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SENATE APPROPRIATORS HEAR FROM ZERHOUNI

On April 1, 2004, all 27 Institute Directors of the National Institutes of Health (NIH) appeared with agency Director Elias Zerhouni before the Senate Labor, Health and Human Services, and Education Appropriations Subcommittee.

Subcommittee Chair Arlen Specter (R-PA) opened the annual hearing by asserting that "medical science and humanity are deeply indebted to the research that comes out of NIH." Declaring that the budget process is always complicated, Specter further observed that his "instant response" upon the completion of the five-year doubling of the agency's budget, was to "triple it." There is "no higher priority," the Chairman stressed. He noted that Ranking Member Senator Tom Harkin (D-IA) agrees with him and they both understand that you have to cross party lines to get things accomplished. But it will "get you in trouble," Specter warned, noting that his Republican primary opponent "thinks that you should not talk to the other side." That opponent, Rep. Patrick Toomey (R-PA), was author of the amendment to the 2003 House Labor HHS appropriations bill last July to rescind the funding for five previously funded sexual behavior and health grants. The amendment was narrowly defeated. (See *Update*, July 14, 2003).

Underscoring that the Subcommittee is working with a tight discretionary budget, Specter highlighted his success at getting an amendment to the Senate's version of the nonbinding budget resolution for an additional $1.3 billion for the NIH. He recapped that during consideration of the amendment "strenuous arguments" were raised by his Senate colleagues that other Federal science agencies deserve increased resources.

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Inside UPDATE…

NSF TOLD IT'S TIME TO GET REALISTIC

On April 1, the National Science Foundation (NSF) faced the House VA, HUD, Independent Agencies Appropriations Subcommittee, chaired by Rep. James Walsh (R-NY). Although the Subcommittee has provided NSF with substantial increases in the past, the Chairman and Ranking Member Alan Mollohan (D-WV) made it clear to NSF Acting Director Arden Bement and National Science Board (NSB) Chairman Warren Washington that the current budget situation has made funding issues "a challenge."

While praising NSF investments as one of the "reasons we lead the world economically," Walsh and Mollohan suggested that doubling the Foundation's budget,

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Specter acknowledged that he agrees with this point, but asserted that "we can afford the funding for research," and added that "It is the best investment we are making."

He then noted that NIH has its own problems including the appearance of conflict of interest and issues surrounding compensation. Both issues are being addressed, he continued. Specter articulated that the agency is also being attacked on an ideological level and referenced the November 28, 2003, editorial, *Don't Let Ideology Trump Science* in the journal *Science.* Referencing the "amendment offered by Rep. Pat Toomey to strike four NIH grants because sex was mentioned in the title," Specter observed that "if you have sex in the title it makes a good 30 second commercial" to use against your opponent. "Surprisingly," Specter noted, "it almost passed." He also noted that Toomey has voted against every domestic spending bill which includes funding for Head Start and labor reform. "You have to be prepared to defend yourself," Specter warned the NIH director. And prevail, he added.

Harkin commended Zerhouni for his efforts to develop the NIH Roadmap and thanked him for his leadership. He applauded the Director for "including more risk taking" in the Roadmap. Harkin, as did Specter, expressed his concern regarding the reneging of the NIH promise to include a 3 percent inflationary increase for grants. The FY 2005 budget would allow only for a 1.9 percent increase in the average dollar amount of research grants. Researchers, Harkin noted, will receive less funding than what the NIH committed to them. "Will it cause them to change their research in midstream," he asked. Noting that he understands Zerhouni's dilemma and the trade off he is being forced to make – to either maintain the number of grants supported by the NIH or increase the size of the grants – Harkin remarked that "this is why we need to actually get this budget back up. I am particularly concerned about the years ahead," Harkin lamented.

NSF and Intelligence Agencies Priorities

Ted Stevens (R-AK), Chair of the full Senate Appropriations Committee, observed that the NIH was "more important to the future of the country." The "long range impact of NIH is staggering," he added. That said, Stevens noted that increasing the budgets of the National Science Foundation and the Intelligence agencies will take precedent this year.

'Obesity Lends Itself towards Prevention Research'

Senator Thad Cochran (R-MS) noted that he was "impressed with the NIH's work in health disparities." He expressed that he was pleased to see the agency "exploring research previously relegated to a low priority." Cochran highlighted the collaboration of the National Center for Minority Health and Health Disparities (NCMHD) and the National Heart, Lung, and Blood Institute (NHLBI) with the University of Mississippi and Jackson State University on the Jackson Heart Study. He also emphasized the need for "more research to be conducted in the places where we are experiencing health disparities." It is "long overdue," the Senator observed.

Cochran wanted to know "what emphasis" the agency was putting toward fighting obesity. "It is important" to the NIH, Zerhouni responded, and informed the subcommittee that NIH has been funding research on obesity the past 10 years. He noted that in 1996 obesity was one of the agency's top ten research topics. The rate of increase in the number of Americans overweight or obese, however, was greater than the agency expected, he explained. Zerhouni noted his creation of the NIH-wide Obesity Task Force, which has already developed a strategic plan. The budget for obesity research, explained Zerhouni, more than quadrupled, from $86 million to $440 million, while the rest of NIH doubled in funding.

Are you concentrating the funding in areas disproportionately affected?, Cochran asked. Zerhouni responded that NIH research will focus on childhood obesity in rural and minority areas. Echoing Cochran, Specter also underscored that obesity was of enormous importance and asked for a written response from the Director as to what can be done by the NIH to fight the increasing trend toward obesity by Americans.

Harkin expressed his surprise at the recent CDC data which indicates that obesity is surpassing tobacco as the leading risk factor for premature death. "Is it not easier not to become obese?," the Senator asked. Obesity tends to lend itself towards prevention, Harkin stressed. He further emphasized that the National Institute for Child Health and Human Development (NICHD) should have a leading role in this area.

Zerhouni responded by noting that the agency plans to focus on aspects of obesity "to stop the leading edge. The earlier we intervene, the more likely we are to

dampen the trend," the Director added. He further explained that the NIH also plans to look at the end of the spectrum and also address the co-morbidities associated with the morbidly obese. Noting that Zerhouni's answer sounded as if there would be a focus on finding a pill to stop these co-morbidities from occurring, Harkin reiterated that his "nonscientific" opinion is that the agency's efforts should focus on children and preventing obesity from occurring.

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recently enacted in the 2002 NSF Reauthorization Act, was now "unrealistic." In addition, the NSB's report *"Fulfilling the Promise,"* produced in response to a provision in the authorization bill asking what NSF would do with its expanded funding, which called for a $19 billion NSF budget, was also dismissed by the Subcommittee as "out-of-touch" with present budget realities. As the Chairman pointed out, the FY 2005 House budget resolution calls for flat funding of the Foundation until FY 2009.

Given constrained Federal resources, Walsh asked about the NSF's priorities and the possibility of having to choose to scale back some of the major proposals, including Nanotechnology. Bement responded that a flat appropriation would cause NSF to "stick to its knitting," and might require some priorities to "have to wait for awhile." He did not offer any specifics.

Panel members expressed their concern with the continued problem of "feeding the pipeline," particularly with American students, to develop new scientists and engineers. They questioned the proposed move of the NSF part of the Math and Science Partnership program to the Department of Education. Although Bement explained the rationale for the move, Washington, as he did at the Senate hearing, expressed the NSB's opposition to the proposal. Committee members appeared to agree with Washington.

Walsh inquired about the impact of President Bush's Moon/Mars proposal on the NSF budget, given that NASA is also under the jurisdiction of the Subcommittee and the probability of a zero-sum funding situation. Bement noted that some of NSF's research projects relate to the proposed missions. As an example, he mentioned research on "human behavior in closed environments."

The hearing also explored the perennial question of individual investigator-initiated research vs. centers. Walsh cited data that indicated NSF continued to move in the direction of creating more centers, including three in the social/behavioral sciences. He expressed concern that this emphasis led to reductions in funding for the "core" research in NSF's individual programs. Bement suggested that the conduct of science was moving toward large interdisciplinary projects that made the center model advantageous. He also indicated that the ratio between NSF funding for individual and small group research projects and centers had changed from 59 to 6 in 1991 to 56 to 8 in 2001, not a significant difference.

Now that NSF has appeared before both its appropriations panels, it is unclear how the schedule for the rest of the year will play out. The House and Senate are still negotiating the FY 2005 budget resolution. House Appropriations Committee Chairman C.W. Bill Young (R-FL) has floated the idea of an early Omnibus spending bill that would include all agencies and programs, so that the appropriations process would get done with plenty of time for Members to go home and campaign. It is also interesting that Young's counterpart in the Senate, Sen. Ted Stevens (R-AK) announced that increasing NSF funding was one of his priorities for this year (see NIH hearing story in this issue).

COSSA Testifies to Panel

On March 25, Irwin Feller, Senior Visiting Scientist at the American Association for the Advancement of Science and Professor Emeritus of Economics at Penn State University, presented COSSA's testimony to the House VA, HUD, Independent Agencies Appropriations Subcommittee. Feller, who is also the Chairman of NSF's Social, Behavioral and Economic Sciences Directorate (SBE) Advisory Committee, discussed the NSF's FY 2005 budget proposal.

Reflecting the Congressional and Administration commitment to double NSF's budget and the Coalition for National Science Funding's (of which COSSA is a member) statement, Feller argued for providing NSF a significant increase above the proposal to $6.4 billion in FY 2005. He noted that NSF "was a catalyst" for providing research opportunities for those in universities and elsewhere.

Feller strongly supported the NSF priority in Human and Social Dynamics (HSD), asking for an increase in its budget to $30 million. He noted the strong interest in the priority, indicating that the first major HSD solicitation had garnered over 1,000 letters-of-intent from researchers in all disciplines from around the country. HSD's emphasis on studying change makes it an important area that deserved increased support.

He also made a strong case for improving NSF's statistical capability through enhanced funding for the Science Resources Statistics division of the SBE directorate. Feller stressed the importance of improved data collection for understanding the many issues that face the scientific research community, particularly those involving science education and training.

A copy of COSSA's written testimony to the Subcommittee is available at www.cossa.org.

GERBERDING LAUDED AT HOUSE APPROPRIATIONS CDC HEARING

On March 31, Centers for Disease Control and Prevention (CDC) Director Julie Gerberding appeared before the House Labor, Health and Human Services (HHS), Education Appropriations Subcommittee to present testimony regarding the CDC's FY 2005 budget request. Gerberding was warmly received by Subcommittee Chairman Ralph Regula (R-OH), who opened the hearing by saying the Subcommittee is "very impressed" by Gerberding's work and was interested to hear what the Director "sees as the future challenge for CDC and how we can help…enhance your [agency's] service to the American people."

Gerberding's testimony focused primarily on the two overarching health protection goals guiding the CDC's future efforts: (1) preparedness against infectious, environmental, and terrorist threats and (2) health promotion and prevention of disease, injury, and disability. Gerberding emphasized that in order for the CDC to be successful, it must further modernize public health through scientific research. She told the Subcommittee that "we are working hard on our public health research," and, citing obesity epidemic as the principal example, Gerberding went on to explain how the "research that led to this knowledge and the efforts to define the preventable risk factors is one example of public health research and how it continues to develop the science base that supports our programs, our policies, and our efforts so that we have the credibility we need to take the appropriate steps."

Following Gerberding's remarks, Subcommittee members launched into an extensive question and answer session with the Director that helped to further define the CDC's increasing role in combating chronic illness and as the global leader in the fight against bioterrorism and infectious disease. Although many of the questions and comments were strongly supportive of CDC's present work and future initiatives, several of the members voiced concerns that obesity and its complementary initiatives were overshadowing HIV/AIDS, mental health, and other chronic illnesses. Notably, Rep. Kay Granger (R-TX) twice raised concerns about the health protection initiative "Steps for a Healthier U.S." and the Administration's decision to divert funds from successful programs such as VERB Campaign, which encourages young people ages 9-13 to be physically active every day, and Vaccines for Children. Gerberding successfully assuaged Granger's concerns by explaining that many of the CDC's public health initiatives have an "extinction factor" in that the public is vulnerable to short attention spans with messages. She also notes that programs like Vaccines for Kids, which will expand vaccination locations and increase eligibility for the upcoming fiscal year, have received funding through other congressionally provided resources.

Rep. John E. Peterson (R-PA) lauded Gerberding and HHS Secretary Tommy Thompson as "shining stars" and suggested that the Subcommittee initiate a national debate by holding an event on health promotion and obesity. Gerberding, Thompson, Surgeon General Richard Carmona, and President Bush would all be invited to participate. Rep. Rosa DeLauro (D-CT) and Regula enthusiastically lent their support to Peterson's proposal.

CONGRESS BRIEFED ON SELF MANAGEMENT OF CHRONIC ILLNESS RESEARCH

More than 45 percent of adults struggle with a chronic health condition that affects their daily activities. From diabetes to asthma, heart disease, depression, obesity, and AIDS, more and more Americans are living with chronic illnesses. More than 90 million Americans live with one or more chronic illness; at least 22 million live with three chronic illnesses. Coping with a complex chronic illness such as diabetes affects the individual as well as family members throughout the entire lifespan.

On March 12th, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR), along with the Decade of Behavior, the American Psychological Association, COSSA, the Federation of Behavioral, Psychological and Cognitive Sciences, and the Society for Research in Child Development, sponsored a congressional briefing to bring the need for additional research to help

Americans effectively manage their chronic conditions to the attention of policymakers. Three distinguished social and behavioral scientists, Jacqueline Dunbar-Jacob, James Hill, and Dana Goldman, discussed the current scientific knowledge about self-management and directions for research that have the potential to improve the ability of people to manage and enhance their health.

Virginia Cain, Acting Director of the National Institutes of Health (NIH) Office of Behavioral and Social Sciences Research (OBSSR) served as the event's moderator. She informed the audience of Congressional staff, NIH officials, and scientific community representatives that the issue of self management is becoming critically important. We are seeing more and more cases of chronic disease, Cain explained, that are not readily fixed and require ongoing management by the patient. This includes issues surrounding adherence to the medical regimen, including medication regulation and/or behavioral intervention, frequently both, she noted. Genetic progress, Cain pointed out, does not explain everything; individual behavior and the environment can affect outcome. She underscored the fact that later disease states have routes in early behavior.

Accordingly, in its FY 2005 budget proposal, NIH noted its intention to increase the agency's focus on chronic disease, which, NIH stressed, has overtaken acute conditions as the nation's leading killers.

Complexity of Regimen Management

Jacqueline Dunbar-Jacob, University of Pittsburgh, began the discussion by highlighting some of the difficulty individuals have in managing their chronic conditions in a presentation entitled *Taking Control of Our Health – The Complexity of Regimen Management in Chronic Illness*. She defined chronic disorders as "permanent or ongoing conditions requiring long periods of observation and management." Such conditions include: heart disease, arthritis (the most common), diabetes, cancer, chronic obstructive pulmonary disease, asthma, obesity, and HIV/AIDS, she noted.

According to Dunbar-Jacob, chronic conditions are experienced by approximately 45 percent of Americans; 24.6 percent of children under age 18, 35.1 percent of young adults (18-44), 67.7 mid-life adults (45- 64), and 87.6 of adults 65 years of age or older. Clearly, it is a major problem for the country and health care, she asserted.

Dunbar-Jacob explained that the goals of treatment are to (1) slow the progression of the disease; (2) prevent complications; (3) maintain function; and (4) sustain the quality of life "so that individuals can work and manage their own lives in their own homes." These conditions are managed through medication, physical activity, dietary modification, and other lifestyle adjustments.

She observed, however, that any one chronic condition requires management of several regimens and used high blood pressure as an example. An individual with high blood pressure, Dunbar-Jacob observed, needs to take one or two medications, maintain a salt-controlled diet, perform regular physical activity, and monitor their blood pressure. At least 22 percent of Americans have two or more chronic conditions, she noted. For instance, according to Dunbar-Jacob, diabetes is often accompanied by high blood pressure, high cholesterol, obesity/ overweight, vision impairment, or arthritis, each with its own regimen.

Clinical support for regimen management for individuals with chronic disease averages only about one hour of health system contact per year, spread out over three visits. Accordingly, after being diagnosed and given prescriptive advice, with episodic monitoring, patients must perform the day-to-day management of their own regimen and disease(s) themselves, she explained.

How successful is this partnership in managing chronic disease? Only 30 percent of persons with high blood pressure are controlled, a mere 28 percent of persons with diabetes are controlled and approximately 39 percent of individuals are of a desirable weight. Conversely, specific modifiable behavioral factors account for: 70 percent of stroke, 70 percent of colon cancer, 80 percent of coronary heart disease, and 90 percent of adult onset diabetes.

Contributions to poor regimen management include: errors in managing symptoms or side effects; errors in carrying out the regimen, both intentional and unintentional; belief about disease and/or treatment; tired of carrying out regimen; inadequate education and/or clinical support; and a lack of awareness/monitoring of behavior, explained Dunbar-Jacobs. Behavioral errors, meanwhile, include: failure to adopt the regimen, early stoppage of treatment, reduction in levels of treatment, over treatment, variability in the conduct of treatment, "dosage" interval errors, performance errors, and management of symptoms, she further explained.

To improve this picture, Dunbar-Jacob stressed the need for intervention research, behavioral assessment

research (self-monitoring), and recognition of the factors that contribute to successful self-management. "We need to develop and evaluate self-monitoring technologies that are accurate, provide feedback, and are portable and easy to use," she stressed. She also called for an examination of factors that contribute to effective self-management, noting that most studies have relied on self-report of behavior. "We are unlikely to change these data until we learn how to promote self-management capabilities among patients," Dunbar-Jacob concluded.

Self Management and Health Disparities

According to Dana Goldman, RAND, Inc., there are large differences in health outcomes by socioeconomic status (SES) that cannot be explained fully by traditional arguments such as access to care and poor health behaviors. Goldman hypothesized that there are health benefits to having a college degree. Discussing his research, which examined differences by education in treatment adherence among patients with diabetes and HIV, Goldman noted that for both illnesses he found that significant effects of adherence are much stronger among patients of higher SES.

Echoing Dunbar-Jacob, Goldman noted that there are a lot of new treatments available and they are complicated. "Treatment regimens often require high quality and persistent self-management on a daily basis, and not all patients are equally adept at complying," he continued. Compliance requires an understanding of the medical necessity and an ability to select the most appropriate regimens, he explained. It also requires "a willingness to internalize the future costs of incomplete compliance," Goldman said.

He noted that HIV provided a good test of his hypothesis. Highly active antiretroviral therapy is complicated and often involves over two dozen pills daily. In addition, medications must be carefully synchronized with meals and each other. "It is a pernicious regimen," he explained. If you do not adhere and are using such therapy as highly active anti-retroviral therapy, given the biological nature of the disease you are actually making your health worse, Goldman emphasized. The better educated adhere to treatment, explained Goldman. Education matters as much as race and sex for HIV adherence, he emphasized, noting that adherence explains health outcomes among HIV survivors.

Diabetes, he noted, is the prototype chronic illness. It is very hard to manage. Tight glycemic control is the key to better outcomes for both Type 1 and Type 2 diabetes, he explained. It requires patients to continually monitor levels of glucose-medication titration. When it came to taking their diabetes medication, Goldman found that the less educated switched both oral medications and insulin more.

Summarizing his findings from the Health and Retirement Survey (HRS), supported by the National Institute on Aging, Goldman stated his research shows that the better educated are more likely to maintain high quality treatment and high quality treatment leads to improved general health.

The findings of the research suggest several explanations for why education matters, Goldman noted. Good adherence to a treatment regimen requires several attributes that may be strongly related to education, including complying with physician orders through comprehending what is being prescribed and adjusting the daily routine to execute it. The results also suggest differential health outcomes across SES levels because of different abilities to self-manage a demanding behavioral regimen are amenable. "Less educated patients would benefit more from frequent follow-ups, simpler drug regimens, and clear instructions about how to comply and the consequence of noncompliance," Goldman asserted.

Goldman concluded by emphasizing that the study demonstrates that SES disparities can be altered through clinical intervention. Intensive monitoring, he stressed, is more valuable for the less-educated.

Our Most Serious Public Health Problem

According to James O. Hill, University of Colorado Health Sciences Center, 75 percent of Americans will be overweight or obese if the current trend in obesity continues through 2008. If those trends continued further, all Americans will be obese in 2040, Hill joked. Hill cautioned that children are not immune to overweight/obesity. Approximately 15 percent of kids are overweight/obese and that may be an under estimation, warned Hill.

Obesity is related to the diseases we die from, Hill observed. There are problems reversing the trend because of the complexity of the disease. It is one of the most complex things we have ever dealt with, he underscored. It is an issue that crosses disciplines: biology, economics, sociology, and city planning. A lot of people, however, are hung up in the complexity, he continued. He cautioned that we cannot concentrate on individual behavior or environment alone.

Sixty percent of Americans get no physical activity. Today's sedentary lifestyle is totally wrong for the

environment. We are using our heads instead of our physiology, Hill explained – we have the right biology for a different environment. We have taken the physical activity out of work and can go about the act of daily living without any physical activity. We have more leisure time; we spend more time in front of the HDTV. Change is hard to do in this environment, Hill emphasized.

We are not going to fix the obesity problem in the U.S. by the next election, he warned. We have to come up with a logical plan and set specific behavior goals. Hill stressed the need for individuals to manage their weight like they manage their finances. We can get behavior change, he noted, but is difficult to sustain. We also have to change the environment to support and sustain these goals, Hill continued.

He cited several relative successful Federal campaigns as examples of what is needed, all of which had very specific behavioral goals. To lower the number of deaths in car accidents, we promoted the use of seat belts; to address suboptimal infant nutrition, we encouraged mothers to breast feed; to limit the negative consequences of tobacco use, we told individuals not to smoke; and to prevent the negative environmental impact of waste, we implemented recycling programs, noted Hill.

We do not have a comparable solution to combat the negative consequences of obesity, lamented Hill. He noted that Healthy People 2010 contains two goals: (1) to reduce obesity to 15 percent and (2) to reduce childhood obesity to 5 percent. "What Healthy People 2010 does not have incorporated in it is how to do this," explained Hill. We don't have the solution, Hill asserted. We have to come to better agreement on what change is needed, he explained.

'Prevention is Doable'

There are huge benefits to a 5-10 percent weight loss, said Hill. What we have to do first is to prevent weight gain. "Prevention is doable," Hill insisted.

colleagues test the hypothesis that small lifestyle changes can be achieved and sustained and can prevent weight gain. He warned, however, that the program has not been successful in producing and sustaining large lifestyle changes.

America on the Move inspires people to make small changes to stop weight gain. He shared that most weight gain is caused by less than 100 excess calories per day. Accordingly, most weight gain can be prevented by modifying energy balance by this amount. This includes increasing walking by 2000 steps per day and choosing one behavior each day to eliminate 100 calories. Individuals continue to make more small changes by making incremental changes in walking and improving diet quality. The program also provides programs for target populations to reinforce the simple change messages. It creates a grassroots initiative to get Americans excited about taking control of their weight, Hill explained.

The program can be tailored for individuals, schools, worksites, churches and other organizations, families, health care professionals, and communities, said Hill. The long term goal is to work to change the environment and teach our children the skills they need to manage their weight in the current environment, which include skills in energy balance, skills learned in school, and skills reinforced in the "real world" of restaurants and grocery stores.

America on the Move works, emphasized Hill, because it focuses on the consumer and inspires change. It is simple and fun. It is about energy balance. It advocates small changes; people can actually do what is recommended. It starts where people are right now. It provides a starting

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