

ELECTION 2000: IMPLICATIONS FOR SCIENCE AND TECHNOLOGY *AS*

"Would you tell me, please, which way I ought to go from here?"

"That depends a good deal on where you want to get to," said the Cat.

"I don't much care where --" said Alice.

"Then it doesn't matter which way you go," said the Cat.

"-- so long as I get SOMEWHERE," Alice added as an explanation.

"Oh, you're sure to do that," said the Cat, "if you only walk long enough."

- from "Alice in Wonderland"

Under the new president, whether his name is Gore or Bush, the "partisan acrimony" that exists in Congress will continue, agree Norman Ornstein and William 'Skip' Stiles, two observers of the political process. Ornstein is resident scholar at the American Enterprise Institute and a well-known political analyst. Stiles was legislative director for the Democratic staff of the House Science Committee under the late Representative George Brown (D-CA) and is currently the executive director of the Genetic Resources Communications System.

They were the speakers at a November 15 breakfast, "Election 2000: Implications for Science and Technology," sponsored by the Washington Science Policy Alliance (a loosely-knit coalition of institutions) and the American Association for the Advancement of Science's Directorate for Science & Policy Programs. The sponsors of the event acknowledged that it was planned on the presumption that we would have a President-elect.

"Who knows where we are?," began Ornstein. Partisanship does not necessarily lead to "utter gridlock," he explained. We are in for an "era of limited and incremental policy making," Ornstein told the standing-room-only audience of advocates for science and technology funding.

(Cont'd on page 2)

WITH ELECTION ON HOLD, SOME FY 2001 BUDGETS REMAIN UNDONE *AS*

With the results of the presidential election still in dispute on November 14, Congress returned to Washington and almost immediately recessed again until December 4. They decided that it would not be useful to continue to debate the remaining issues on the four uncompleted Fiscal Year 2001 appropriations bills. Congress passed, and the President signed, a sixteenth Continuing Resolution to keep the government operating until December 5. By then the fiscal year will be two months old.

The four outstanding appropriations bills are: Labor, Health and Human Services, and Education; Commerce, Justice, State, and the Judiciary; Legislative Branch; and Treasury, Postal Service, and General Government. (The District of Columbia appropriations bill passed Congress and awaits the President's signature.) With the delay in funding these departments and agencies, the National Institutes of Health is concerned that the assumed 15 percent increase for next year cannot be put into current use — the Continuing Resolution only allows agencies to spend at the previous year's levels.

With the partisan rancor continuing over the presidential election, what will happen when the 106th Congress returns for its swan song after Thanksgiving remains unclear. Will there be a swift conclusion to the budget wrangling, or will the fallout from the election and other factors prevent easy solutions?

Inside UPDATE . . .

- Two Social Scientists Win the National Medal of Science
- Human Genome Research Yields Opportunities for Study
- Sources of Research Support

TWO SOCIAL SCIENTISTS WIN THE NATIONAL MEDAL OF SCIENCE *CR*

On November 13, President Clinton announced that economist Gary Becker and geographer Gilbert F. White are recipients of the 2000 National Medal of Science award, the nation's highest science honor. The medals will be conferred at a ceremony at the National Building Museum in Washington, DC on December 1, 2000.

Becker, of the University of Chicago, pioneered the economic analysis of racial discrimination and led recent developments in learning how social forces shape individual economic behavior.

White, of the University of Colorado, Boulder, is recognized for his approaches to using non-structural methods to reduce damage from flooding. His research on floods, their social costs and benefits, and society's management and mismanagement of them provided the basis for a new research paradigm and more enlightened public policy.

"These exceptional scientists and engineers have transformed our world and enhanced our daily lives," noted President Clinton when announcing the awards. "Their imagination and ingenuity will continue to inspire future generations of American scientists to remain at the cutting edge of scientific discovery and technological innovation."

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Established in 1959 by Congress and administered by the National Science Foundation, the National Medal of Science honors individuals for contributions to the present state of knowledge across a variety of science frontiers. Including the 2000 recipients, the Medal of Science has been awarded to 386 distinguished scientists and engineers.

ELECTION (Cont'd from page 1)

Regardless of who eventually wins the White House, Ornstein said, there is only one consensus that is likely to emerge and that is to double the budget of the National Institutes of Health (NIH). There is a big impetus to do so; it is a "slam dunk" for everyone, he declared. However, basic research and development (R&D) in the Department of Defense's budget, he suggested, will be harder to come by. The other "claimants" for research funding will have to wait in a long line, he continued. Ornstein added "a tiny caveat:" Vice President Gore has a continuing and abiding interest in science and the cutting edge of new technology. Gore, said Ornstein, would pay closer attention to those issues.

According to Stiles, continued success for the science community will depend on whether or not the Office of Science and Technology Policy (OSTP) is able to continue its alignment with the power center of the White House (the Chief of Staff and the Council of Economic Advisors) — something that current OSTP Director Neal Lane has done very effectively, he underscored. He indicated that there may be a change in the way science is used in the regulatory process.

Agreeing with Ornstein regarding the current political situation and its impact on science and technology issues, Stiles made some further predictions. He said that the NIH will continue to do well. The National Science Foundation's recent gain — a 14 percent increase in FY 2001, due largely to Lane's influence — is in no danger (see *Update*, Oct. 23, 2000). The Department of Defense's R&D budget will go up. The Department of Commerce has escaped being abolished, and no one will want to spend scarce political capital on that issue, said Stiles. NOAA (the National Oceanic and Atmospheric

Administration), he continued, is not under any great threat. The Department of Energy is a survivor. The Environmental Protection Agency is not an issue and NASA has no problem, said Stiles. Research and Development, however, is affected by general trends in discretionary budget. It is too early for much other speculation, concluded Stiles.

Congress Will Mirror a "Survival Show"

Watching Congress will be like viewing one of those "survival shows" — completely unpredictable, Stiles exclaimed. The Senate is in a deadlock, the House is being run by a coalition, and we don't know who the President will be. He noted that major "shifts by the Congress will be unimaginable." Under a Bush presidency, the "stop jam" will be in the Senate under Minority Leader Tom Daschle (D-SD), Stiles claimed.

Fights for House committee chairmanships will create turmoil, Stiles predicted. This will result from the term limits imposed by the new Republican majority in 1995 to prevent long-serving chairmen from becoming too powerful; this situation will also deprive the House of seniority expertise, said Stiles. Coincidentally, that afternoon, House Republicans voted to retain the six-year term limits on the tenure of committee and subcommittee chairmen. A proposal by Representative Ileana Ros-Lehtinen (R-FL) to eliminate the term limit was soundly defeated by a vote of 27 - 141, as was (by a voice vote) a proposal eliminating the term limit for subcommittee chairs. Furthermore, under a Bush administration, one can see many Republican staffers moving downtown to the White House, Stiles Suggested.

Compounding the change, many senior Democrats talked into running for reelection this year are expected to announce their retirements during the 107th Congress because the following House will reflect reapportionment resulting from the 2000 Census. Speaking from the experience of working for a member whose home was twice reapportioned out of his congressional district, Stiles stressed that a reapportioned Congress will be very constrained in what it can accomplish.

The silver lining with regard to science and technology, he interjected, is that Representative Sherwood Boehlert (R-NY), should he get the

chairmanship of the House Science Committee, has a good relationship with the Ranking member, Representative Ralph Hall (D-TX).

Governing Will Be Extremely Difficult

Ornstein declared that under the best circumstances, during the next two years, governing will be extremely difficult. We have the closest margin of partisanship, in every segment of American society, ever, in the history of America, he remarked. The House and Senate have the closest margins ever, party identification is dead even, and once they are finally determined, he argued, state legislatures will be dead even. It is clearly a reflection of change, said Ornstein. We have two equal parties; this trend is likely to continue, he predicted.

The outcome of the presidential election, Ornstein continued, could make a significant difference in the future balance of power. He suggested that we have a formula for turning a slim margin of power into a significant margin: since whomever wins the presidency will do so under a cloud, there could be more upheaval over the next two years that could help one party (possibly the one that loses the White House) to emerge victorious.

Both also agreed that an increase in the budget of the Federal Election Commission (FEC) is almost certain.

Personnel Uncertainties in the Transition of Power

Ornstein also expressed concern regarding the effect on science and technology of the ability of the President-elect to get his appointments confirmed in a timely manner. Under the Kennedy Administration, he explained, individuals were vetted and confirmed within two months. The Bush and Clinton administrations took an average of nine months to win approval of their key choices. Given the current electoral uncertainty, little is being done as yet for a transition of power, he said.

In addition, Ornstein further warned that there is about to be a generational change in the Senior Executive Service (SES). There is no group of people with the right qualities or the qualifications ready to take over the positions of retiring baby

boomers in SES positions within the government. He again predicted a "huge crisis." It is a problem that we have not even begun to confront, Ornstein concluded.

HUMAN GENOME RESEARCH YIELDS OPPORTUNITIES FOR STUDY *AS*

The National Human Genome Research Institute (NHGRI) "needs the social and behavioral science community," according to Francis Collins, Director of the Institute. Speaking at the American Psychological Association's annual meeting this summer, Collins said that NHGRI has not made the connection between the ethical, legal, and social implications (ELSI) surrounding human genetics and genomics research as vigorously as it needs to.

Acknowledging a role for social and behavioral scientists in genome research, Collins explained that human beings are 99.9 percent alike. The human species is "very young" and can be traced back to 10,000 folks in Africa, he added.

How are we going to get ready to practice genome medicine?, asked Collins. It is a huge challenge. He stressed that there are opportunities for the social and behavioral science community in human genetics and genomics research. He specifically highlighted the need for investigation into how people will react to genetic information in making medical decisions. Although some conditions revealed by genome medicine will require no action, others will prompt a lifestyle change or pharmaceutical intervention, Collins underscored.

All of us are at risk for something, explained Collins. We each have approximately 40 to 50 glitches in our DNA that put us at risk for disease. Although, many of these glitches may not be revealed, Collins argued that scientists do not know how people will react to the genetic information that is revealed about themselves or others. This presents an opportunity to do some interesting research, he emphasized.

Referring to the difficult and complex problem of information exchange between patients and their doctors, Collins emphasized that many physicians are not skilled at conveying such information.

Similarly, many individuals receiving the information will not be able to "translate it into a quantitative schema," he said. And the more we know, declared Collins, the more complicated things will become. On the other hand, he noted, genetic tests do not always give you bad news.

Collins explained that NHGRI has five percent of its budget (a major commitment on the part of the Institute) set aside to fund this kind of research. Social scientists, ethicists, biologists, chemists, engineers, and theologians all have a role to play in this enterprise. The potential is enormous, Collins concluded.

NHGRI's ELSI Program

Within NHGRI's Division of Extramural Research resides the Ethical, Legal, and Social Implications (ELSI) Research Program. The program supports basic and applied research that identifies and analyzes the ethical, legal, and social issues surrounding human genetics research. The ELSI Research Program, established in 1990, is currently the largest federal supporter of bioethics research, with an annual budget of more than \$12 million.

Since 1990, the ELSI program has supported nearly 200 research and education projects and conferences. Activities supported by the project have ranged from relatively small historical, philosophical, and theoretical research projects and legal analyses of specific ELSI issues to large clinical studies designed to examine the efficacy of particular genetic testing or educational interventions. Principal investigators have come from a variety of disciplines, including philosophy, nursing, behavioral sciences, anthropology, history, law, genetic counseling, education, and consumer advocacy.

NHGRI's ELSI program has been organized around four research areas: (1) privacy and fairness in the use and interpretation of genetic information; (2) clinical integration of new genetic technologies; (3) issues surrounding genetics research; and (4) public and professional education.

In 1998, the ELSI Research Planning and Evaluation Group (ERPEG), the ELSI programs at the Department of Energy, and the NIH identified

five new goals for the ELSI Research Program for 1998-2003. They are:

- 1) Examine the issues surrounding the completion of the human DNA sequence and the study of human genetic variation. This research will raise a number of unique ethical, legal, and social issues, many of which may be of special concern to individuals from diverse communities. According to NHGRI, these issues will become more acute if genetic variation research reveals data on the interactions between genotype, disease, and traditional, socially-constructed concepts of race, ethnicity, and culture.
- 2) Examine issues raised by the integration of genetic technologies and information into health care and public health activities.
- 3) Examine the issues raised by the integration of knowledge about genomics and gene-environment interactions into non-clinical settings.
- 4) Explore the ways in which new genetic knowledge may interact with a variety of philosophical, theological, and ethnic perspectives.
- 5) Explore how socioeconomic factors, gender, and concepts of race, ethnicity, and culture influence the use and interpretation of genetic information, the utilization of genetic services, and the development of policy.

For more information on NHGRI's new goals for the Human Genome Project (1998-2003), see the website: www.nhgri.nih.gov/98plan/elsi.

Research Gaps in ELSI Program

Earlier this year, ERPEG released its report, "A Review and Analysis of the ELSI Research Programs at the National Institutes of Health and the Department of Energy," in which ERPEG identifies a number of areas requiring additional attention.

Regarding the issue of genetic discrimination, the group notes that the small amount of "rigorous empirical work on genetic discrimination in the ELSI research portfolio may turn out primarily to be a consequence of the fact there have been relatively few documented cases of genetic discrimination to date." Nevertheless, states ERPEG, "much more

work needs to be pursued in this area." Additionally, more *empirical* work is needed surrounding the experiences of consumers and the attitudes of the general public with respect to "stigmatization" based on genetic status.

While the genetic research portion of the ELSI portfolio has generally been well balanced, the group notes, gaps exist in that area as well. The impact of economic and commercial interests on genomic research and on the development of genetic tests has been largely overlooked. Other topics requiring additional attention, ERPEG states, extend to the ethical problems involved in the design of genomic research studies, how cultural factors influence the way genetic and genomic researchers design and carry out their studies, and how the genetic research enterprise is shaping cultural perceptions of genetics.

The group also identified a number of deficiencies in the education and resources portion of the portfolio. Despite the considerable efforts in ELSI-related education, the report notes that a lack of consensus remains regarding the basic question of what constitutes adequate knowledge of genetics. A major gap in the education and resources portion of the portfolio "is the absence of studies that examine such fundamental issues as what each audience (such as students, teachers, nurses, judges, and the lay public) actually needs to *know* about ELSI." Additionally, the report recognizes that no research has been done to address other basic education issues, such as how various audiences learn genome-related content most effectively.

The report then considers genetic issues in a broader context, drawing attention to the lack of studies in the ELSI program that focus on the interactions between genetic issues and other aspects of the health care environment and society at large. The report emphasizes the under-representation of investigators from certain disciplines such as economics, cultural and physical anthropology, and religious and moral philosophy. The report states that "while some research topics . . . do not lend themselves as easily to broad, theoretical studies, a need still exists for greater cross-fertilization among ELSI researchers and for more involvement in ELSI projects by persons in disciplines that have traditionally been under-represented in ELSI research."

ERPEG'S report highlighted another weakness of the ELSI research portfolio: very few of the principle investigators in funded projects have been members of minority racial or ethnic communities. While this is not unique to ELSI research, the report states, given the significant cultural and societal impact that genetic research and technologies may have on individuals and groups, it is important that the ELSI research programs strive for broader representation in the planning and implementation of their projects.

Solicitations for Research Applications

To facilitate accomplishing the goals set for ELSI research, the NIH recently released three program announcements (PAs) encouraging research applications pertaining to ELSI. In the first program announcement, NHGRI, with eight of the NIH Institutes (Drug Abuse, Aging, Child Health and Human Development, Deafness and Other Communication Disorders, Environmental Health Sciences, General Medical Sciences, Mental Health, Nursing, and Neurological Disorders and Stroke), has reissued the program announcement (PA-00-133) seeking applications that "anticipate, analyze, and address the ethical, legal, and social implications of the discovery of new genetic technologies and availability and use of genetic information resulting from human genetics and genomics research."

The second program announcement (PA-00-132) is supported by NHGRI and the Institutes of Aging, Drug Abuse, Deafness and Other Communication Disorders, and Mental Health. The announcement is designed to solicit small research programs that anticipate, analyze, and address the ethical, legal, and social implications surrounding the human genome project.

The third PA (PA-00-134) is aimed at "developing innovative educational approaches that increase knowledge and understanding of genetics and genomics research and its ethical, legal, and social implications." Applications to the program are expected to focus on developing and evaluating new and innovative interventions that are designed to reach a large and diverse audience or that can be successfully exported to other institutions or learning environments.

NHGRI encourages inquiries regarding these PAs. For general inquiries regarding program issues contact: The ELSI Research Program, NHGRI, Building 31, Room B2B07, 31 Center Drive, MSC 2033, NIH, Bethesda, MD 20892-2033; Tel: 301/402-4997; Fax: 301/402-1950; e-mail: elsi@nhgri.nih.gov; or see the NIH guide at: <http://grants.nih.gov/grants/guide>.

Postdoctoral Fellowships

To develop the cadre of scientists needed to accomplish the goals of the Human Genome Project (HGP) and to use the knowledge, resources, and data that will be generated for further research, NHGRI is providing individual postdoctoral fellowships. The fellowships are designed to train scientists who will have multidisciplinary skills that will allow them to engage in research to accomplish the short- and long-term objectives of the HGP and similar genomic projects. Such training would allow these scientists to take advantage of the resulting genomic data and resources to solve biomedical and bioethical problems.

NIH encourages scientists and scholars at all career levels to apply for the fellowships. Individuals who have already completed one postdoctoral fellowship in another scientific discipline may be eligible for a waiver of the three-year limit on NRSA (National Research Service Award) support to allow the awarding of a postdoctoral fellowship in genomic or ELSI research if the additional training can be justified in the context of the individual's future commitment to pursuing a career in genomic or ELSI research.

For more information regarding the fellowships, contact NHGRI staff: Joy Boyer (joy_boyer@nih.gov), Elizabeth Thomson (elizabeth_thomson@nih.gov), or Jean McEwen (jean_mcewen@nih.gov).

"Decade of ELSI Research" Conference

Finally, the NIH and the Department of Energy will hold a conference on January 16 -17, 2001 to celebrate a decade of ethical, legal, and social implications research. The conference is designed to provide an opportunity to reflect on the past, present, and future of ELSI research and consider its impact on research, health, and public policies and

practices. For more information on the conference see: www.tech-res-intl.com/ELSI/index.asp.

SOURCES OF RESEARCH SUPPORT *CR*

COSSA provides this information as a service, and encourages readers to contact the sponsoring agency for additional information. Further application guidelines and restrictions may apply.

Solicitation for Investigator-Initiated Research by NIH

The National Institute of Justice invites proposals under their (Office of Research and Evaluation) 2001 Solicitation for Investigator-Initiated Research. They encourage proposals that "explore topics of relevance to State or local criminal justice policy or practice with potential for informing policy and practice on a national basis, and proposals that fill important gaps in the development of key areas of scientific knowledge." NIH has recently awarded grants under the investigator-initiated solicitation "ranging from less than \$100,000 to \$300,000 and occasionally more." They encourage researchers from all disciplines to explore opportunities for collaborative efforts.

NIJ requests that (non-binding) letters of intent be received by December 17, 2000. Complete proposals must be received at the NIH by January 17, 2001. Applicants can obtain application forms and proposal guidelines online at www.ojp.usdoj.gov/nij/funding.htm, by mail by calling 800-851-3420, or by fax by calling 800-851-3420 (select option 1, then option 1 again for NIJ; code is 1023).

New Program to Fund Minority Scholars in Health Disparities

The W. K. Kellogg Foundation has awarded a \$1.5 million, three-year grant to the Center for the Advancement of Health to train a new generation of minority scientists in researching the causes of health disparities and in developing solutions. The pilot program will award postdoctoral fellowships to minority scholars at the University of Michigan Institute for Social Research, the Harvard Center for Society and Health, and the Morgan State University Center for Urban Health Assessment, Evaluation, and Policy.

According to David Williams, professor of sociology and program site director at the Institute for Social Research at the University of Michigan, "There is a dramatic need for minority scientists and policy makers not only to be represented but to take leadership roles in promoting good health and in developing health and social policy solutions for the 21st century for our increasingly diverse U.S. population."

The scholars will be asked to examine the causes of health disparities by race/ethnicity, gender, and socioeconomic status and to consider policy solutions. Scholars are eligible for stipends of up to \$50,000 a year for two years, plus fringe benefits and research/travel expenses.

Further information can be found at the Center for the Advancement of Health website: www.cfah.org. Or contact Barbara Krimgold, director of the scholars program: bkrimgold@cfah.org. Applications are due by February 1, 2001.

Research Fellowship Program National Center for Education Statistics (NCES)

Sponsored by the American Statistical Association, this program brings researchers to the NCES headquarters to conduct research using NCES data while interacting with agency staff. Stipend is commensurate with qualifications and experience. Fellowships generally last from six months to a year. The prospective Fellow should have considerable experience in survey methodology or statistical analysis and be able to indicate the value of this program to his/her continued development and to the Center's objectives. Proposals are due December 10, 2000. For more information, contact: Carolyn Kesner, ASA/NCES/NSF Research Fellow Program, American Statistical Association, 1429 Duke Street, Alexandria, VA 22314; (703) 684-1221.

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