

HOUSE SUBCOMMITTEE SHOWS INTEREST IN NSF PROGRAMS *DH*

The House Science Committee's Basic Research Subcommittee heard testimony from National Science Foundation (NSF) Director Rita Colwell and National Science Board Chairman Eamon Kelly on April 28. Both Colwell and Kelly spoke of NSF's Fiscal Year (FY) 2000 request and the agency's research priorities for the 21st century. Representative Nick Smith (R-MI), Subcommittee chairman, warmly welcomed Colwell and Kelly, but reprimanded NSF for requesting \$35 million more than the authorized funding level for FY 2000.

In his opening remarks, Smith noted that "while it may seem a minor complaint, I would note that the authorizations under which NSF operates were passed with the strong bipartisan support of both houses of Congress and with the backing of the administration." Nevertheless, the Chairman noted that the Subcommittee and the full Science Committee will continue to support NSF now and in the future. He also commended Colwell and the NSF for establishing "clear priorities in information technology, biotechnology, and education."

Colwell and Kelly told the members that the NSF budget focuses on three priorities: 1) information technology; 2) biocomplexity, a multidisciplinary approach to understanding the world's environment; and 3) math and science education, given the recent "not-so-good news" of the most recent Third International Math and Science Study (TIMSS), which compares the achievement of students across a number of nations.

Several different themes emerged during the question and answer period. Chairman Smith focused his comments on the Government Performance and Results Act (GPRA) and the need to ensure measurable outcomes from basic research. He realizes it is difficult to measure outcomes from

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NSF DIRECTOR ADDRESSES PRESS CLUB; SUPPORTS SAMPLING IN CENSUS *HS*

Rita Colwell, Director of the National Science Foundation, participated in a Washington, DC ritual when she addressed the National Press Club luncheon on April 29. Colwell's speech, *Beyond Barcodes: Wisdom in the Age of Information*, discussed how "our embrace of information technology" is "rapidly changing our lives."

Stressing the need for support of "long term basic research," Colwell defended the federal role asserting that "private companies support research with only a three-to-five year time line." She noted that key advances in computer and information technology "were spurred by federally sponsored research." Citing ARPANET and NSFNET (forerunners of today's Internet), the creation of the first web browser at the University of Illinois, and other NSF investments, Colwell said these developments "helped to lay the foundation for what is fast becoming a trillion-dollar share of the U.S. economy." She referred to the President's Information Technology Advisory Committee (PITAC) report that said federal funding for long-term research on information technology was dangerously inadequate.

Noting that information technology has already brought about fundamental social change, Colwell made numerous references to the role of the social sciences in the information revolution. She argued

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that: "we need to know how this technology can affect what it is to be a person, a community, a society." She referenced an article in the *Los Angeles Times* that called Rachele Hollander, one of NSF's social scientists and head of the Societal Dimensions of Engineering Science and Technology Program in the Social, Behavioral, and Economic Sciences Directorate, a "Hero of the Information Age."

Colwell mentioned studies by sociologists of computer use and the disparities between the information haves and have-nots. Colwell further referred to studies of computers and education, and how sociologists and others have stressed the context of their use. She said that "we know that research has measured real benefits from information technology. But we don't yet know how these techniques and methods square up against other kinds of instruction."

She stressed interdisciplinary collaborations as the "future excitement" for science, "nourished by progress in the core scientific areas." She noted that collaborations between software designers and experts in social ethics can design features to deliberately encourage broad public access to technology. She cited research in complexity theory and its application to the social sciences, so that

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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 \$75; institutional subscriptions, \$150, overseas mail, \$150. 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>

studies on fish that congregate in schools and birds that flock together might actually yield insights for human crowd control.

The question and answer period seemed to reflect the dearth of scientists who address the press club (the next two speakers in the series are Miss America and George Carlin). Colwell was asked about all sorts of science, including the space station, and sampling in the upcoming Census. On the latter, she replied that sampling was indeed scientific, citing how part of the core training of researchers involves experimental design and statistical sampling. She also suggested that using sampling in the 2000 Census would "save money" and be "more accurate."

COSSA ADVOCATES LARGE INCREASE FOR NSF AT HOUSE HEARING *HS*

COSSA Executive Director Howard J. Silver made his annual appearance to testify on the appropriation for the National Science Foundation (NSF) before the House VA, HUD, and Independent Agencies Appropriations Subcommittee on April 28. Reflecting the statement of the Coalition for National Science Funding (CNSF), which he chairs, Silver called for a \$562 million or 15 percent increase for NSF over its FY 1999 level. This would bring NSF's budget for FY 2000 to \$4.3 billion. The President's budget requests a 5.8 percent increase for a total of \$3.954 billion.

The 15 percent increase corresponds to NSF's view regarding its needs in the request made to the Office of Management and Budget. It also reflects NSF Director Rita Colwell's assertive approach to the funding needs of her agency.

In advocating for increased funding for the Social, Behavioral and Economic Sciences (SBE) Directorate, Silver told the Subcommittee that the proposed 4.2 percent or less than \$6 million increase in the President's proposed budget "is totally inadequate to fund researchers searching for scientific breakthroughs to answer the many challenges posed by society and its people."

Citing the large volume of proposals for the recent competition, Silver focused on requiring more resources to fund the "tremendous need to improve the infrastructure in these sciences." He also reiterated the call by the President's Information Technology Advisory Committee (PITAC) for significant funding for research on socio-economic issues relating to the information revolution. Addressing the proposed Information Technology for the Twenty First Century (IT²) initiative, he asked that the \$10 million proposed for research on the social, economic and workforce implications be moved from the Computer Science directorate to SBE, since it already supports considerable research in that area. Silver further discussed the enhancement of support for research on human origins, the many contributions of the National Center for Geographic Information and Analysis, and cited examples of SBE supported research.

Silver advocated strongly for the Interagency Education Research Initiative (IERI), which is spending \$30 million (\$22 million from NSF) in FY 1999 and has a proposed budget of \$50 million for FY 2000 (\$25 million from NSF). This initiative, a collaboration among NSF, the U.S. Education Department and NICHD, is evidence of the increased interest in enhancing support for education research.

In addition to Silver and COSSA's testimony, many other groups from across all the sciences testified in support of the 15 percent increase for NSF. Those from the social and behavioral sciences also advocated large increases for SBE.

NIH PUBLIC ADVISORS MEET FOR FIRST TIME

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On April 21, National Institutes of Health (NIH) Director Harold Varmus convened the inaugural meeting of the NIH's Council of Public Representatives (COPR). The COPR (pronounced "copper"), a new advisory committee to the NIH Director, is designed "to be a forum for discussing issues affecting the broad development of NIH policy and research programs." The 20 members selected for the committee will also advise the Director on

increasing the public understanding of the NIH and public participation in NIH activities.

COPR was established in response to the 1998 Institute of Medicine report, *Scientific Opportunities and Public Needs*. Recommendation eight of the report states that: *The director of NIH should establish and appropriately staff a Director's Council of Public Representatives, chaired by the NIH director, to facilitate interactions between NIH and the general public* (See UPDATE, 7/13/98).

"NIH is among the government agencies that interacts most dramatically with the public," noted Varmus in his opening remarks, and the "perception is that NIH was not doing enough, particularly the Office of the Director." Varmus says that COPR will help the NIH "enrich" its already "extensive interactions with the public by bringing a greater diversity of perspectives and ideas, and by helping the [NIH] ensure that more Americans understand the NIH and its work."

He noted that the themes for COPR emerged from an earlier meeting held by NIH September 23, 1998 with 23 members of the public. That meeting was convened to develop eligibility criteria for nominees to COPR. According to Varmus, the NIH received 250 "excellent applications" that were vetted by an outside group. Varmus made the final selection of the 20 COPR members. Because advisory committee members normally serve three-year terms, this first group's terms have been staggered with members serving 1-, 2- and 3-years so that every year one-third of the council will consist of new members. The 230 people not selected have been invited to join a *COPR Associates* program and to serve as links between the NIH and the public. Varmus explained that COPR Associates may be asked to comment or advise on COPR agenda items, and may serve on future COPR or NIH committees.

COPR will have two main meetings a year — one in April and a one in October. Their responsibilities will include participating in Institute and Center Directors' reviews, and implementation of the Government Performance and Results Act. Varmus noted that COPR will have specific emphasis on issues that affect special populations, public health issues, ethical and privacy issues, and issues

around consent. Volatile public policy issues will also be brought to this group, said Varmus. He added that initially, at each of the meetings, four Institute Directors will make presentations on models of public participation within their Institutes.

The initial COPR membership is multiculturally and geographically diverse. Members' ages range from the 20's to the 70's. Most, if not all, have personal and professional experience with a broad span of disease conditions and physical and mental disabilities. Each member has agreed to subordinate his or her individual interest or involvement in specific disease or programs. COPR members include Melanie C. Dreher, a nurse, a medical anthropologist, and currently Dean and Professor at the College of Nursing, University of Iowa; Barbara Lackritz, a speech/language pathologist for a St. Louis public school district; and Rosemary Quigley, currently an honor graduate student in a joint degree program at the University of Michigan Law School and School of Public Health.

Health Disparities Discussed

One of the first issues discussed by COPR was the issue of health disparities. Varmus noted that a number of factors contribute to differing health outcomes, including education, rural versus urban, environmental exposures, age, and inheritance. Despite the numerous factors, much of the focus is on minority populations. He stressed the importance of understanding the differences and how they can contribute to equity in health outcomes.

A panel consisting of: John Ruffin, Associate Director of the NIH Office of Research on Minority Health; Ed Sondik, Director, National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention; Norman Anderson, Associate Director for Behavioral and Social Science Research; Otis Brawley, Director, Office of Special Populations for the National Cancer Institute; and Michael Gottsman, Deputy Director for Intramural Research, presented various aspects of the problem.

Ruffin emphasized that the most difficult part of having a dialogue on health disparities is convincing those who are in key positions that the issue is real and scientifically quantifiable. "This is progress,"

claimed Ruffin, since "this is the first time we seem to be unified in acknowledging the disparities in health outcomes." The issue, said Ruffin, is complex and serious and includes such issues as access to health care, biology, cultural factors, socioeconomic status, and environmental and psychosocial stresses. He also noted that the issue of health disparities is one of the NIH Special Areas of Emphasis for FY2000.

Sondik reiterated that disparities in health outcomes are the result of a variety of risk factors and cited several examples of disparities in health from the NCHS' publication, *Health, United States, 1998*. We know that in order to reduce the gap, explained Sondik, we need to do the research, test the interventions, and apply the resources. Echoing Varmus and Ruffin, Sondik emphasized that health outcomes are not uniform. For example, he said, statistics that show that individuals who live in the southeastern United States have a lifespan of 60-68, whereas individuals from the north-central part of the U.S. live to be 74-80 years of age.

A second example cited by Sondik regarded life expectancy and family income. Life expectancy is related to family income; people with a lower family income die at younger ages than those with a higher income. During 1979-89, white men who were 45 years of age and who had a family income of at least \$25,000 could expect to live 6.6 years longer than men with family income less than \$10,000 (33.9 years compared with 27.3 years). Adults with low incomes are far more likely than those with higher incomes to report fair or poor health status.

In adjourning the meeting, Varmus recited a number of topics and asked the COPR representatives to think about them and to decide in which of these areas they had an interest. The topics included: participating in the NIH's annual budget retreat; participating in organizing town meetings; working with the COPR Associates; working to implement the Government Performance and Results Act; reviewing the Institute directors and which ones; and any other item in which individuals have an interest. He further asked them to let him know what issues they would like to see as agenda items, such as patient protection; if they would like to hear from other science agencies, such as the CDC; if they

would like information on the newly created center — National Center for Complimentary and Alternative Medicine; health communications; ideas for greater access to information on the Internet but not available any other way; technology transfer; NIH and proprietary research; and genetics and medical privacy

HOUSE SUBCOMMITTEE SHOWS INTEREST IN NSF PROGRAMS (cont.)

basic research, but the federal government must ensure that resources are appropriately spent.

Representative Eddie Bernice Johnson (D-TX), Subcommittee Ranking Member, expressed interest in ensuring high achievement and involvement in math and science programs for all students, especially African American and Hispanic students. Kelly noted that without increased minority involvement in math and science higher education programs, the U.S. will have to depend on foreign scientists to fill science and high technology positions. This, he said, would certainly have economic repercussions.

Representative Bob Etheridge (D-NC) also showed interest in NSF's initiatives to improve math and science education. Etheridge asked Colwell how she would ensure improvement in math and science education for our nation's students if NSF had an unlimited budget. Colwell remarked that NSF would do more of what it is currently doing: the Interagency Education Research Initiative (IERI), a cooperative venture among NSF, the Department of Education, and the National Institute of Child Health and Human Development (NICHD); graduate students in the classroom program; NSF-sponsored teaching-training programs; and the biocomplexity program, which will be part of an effort to the couple research of many different and diverse disciplines to address education.

Representative Connie Morella (R-MD) focused on computer and Internet security, especially in light of the recent "Melissa" and "Chernobyl" computer viruses. Colwell noted that a portion of the new \$146 million Information Technology for the 21st Century

(IT²) will be used to study and further computer security to prevent these types of viruses.

Representative Frank Lucas (R-OK) commended NSF for its Experimental Program to Stimulate Competitive Research (EPSCoR) program (See *UPDATE*, April 5, 1999). The program, he said, allowed smaller states and regions to gain a scientific base. Colwell agreed with Lucas and said EPSCoR is an "empowering and enabling" program. She said that the strength in science and technology must be diffused throughout the country, and not just concentrated on the East and West coasts. There is an intellectual potential throughout the nation which must be tapped if the U.S. wants to lead the world in science and technology in the 21st century, Colwell concluded.

COSSA BRIEFING CONSIDERS MEDICAL TREATMENT/ADVICE COMPLIANCE: A MULTI-DIMENSIONAL PROBLEM *DH*

On Friday, April 16, COSSA held its second congressional briefing of the year. The title of the briefing, which featured four social scientists, was "Not What the Doctor Ordered: Challenges Individuals Face in Adhering to Medical Advice/Treatment." The four presenters discussed various factors that lead to non-adherence and some of the social and political implications resulting from patients not adhering to medical advice. The briefing was moderated by Norman Anderson, Director of the National Institutes of Health's (NIH) Office of Behavioral and Social Science Research (OBSSR).

After a brief welcome by COSSA Associate Director for Government Affairs Angela Sharpe, Anderson noted the importance of the briefing's focus and said that "adherence is a problem that is of very high interest among all of the Institutes of NIH." The NIH, he said, realizes that the issue of adherence is not simply an issue of an individual's behavior, but a problem that is embedded in a very complicated psychosocial and cultural context. Thus, he said, that adherence involves not only patient behavior, but provider behavior, the medical system in which the provider operates, family factors, and psychosocial or cultural factors.

Bernice Pescosolido, Chancellors' Professor of Psychology at Indiana University, and Karen Luftey, one of Pescosolido's advanced doctoral students and a pre-doctoral fellow of NIH's National Institute of Mental Health (NIMH), were the briefings first presenters. The two gave a brief overview of the history of compliance and adherence research and provided several answers to the question: Why don't patients follow medical treatment recommendations?

The conclusions of a literature review conducted by Luftey showed that overall treatment adherence for all maladies is "relatively low." For diabetes patients in particular, said Luftey, an early study found that "only 7 percent of patients comply" with medical regimens. Compliance in cases of mental illness is closer to 10 percent on average, ranging to a maximum of about 30 percent, noted Luftey. In general, Luftey concluded that implicit in the literature is the notion that compliance is simply an issue of patient behavior. Additionally, the research has largely assumed that non-compliance is a problem associated with patients of lower socioeconomic status and minority groups. This, according to Pescosolido, however, is not the case. In fact, she noted that "almost everyone is non-compliant."

The two suggested, like OBSSR's Anderson, that compliance is an issue that is much more complicated. Pescosolido, therefore, suggested that we need to reconceptualize it. She said that we must consider the entire medical system, not simply the patient. According to the two, compliance is based on at least four different factors: 1) patients, 2) providers, 3) the context in which medical treatment is provided (private vs. public treatment and single provider vs. multiple provider), and 4) the patient's social network. The conclusions, said Luftey, were supported by a study she performed on patients in two different diabetes clinics. Information sharing between medical provider and patient, she concluded, is a key factor in compliance.

Pescosolido further noted that we must consider the medical system and whether the patient has a single provider or multiple providers, whether the providers share information with patients, and what type of medical treatment system the patient is enrolled. A study performed by a researcher in

Puerto Rico, said Pescosolido, showed that patients have a much higher compliance rate (39.2 percent) if they have a single medical provider. In comparison, the same study showed that patients with multiple providers have a "very low" compliance rate (26.3 percent).

Pescosolido concluded the first presentation by offering a few policy recommendations. First, she declared that there should be increased funding for compliance research that extends beyond the patient and considers the entire medical system. Second, she stated that it is "important to take a second look at the aspirations and realities of managed care." Managed care's focus on lowering costs of medical care may in the "long-run increase non-compliance and result in poorer health" of patients. Finally, she stated that "we really need to think about how we can put together a team of individuals who can maintain a real trust and bond with the people they are caring for" to increase compliance and patients' health.

Social and Cultural Factors

Noel Chrisman, Professor of Community Health and Nursing at the University of Washington, was the third speaker. He echoed Pescosolido's and Luftey's premise that adherence is much more than an individual level concern. While he discussed three levels of compliance — individual level, health system level, and population/community level — he concentrated on the social and cultural factors that affect adherence. He drew specifically from some research he had conducted and some of his experiences working with and conducting research on the Yakima Native American Indian tribe reservation.

Chrisman identified several individual level factors that affect medical adherence. First, he said that patients often do not comply because the "treatment does not make sense," or the treatment is contrary to the person's belief system. For example, he noted that the Yakima Indian women would not undergo pap smears because they would lose "part of their bodies" and their ancestors would not accept an incomplete body. Second, people fail to comply because the treatment is "no longer needed," or the person feels better and therefore stops adhering to the medication or treatment. Third, a person often fails to comply with medical advice and treatment because "it could not be done." For example, the person did

not have the proper insurance to cover treatment or medication.

At the health system level, Chrisman identified several barriers to patients' full adherence. One reason, he said, was time. He noted that medical professionals do not have the time to listen, to teach patients about their ailments, or to perform "culturally appropriate care." This, he said, is nowadays blamed on managed care, as noted by Luftey and Pescosolido. But, Chrisman said that he does not believe that managed care is to blame. Twenty-five years ago, when managed care was not around, doctors also complained that they did not have enough time to spend adequate amounts of time with patients, said Chrisman. Another barrier to adherence, said Chrisman, is language. "In spite of the fact the Civil Rights Act requires that we not discriminate against people on a large number of grounds, including language," he noted that most hospitals do not have interpreters. Clinicians, he said, are also not taught in medical school how to deal with interpreters.

He noted that the population/community level is extremely important to consider because in many instances the community is closely involved in an individual's decision-making process. Therefore, Chrisman said that clinicians must recognize how to work with members of the community and community assets (allopathic doctors and spiritual healers) to find an effective approach to ensure adherence. The community needs to become involved in the health seeking process, he said.

Chrisman offered several recommendations, including cultural training for clinicians. Additionally, he said that there needs to be "organizational cultural competence." Specifically, he noted that hospitals and hospital staff need to "understand how to provide for trained interpreters . . . along with a whole series of things."

Adherence and AIDS

Margaret Chesney, Professor at the University of California, San Francisco, spoke about adherence and HIV/AIDS, where the "challenge of adherence takes on critical dimensions. I mean critical." She said the challenge to make HIV/AIDS patients to adhere to their medical regimens is "greater than anything I've faced in all my adherence work."

She noted at the outset, that even adherence rates of 80 percent for individuals with HIV/AIDS will lead to a failure in the treatment regimen and the development of antibiotic resistant strains of HIV/AIDS. The HIV/AIDS virus, she said, waits for a crack in adherence. When this break occurs, the virus attacks and "creates a form of the virus that outsmarts the drug."

To make the point of the difficulty of complying with the drug regimen for HIV/AIDS, Chesney showed a picture of a patient's actual regimen. The daily regimen, according to the picture, included 11 drugs that needed to be taken at specific times throughout the day. She said, however, that taking the drugs was not the most difficult part of patients' adhering to the regimen, contrary to the opinion of medical professionals. She said that surveys of medical patients suggest that the biggest factor in non-adherence is meal instructions. Several of the HIV/AIDS medications, she said, must be taken in accordance with very specific meal instructions. Another factor which lowers the adherence rate is the stigma attached to HIV/AIDS. Persons living with HIV/AIDS may not properly adhere to their regimens since it would mean taking drugs in public settings. Privacy, she said, is therefore a big issue. She also noted that some people say they "just forget" to take their drugs.

The medical regimen must be tailored to a person's life to increase adherence; taking medications can be turned into a ritual, like turning your alarm off in the morning. She provided an example of a woman living with HIV who takes her medications based on her daughter's life. For instance, the woman takes her first medication in the morning when she brushes her teeth. The woman takes her afternoon dosage when she picks her daughter up at school, and her evening dosage when she is making her daughter's lunch for the next school day.

Chesney concluded by noting that it is important for patients to establish a relationship with a counselor — preferably a social or behavioral scientist — who can help the person tailor a regimen. Also, the counselor can help the person address or overcome any cultural or social factors that may affect adherence. She said that adherence needs to be addressed through a team — a team, led by the patient — composed of many individuals, including social or behavioral scientists, pharmacists, the persons' social network, and a nutritionist.

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