a Contributor. We are looking forward to working with this organization on issues of common concern.

(NINR), Suzanne Hurd. Research on pain is a priority of the institute: "While basic research investigators supported by other NIH institutes are tackling the neurophysiology of pain, research sponsored by the NINR investigates methods to understand, predict, or reduce the intensity and frequency of this often excruciating experience," she explained.

Other NINR priorities identified by Hurd include: 1) research which focuses on ways to manage symptoms and modify the social environment for Alzheimer patients, their families, and caregivers, so that independence and ability to function can be preserved and costly institutionalization avoided as long as possible; 2) research on the psychosocial and clinical impact of genetic tests in families with heritable cancer; 3) research that would encourage the use of breast self exams and regular mammograms; 4) research that would help women, their families, and their care providers make diagnostic and treatment decisions that will result in increased use of effective, less costly, less invasive treatments such as hysterectomies; 5) research to develop and evaluate model programs of prevention targeted at rural populations and involving the community and family; 6) research in preventing the spread of HIV/AIDS especially among inner-city teenagers; and 7) research encouraging adolescents to adopt healthy behaviors to prevent serious illnesses in adulthood.

## SENATE HEARING LOOKS AT FEDERAL ROLE IN SCIENCE

A March 30 hearing by the Senate Science, Space, and Technology Subcommittee, chaired by Sen. Conrad Burns (R-MT), examined the federal role in science and technology.

In his presentation, Lane cited as a specific contribution of basic research NSF's support of game theory economics, which became the basis of the Federal Communication Commission's recent auction to award electromagnetic spectrum licenses. Lane commented that the record amount of revenue generated by these auctions would not have been possible if it were not for this basic research in experimental economics.

The panel's ranking member and former chair, Sen. Jay Rockefeller (D-WV), spoke of the conflict between developing our nation's R&D needs versus severe budget constraints at the federal level. While praising the administration's balancing of these conflicting goals, he said that the "divergence is growing sharper" between Democrats favoring an active government role in R&D and Republicans favoring greater reliance on the private sector and the avoidance of an industrial policy. He speculated that if the government had such a policy, industry would be the first to complain, but he claimed such concerns have not been raised.

Chairman Burns spoke of concerns that the Federal government was "picking winners and losers" through initiatives it opts to pursue or not pursue and advocated strict criteria to ensure that this did not occur.

Addressing the points raised by both Senators, Gibbons said that while industrial policy means different things to different people, picking winners would be "a terrible way to go." He said that rigorous merit review and strict guidelines ensure that federally-sponsored research has a system of "checks and balances." Gibbons said that the Clinton policy is to work with private industry in creating a diverse set of activities to expand fundamental research in ways that link public and private goods in "mutual self-interest." He said that such activities must have a strong public return, and that this policy is emulated by many industrial nations.

Lane said that NSF's cooperation with industry occurs at the college and university level, where individual researchers may have corporate partners. He said that the reasons for industry involvement with university-based research and the nature of the cooperation vary, but that all parties involved view these activities as positive.

#### A DEPARTMENT OF SCIENCE?

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their options and expect to introduce legislation soon calling for the creation of the new Department. He admitted that restructuring science and technology agencies will not be easy and simplistic solutions such as sending the Energy Research and Development Administration to the National Science Foundation will not work. He claimed the Department will allow for a "more rational approach" to S&T.

At a press conference following the meeting, both Gibbons and Young opposed the idea of a Department of Science. Gibbons called it unnecessary and argued that the current National Science and Technology Council already operates as a "virtual" department, providing the coordinating role for science and technology efforts by the federal government.

Walker also argued for a permanent research and development tax credit for business. The tax credit provided for in the Economic Recovery Tax Act of 1981 has allowed businesses to take a credit for certain R&D investments. Walker would like to expand the eligible categories to encompass industrial support for universities, including research and facilities modernization. Acknowledging that NSF's \$100 million facilities program will not expand to meet the \$10 billion problem, Walker pushed the tax credit as an alternative that needs exploration.

Brown focused his remarks on the oversupply of researchers and the need to provide alternative careers for Ph.D.s besides the traditional path of professor/researcher. "We must train them for truly significant opportunities, not outdated prestigious positions," he said. Given the budgetary situation, the stream of funding to universities will not increase and restructuring and downsizing will continue. Brown agreed with Walker on using the R&D Tax Credit to fund science and technology.

At PCAST's earlier session on March 27, Murray Gell-Mann of the Santa Fe Institute and David Shaw, who owns his own venture capital firm, again argued for greater emphasis on PCAST's agenda for social problems and research in the social and behavioral sciences. Both mentioned crime. Another member, David Hamburg, President, Carnegie Corporation of New York, currently leads a PCAST working group on

#### **EDITOR'S NOTE**

With Congress in recess for most of April, the next *Update* will be published on April 24 and will review actions of the first 100 days of the new Congress affecting social science research.

the origins and prevention of deadly conflict.

## COALITION SPONSORS SCIENCE EXHIBITION

The Coalition for National Funding (CNSF), a group of over 70 scientific societies, higher education associations, and industrial organizations, chaired by COSSA Executive Director Howard Silver, held its first "CNSF Exhibition and Reception" on March 21. The exhibition's purpose was to demonstrate the results of research sponsored by the National Science Foundation, whose funding is the major concern of the Coalition.

Over 150 people attended, including NSF Director Neal Lane, members of the House Science Committee staff, and staffers from many congressional offices. They viewed 20 exhibits sponsored by 18 scientific societies. COSSA groups presenting included the American Anthropological Association (AAA) and the American Psychological Association (APA). The AAA's booth featured 3 anthropology projects on: Human-Environmental Interactions and Sustainable Agriculture in the Andes; Reforestation in the Deforested Amazon; and the Human Genome Diversity Project. The APA exhibit featured research in cognitive neuroscience that explores the nature of the brain and how it works. Professor Joseph Hellige of the University of Southern California explained his research.

Other exhibits included: innovative ways to teach chemistry to elementary and secondary school students; "Bob," the walking machine from the University of Maryland; new educational techniques for teaching calculus; undergraduate researchers from MIT discussing their work; the climate simulation laboratory; and the women in science mentoring project.

CNSF expects to make this an annual event.

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