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ZERHOUNI APPEARS BEFORE HOUSE SUBCOMMITTEE

In 2003 Congress provided the National Institutes of Health (NIH) with the last installment of a five-year effort to double the agency's budget. Since that time, NIH Director Elias Zerhouni, who arrived at the agency in the last year of the doubling, has attempted to answer constant questions from Congress regarding the scientific impact of this largesse. At his annual appearance before the House Appropriations Subcommittee on Labor, Health, and Human Services and Education (Labor-HHS) on April 6, 2006, Zerhouni once again endeavored to explain to Members the nature of the scientific enterprise and provide concrete examples of the returns on doubling the agency's budget.

Subcommittee Chairman Ralph Regula (R-OH) opened the hearing by noting that he is "impressed with the discoveries that come out of the NIH" but at the same time he is "concerned that the advances reach the local doctors." Ironically, the NIH appropriations hearing was taking place on the day the House was scheduled to vote on the House budget resolution and an amendment which would have increased the amount of resources available to the Labor-HHS subcommittee.

Referencing the pending vote, Regula explained that the Subcommittee was "wrestling with the budget in the House." According to the Chairman, "when it's all wrapped up," the Subcommittee will be on "short rations." "Therefore, we're going to have to make sure that the dollars we spend get us the greatest possible benefits to the people we represent," said Regula.

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UPDATE IS NOW ELECTRONIC

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CYBERINFRASTRUCTURE IN THE SBE SCIENCES

Over a year ago social, behavioral, and economic (SBE) scientists met with computer and information scientists to discuss how new advanced computing capabilities can enhance research in the SBE sciences. The National Science Foundation (NSF) has recently released the report of that workshop written by Henry Brady, Professor of Political Science at the University of California, Berkeley, and Francine Berman, San Diego Supercomputer Center, University of California, San Diego.

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CYBERINFRASTRUCTURE (Cont. from Page 1)

The meeting was intended to help identify the SBE sciences' needs for infrastructure, their potential for helping the Computer and Information Science and Engineering directorate (CISE) develop this infrastructure for all the sciences, and the capacity to assess the societal impacts of Cyberinfrastructure.

The group concluded that the new computing capacity "can make it possible for the SBE sciences to make a giant step forward." Because of its ability to use distributed networks and powerful tools, Cyberinfrastructure will enable more realistic models of complex social phenomena. It will also allow the production and analysis of larger datasets, such as surveys, censuses, textual corpora, videotapes, cognitive neuroimaging records, and administrative data that will more completely record human behavior. SBE scientists will then have the capability to integrate and coordinate disparate datasets for deeper investigations. In addition, advanced computer technology will enhance the collection of better data through experiments and simulations on the Internet.

With their expertise about organizations, communications, social dynamics, and human factors, SBE scientists are also in a position "to help CISE researchers design a functional and effective Cyberinfrastructure which achieves its full potential." The report suggests organizational researchers and political scientists can help develop appropriate management, decision-making and government structures for Web-enabled research communities. Economists can design incentive-compatible resource allocation methods for sharing multiple and diverse resources. Behavioral scientists can help develop better modes of human-computer interaction. Sociologists can analyze the implication for knowledge production of social networks developed on the Web. Psychologists and linguists can help computer scientists develop computer programs that understand and translate national languages. Finally, together SBE and CISE scientists can develop better statistical and analytical methods for dealing with data.

SBE scientists can also assess the impacts of Cyberinfrastructure on society, in particular, understanding changes in social interactions, detailing changes in jobs and incomes, explaining the impact of policy, and illuminating new conceptions of privacy and trust in the networked world.

The report also calls for enhanced funding, especially to develop new researchers at the SBE-CISE interface and to help organize the SBE-CISE cyberinfrastructure research community. The full report is available at: www.sdsc.edu/sbe.

ZERHOUNI TESTIFIES (Cont. from Page 1)

Ranking Member David Obey (D-WI), acknowledging that Zerhouni could not do anything about the NIH's budget, emphasized its budget presented to the Congress, represents "a four percent loss of purchasing power compared to the current year, and an 11 percent loss of purchasing power since the budget doubling period ended in 2003." This means, said Obey, that there will be 650 fewer NIH research project grants than the year before and 15,070 fewer grants than three years ago. While the hearing was focused on what happened under the doubling, Obey noted there are also some things that have happened since the doubling. "And there are also some things that are going to happen that are not very pretty if we take the administration's budget and stick to it for the next five years," he continued.

NIH Poised to Transform Medicine

Summarizing what he thinks are the major questions facing NIH, Zerhouni emphasized that the doubling of the NIH's budget has "poised [the NIH] to transform medicine in an era" where interventions were used once the disease struck us to an era to what he calls "the three Ps of medicine" – predictive, personalized, and preemptive (see Update, March 6, 2006).

In his testimony, Zerhouni attempted to answer three questions:

- What is the return on the investment the American people have made in NIH over the past 30 years?
- What has the NIH doubling accomplished?
- What is the NIH strategy for the future?

The achievements of NIH and our private sector partners in medical research are difficult to overstate, Zerhouni argued. He highlighted the latest report on the Nation's health from the Centers for Disease Control and Prevention (CDC) which documents a continued rise in life expectancy, now at an unprecedented 78 years for the total U.S. population. Zerhouni also pointed out that "since 1950, the age-

adjusted death rate for the total population declined a remarkable 43 percent.” He further noted that the “disability rate of Americans seniors dropped by nearly 30 percent in the last 20 years, owing to a range of scientific advances.”

NIH is spending \$95 per American this year on medical research, Zerhouni testified. The estimated cumulative investment at the NIH per American over the past 30 years including the doubling period is about \$1,334 or about \$44 per American per year over the entire period. In return, Americans have gained about six years of life expectancy and are aging healthier than ever before, he informed the Subcommittee.

Zerhouni related “how discoveries fueled by this investment are transforming the practice of medicine. We can now clearly envision an era when the treatment paradigm of medicine will increasingly become more predictive, personalized and preemptive,” he explained. He also discussed “selected accomplishments” of the agency and their impact on health, including the advances made in cardiovascular disease and stroke, cancer, HIV/AIDS, against the threat of pandemic influenza, diabetes and related illnesses, health information for scientists and the public, and biodefense.

IDeA and Public Access

Rep. Ernest Istook (R-OK) expressed his concern with the distribution of research funding, and the dissemination of research results particularly the IDeA (Institutional Development Award) Program and Public Access. The IDeA program broadens the geographic distribution of NIH funding for biomedical and behavioral research. It is designed to foster health-related research and enhance the competitiveness of investigators at institutions located in states in which the aggregate success rate for applications to NIH has historically been low. He lamented, however, that “the 23 states involved in the IDeA program have 17 percent of the population of the country, but only five percent of the grants... I am troubled by the fact that the NIH budget actually proposed a reduction in the IDeA Program that’s intended to accomplish” the expansion.

Zerhouni responded that the NIH is “really supportive” of the program and over the years NIH has increased its investment in IDeA. The program, he explained, “tripled during the doubling period.” In terms of cuts, he continued, “we have not cut the IDeA Program anymore than we have had to adjust many of our programs in tough times.”

With regards to NIH’s public access policy, Zerhouni stressed that three goals need to be accomplished: (1) Creating a NIH a database of what it produces in terms of science; (2) Connecting the databases of the 5,000 libraries that are connected to the National Library of Medicine; and (3) Providing reasonable access to public-supported data. A fourth goal, Zerhouni added, is not to have public access “at the expense of losing the viability of peer review scientific societies having revenues from these journals.”

National Children’s Study

Highlighting the fact that the NIH’s budget zeroed out the National Children’s Study (NCS), Rep. Dave Weldon (R-FL) related to Regula that while he knows this is a very tight budget year, the elimination of the Study deserved discussion. NCS, said Weldon, “was going to be a very useful tool along the lines of . . .genetics and health. The Children’s study . . .could prove to be very, very interesting and have some direct application in that.”

Zerhouni responded that “obviously you have to make difficult choices in the budgetary environment we’re in.” He cited the long-term cost of the NCS and noted that when you “look at this, and you look at the other priorities that we have to take, a decision was made, perhaps, this was not the time to engage in this very long-term study while we have the Gene, Environment and Health Initiative developing new environmental measures and getting new preliminary data...I think primarily the budget was driving the decision,” he concluded (see Update, March 6, 2006).

Accepting the fact that the decision to eliminate the NCS was “budget driven,” Rep. Lucille Roybal-Allard (D-CA) pointed out that Congress mandated the NCS in 2000. She also noted that over the last five years \$60 million have been spent developing the study and more than 200 investigators have provided input into the study. Recently, she added, contracts have been let out for vanguard study centers, which have been “working very vigorously over the last six months to understand the impact of the environment and the influences that it has on children’s development.”

Mental Health

Rep. Patrick Kennedy (D-RI) expressed his displeasure that the Subcommittee planned to hold only one hearing on the NIH compared to previous years when all 27 institute and centers directors would appear before the Subcommittee. Kennedy expressed “outrage” that the directors from the National Institute of Alcohol Abuse and Alcoholism, National Institute on Drug Abuse, or National Institute of Mental Health were not among the directors accompanying Zerhouni to the hearing.

“The mere fact that...mental illness is the second leading cause of disability in this country... further stigmatizes the illness” when the NIH “makes the decision not to bring them up here,” Kennedy declared. We need to “bend over backwards to make it clear to the American people that [mental illness] is not a second-class illness. Unfortunately, they get that message repeatedly from the government,” he lamented.

“There is no message here about not paying attention to behavioral and mental health research,” explained the director. “We really agree with you that mental health issues, behavioral issues are important strategically. We spent over \$3 billion on behavioral research,” Zerhouni continued. He emphasized the neuroscience blueprint which focuses on mental health issues. “It is far from our mind that we do not look at behavior issues as being important.” “We do believe that they drive a significant amount of the disease burden. “

Health Disparities

Noting that Zerhouni’s testimony showed remarkable declines in deaths from heart diseases, cancer, stroke, and other, Rep. Don Sherwood (R-PA) pointed out that “American life expectancy is still exceeded by several other countries.” Sherwood inquired if NIH “is looking into the differences in health care or personal fitness or nutrition, habits, environment, and other things that might account for differences in life expectancy.” Of course, said Sherwood, “heredity’s a big deal, but our heredity is pretty wide. And lots of us originally come from those countries that are doing a little better than we are.”

Responding, Zerhouni stressed that “this is actually one of the top five priorities of the NIH. It’s what we call health disparities.” Because when you look at general statistics, you are obviously averaging everything. When you look at the statistics of a

country that is very homogeneous, like Japan or Sweden, you have a different picture,” Zerhouni explained.

The reason the U.S. is not at the same level is because we have health care disparities where, in fact, certain parts of the population, sort of a regions-rule... drive the health results we get. While progress can be seen across all populations, he explained that you still see differences which relates to genetic differences, minority differences, and the differences related to susceptibility to disease. Sherwood concluded the conversation by noting that he thought that a “better job” could be done in the public information campaigns on obesity and lifestyle and exercise.”

Echoing Kennedy and several other Subcommittee members regarding holding only one hearing on the NIH’s budget, Rep. Jesse Jackson (D-IL) explained that there are a number of subject matters for which he “would love to ask questions pan-NIH.” He expressed his interest in the recent Institute of Medicine (IOM) report examining the NIH’s strategic health disparities research plan (see Update, March 20, 2006) and inquired as to how the NIH plans to respond to the report.

The IOM report requires the NIH to “look more strategically” at how you make the money for health disparities research “more effective,” Zerhouni responded. The report, he continued, also points out that the NIH needs to do research beyond just medical research, but also do socio-economic research, as well as change the definition of what minority health and health disparities are, he continued. He concluded that the National Center for Minority Health and Health Disparities director John Ruffin and National Institute for General Medical Sciences director Jeremy Berg have put together a group to look at implementing the recommendations from the report.

COUNTDOWN TO THE 2010 CENSUS

In four years the 2010 Census will take place. Congressionally mandated by Article I of the U.S. Constitution, the Census is a decennial count of the population that collects general statistical information from individuals. In addition to taking a census of the population every 10 years, the Census Bureau conducts censuses of economic activity and state and local governments every five years. Throughout the year the Bureau also conducts more than 100 other surveys.

Businesses, community organizations, and state and local government rely on federally-provided data made possible by the Census. The federal government relies on federal statistics to figure out how to distribute funding for programs like worker training and public works to states and local areas. In addition, congressional seats are reapportioned and districts are redrawn on the basis of the Bureau's decennial count of the population. To educate congressional staff and nongovernmental organizations about the importance of Census numbers, the Brookings Institution agreed to sponsor a series of Capitol Hill briefings.

The first of the series, "The Road to the 2010 Census: Implications for Apportionment, Redistricting, and the Economy," was held on April 7. The panel reviewed the process necessary to produce an accurate count of the American population for the 2010 Census and the impact of Census accuracy on apportionment, redistricting, and decision-making. Speakers included Jay Waite and Cathy McCully of the Census Bureau, Joseph Salvo of the New York City Department of City Planning, and Michael Carliner of the National Association of Home Builders.

The panel discussed the steps that are necessary to obtain a full and accurate count of the population, how the count affects Congressional apportionment and redistricting and the most effective approaches for educating individual members about the uses of Census data. Katherine Wallman, Chief Statistician of the U.S., led the panel discussion.

In a March hearing on "Apportionment in the Balance: A Look into the Progress of the 2010 Decennial Census," Andrew Reamer, of the Brookings Institution's Urban Markets Initiative testified to the U.S. House Committee on Government Reform. Reamer explained why on-going support of the planning and preparation leading up to the 2010 Decennial Census is a necessary and important public investment for urban markets.

In his testimony, Reamer discussed four elements that are necessary for a successful 2010 Census:

- An accurate Master Address File (MAF). People cannot be counted if the U.S. Census Bureau does not know where they live or if there are missing units of habitation.

- Minimal coverage error in order to reduce duplicate enumerations, whereby people are counted in more than one place, and omissions, whereby people are not counted at all.
- A fully and consistently funded American Community Survey (ACS). The ACS will replace the long form to become the primary source of information about the characteristics of Americans—telling us who we are and where we are going.
- Automation of field data collection, digital methods for a digital age. The availability of handheld computers is very important for increasing enumerator efficiency and enumeration accuracy.

This hearing was a follow-up to the April 19, 2005 hearing last year entitled, "Halfway to the 2010 Census: The Countdown and Components to a Successful Decennial Census." The second briefing in the Brookings series, set for June 23, will explore the public and private sector uses of the new American Community Survey, which provides a profile of our population's demographic characteristics.

SBE HEAD EXPLAINS BIRTH AND DEATH OF LANGUAGES

Before a standing room only crowd at the National Science Foundation (NSF), David Lightfoot, Assistant Director for the Social, Behavioral, Economic Sciences (SBE), described how languages emerge, evolve, and sometimes die. Much of his talk came from his new book *How New Languages Emerge*.

Lightfoot noted that languages "come and go." A web site www.ethnologue.com keeps track of the world's known languages. According to their latest count, 6,912 languages exist in the world today with 239 in Europe and 2,092 in Africa. This count is idiosyncratic, Lightfoot explained, since few of these are written and the distinction between language and dialect is often difficult.

Many languages are dying leading NSF and the National Endowment for the Humanities to jointly support an effort to document these endangered languages. Since only 12 languages in the world are spoken by more than 10,000 people, Lightfoot noted, most of the expiring languages are limited to very small numbers of people, in some cases just one person. The importance of recording the death of a language lies in the notion that language encodes culture, he said.

Languages not only die, they also change, Lightfoot declared. One example is the movement from Old English through Middle English to Modern English. Another is from the Indo-European tongue spoken over 2,000 years ago to Latin, followed by its divergence into the Modern Romance Languages of Spanish, French, Italian, Romanian, etc.

In addition, new languages emerge. A modern example, Lightfoot discussed, is Nicaraguan Sign Language. Arising in the past 25 years, following the end of the Somoza regime, which Lightfoot noted considered deaf people “sub-human,” there are now 500 Nicaraguans of all ages in a school in Managua who are learning this new language.

Moving to a discussion of how these new systems emerge, Lightfoot focused on children, who he noted are “cue-based learners.” They scan their “external” linguistic environment – language as it exists in the world – to build their “internal” language as it works in their brain. This distinction, Lightfoot suggests, is crucial to learning languages.

During the question period, Lightfoot was asked about bilingualism, in terms of young children learning two languages simultaneously. He indicated that so far, we know very little about how the brain works in these situations, but future research may give us some clues.

THE ECONOMIC BURDEN OF CANCER

According to the National Cancer Institute (NCI), the economic burden of cancer prevention, screening and care in the United States was estimated to be equivalent to \$174 billion, including \$61 billion in direct medical expenditures. The economic burden of cancer is the economic cost to the nation associated with expenditures on cancer preventive, screening and treatment services, the economic cost associated with time and effort spent by patients and their families undergoing cancer treatment, and the economic cost associated with lost productivity due to cancer-related disability and premature death.

Over the coming decades, the U.S. health care system, including Medicare and Medicaid, will face the challenge of covering an increasing array of health care procedures and services with fiscal resources that are limited by global budgetary constraints.

The National Cancer Institute’s Division of Cancer Control and Population Sciences (DCCPS), and the Agency for Healthcare Research and Quality

(AHRQ), are seeking investigator-initiated grant applications for research directed at increasing the knowledge base surrounding the economic aspects of cancer prevention, screening, and care. The goal of the program announcement (PA-06-304) is to generate new economic knowledge concerning cancer care that will promote the optimal design of cancer prevention and control trial studies and interventions.

NCI is interested in economic and health services studies with particular emphasis on meeting the goals of the NCI Quality Cancer Care Initiative (<http://plan.cancer.gov>).

The NCI Initiative aims to enhance the state-of-the-science on the quality of cancer care and inform federal decision making on care delivery, coverage, and regulation. Research applications are requested on new methods development, the synthesis and extension of existing methods, and innovative data gathering strategies.

Research topics relevant to meeting the goals of the program announcement include, but are not limited to:

- The economic burden of the individual cancer patient, family, and society resulting from cancer and cancer treatment, including time costs, reduced employment opportunities, and reduced access to health and life insurance;
- Economic factors at the individual, community, and health system levels that affect access to and outcomes following the use of cancer-related prevention, screening, diagnostic, and treatment services;
- The costs and organizational structures of delivering cancer prevention, screening, and treatment service in relation to various health care delivery settings and health care market structure conditions;
- The roles of economic factors and financial incentives in determining the levels of participation of patients, physicians, and health care delivery stems in cancer prevention, screening and treatment clinical trials; and
- Methodological studies on the measurement, evaluation, and presentation of data on cost and cost-utility/effectiveness/benefit in relation to cancer-specific issues.

For more information on the announcement visit <http://grants.nih.gov/grants/guide/pa-fi/PA-06-304.html>.

GRANT OPPORTUNITIES AVAILABLE: DRUG AND ALCOHOL ABUSE PREVENTION AND TREATMENT

The National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) are seeking grant applications for health services research on the prevention and treatment of drug and alcohol abuse (PA-06-307).

The goals of the health services research programs at NIDA and NIAAA are to answer questions central to the delivery of prevention and treatment services for all substances abuse: What works? Under what circumstances? For which conditions? and, At what cost? The Institutes seek to stimulate research that will improve the accessibility, utilization and quality, effectiveness of drug-use disorders and/or alcohol-related problems. Ultimately, the institutes seek to reduce the consequences of drug and/or alcohol use and co-occurring medical, psychiatric, and behavioral problems.

The institutes encourage investigators to design research proposals that will advance the delivery of drug and/or alcohol abuse care, so that science-based prevention and treatment services are adopted in diverse settings, effectively implemented by a range of providers, and produce sustainable effects at reasonable cost for all those who need interventions.

Research areas of interest include:

- Factors that affect the delivery of drug and/or alcohol abuse prevention, treatment, and related services: social factors, personal behaviors and attributes, financing, organization, management; and health technologies;
- Dimensions of drug and/or alcohol abuse prevention, treatment, and related services: accessibility, utilization, quality, effectiveness, and costs;
- Processes of (a) blending evidence-based drug and/or alcohol abuse prevention and treatment practices into community-based care, and conversely, (b) translating the questions of concern to practitioners into rigorous research; and

Development or refinement of research tools – including study designs, measurement instruments, and data analytic methods – to facilitate higher quality health services research on drug and/or alcohol abuse. For more information visit <http://grants.nih.gov/grants/guide/pa-files/PA-Or-307.htm>.

COSSA WELCOMES NEW STAFF

La Tosha Lewis has joined the staff as Assistant Director for Government Relations. She will spend part of her time as COSSA's office administrator and part of her time assisting with COSSA's lobbying efforts.

La Tosha recently assisted the National Humanities Alliance with their Humanities Advocacy day. She was a government relations assistant at the National Cable and Telecommunications Association and has also provided administrative support to a number of non-profits, government relations firms, and political organizations in Washington. She began her Washington career as a policy assistant for the U.S. House of Representatives Democratic Caucus.

A native of Tampa, FL, La Tosha earned a dual B.A. in political science and advertising from Iowa State University.

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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.

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