

**WRITTEN CONSENT BILL
OPPOSED BY RESEARCH
AND SOCIAL POLICY GROUPS** AS

A broad-based coalition of over 35 groups, including COSSA, held a June 19 press conference to urge Senate defeat of the Family Privacy Protection Act, which opponents say would actually hurt, not help, families. The widely attended event led to a prominent story in the following day's *Washington Post*.

The legislation, H.R. 1271, would require prior written consent from a parent before a minor can participate in most federally-sponsored research. A component of the *Contract with America*, it was approved by the House last year. After recent committee approval, the bill is currently pending before the full Senate. The legislation is opposed by the Clinton Administration and the sponsor of the press conference, the Research and Privacy Coalition, a union of science, education, and social policy groups.

The bill "might look like apple pie and motherhood, but it is a misnomer," said Felice Levine, Executive Officer of the American Sociological Association and moderator of the event. "We all want to help parents," she said, however, "this legislation does not protect parents; it shields them from information they need to know" by jeopardizing their access to essential information on such issues as nutrition, health care, or high risk health behaviors such as drug and alcohol use, teenage pregnancy, tobacco use and violence. "It is rhetoric to characterize this bill as protecting family privacy from the encroachment of research," Levine said.

The Coalition, Levine said, "believes that parents or guardians should be notified if their child is being asked to participate in a federally-funded survey and that parents should also have the right to deny their child's participation. That is not the issue...The problem is that H.R. 1271 imposes a single standard of written parental consent before a federally-funded survey or questionnaire may be given to a minor." Levine emphasized that it "imposes a single

Congressional solution for parental consent in a context that demands multiple approaches, flexibility, and good judgement and... offers little to parents while providing far less than they will need to deal with high risk behaviors...The surveys that H.R. 1271 would stifle or render ineffective are relied on by policy makers, health care providers, parents, pediatricians, law enforcement officials, and all who care about children and youth."

Parents Will Not Return Forms

Phyllis Ellickson, a RAND behavioral scientist, discussed the findings of her research conducted on how written parental consent works and its effects on the quality of information about our kids. According to Ellickson, "many parents do not send in the forms--not because they object to the research, but simply because doing so is just not that important to them." The data on children that will be excluded from research because no form was sent in are disproportionately likely to be minority and high risk kids, she said. "That means we end up with incomplete, inaccurate and biased picture of how well our children are doing and the effectiveness of programs aimed at improving their situation." These problems are "extremely costly and difficult to implement," she added. "For all of these reasons, requiring written parental consent is likely to prevent important research on children from being undertaken at all and to compromise the value of existing national, state, and local data bases about children," she said. She concluded by saying that a drug prevention

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program called Project ALERT, recently ranked as one of only six A-rated drug prevention programs in the U.S., would not have been undertaken if the proposed legislation had been on the books. *As RAND does not take a position of legislation, Ellickson explained that her views were her own.*

"Many critically important scientific studies would be almost impossible to conduct if legislation like H.R. 1271 was passed and implemented," said J. Lawrence Aber, the Director of the National Center for Children in Poverty at Columbia University. Aber, like Ellickson, emphasized that "written consent procedures will reduce the participation of important subpopulations of children...Without rigorous studies of representative samples of children and families, we cannot accurately track trends in the problems children face. We also cannot evaluate the impact of programs and policies enacted by Congress, paid for by the taxpayer and designed to strengthen America's children and families."

Surveys Do Not "Cause Kids to Go Astray"

Expressing his appreciation for family privacy, David Bourne of the Arkansas Public Health Department, said he did "not know of any evidence that surveys cause kids to go astray." Bourne said he uses survey data to "try and prevent chronic disease...Survey research done over time shows which risk factors are improving -- such as cholesterol is going down nationwide - and which are getting worse-

- such as teen smoking is up 30 percent... I need this data." A family physician, Bourne said "research with flexible consent procedures is ethical, it's useful, and the folks back home support it."

Terry Schwantes, chair of the Save Our Schools Campaign in South Milwaukee, Wisconsin and a school board member, said that her experiences "have made several things very clear. I know how important research-based information is to parents, and I know how important it is to parents to understand the variety of factors influencing our children's activities and behaviors. I am also sure that parents want to be able to deal with their children in a positive way using proven methods. On the other hand, I am concerned about protecting children from an invasion of privacy and unhealthy influences...The current regulations for the protection of human subjects do just that."

PETERSEN URGES ATTENTION TO BEHAVIORAL RESEARCH AS

Continue to pay attention to the opportunities in behavioral research, National Science Foundation Deputy Director Anne Petersen, said in remarks to the National Advisory Council on Child Health and Human Development. "NIH Councils have an important responsibility to identify important policy issues, and bring them to the attention of our scientific and professional communities, as well as the broader public," she emphasized. Petersen underscored what she termed as four "extremely important" research and policy issues.

Research Issues

Petersen, a behavioral scientist who is rotating off the council, sought to call attention to the opportunities and challenges of the field. "I believe that once we solve the mysteries of the brain, and human biology more generally, the next major scientific frontier for health and development will be the relationship of these to human behavior," she said. This pattern, she added, "has already been seen in other fields; for example, many believe that the next advances with technology require integrating human factors."

Petersen stressed that "neglect of research on behavioral development places this scientific progress

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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 scientists. *Update* is published 22 times per year. Individual subscriptions are available from COSSA for \$65; institutional subscriptions, \$130, overseas mail, \$130. 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.

at risk." Noting findings reported in a *Science* article by Phil Smith and Barbara Torrey (Feb., 1996) that reveal decreasing funding for social and behavioral research, beyond the overall expected declines in federal R&D funding, Petersen said that "these fields are already behind many others; we cannot afford to place them further behind. Instead, research in key areas needs to be stimulated."

A second research emphasis needing attention, she said, is interdisciplinary research. As discoveries are made in basic disciplines, "the scientific frontier frequently moves to a higher, broader level of analysis, sometimes involving systems of phenomena." For example, she said, "basic discoveries in geology, chemistry, and physics have permitted research on global climate change and its relationship to land, air, and water masses." Eventually, said Petersen, we need "to move from basic findings in biology, psychology, and sociology to understand child health and development in the context of families and communities."

Research Policy Issues

Petersen noted that it is far easier to communicate knowledge about diseases than the basic properties in physics. NSF studies, according to Petersen, "reveal that while the public approves of the federal investment in research, they understand little about the knowledge discovery process and have inadequate information about major scientific findings." With NIH, she continued, "other studies demonstrate that NIH, and biomedical research more generally, is better understood, and consumed, than research, say, in mathematics... It is imperative that we communicate to the public the benefits of our research if we hope to enjoy strong levels of research funding in the future." Petersen also noted that a "relative challenge is to better educate school children so that they become scientifically literate." Scientists, she said, "are in the best position to communicate about science, because of our knowledge and because of our passion about what we do, and why."

"And most importantly," said Petersen, "we must be mindful that NICHD is about children. Substantial data demonstrate that children are neglected in our current society, including in research... We must invest in the next generation; they are the future of our society... We must be advocates for the investment in

children, including research on children." She urged Council members to "remember, the 'child' in NICHD."

Concluding her remarks, Petersen noted that she and Lynn Goldman, a pediatrician working at the Environmental Protection Agency, are co-chairing an initiative analyzing the federal research investment in children. It will be conducted under the auspices of the National Science and Technology Council, specifically, the Committee on Fundamental Science and the Committee on Health, Safety, and Food.

HOUSE PASSES AGRICULTURE APPROPRIATIONS: NRI HELD CONSTANT

On June 12, the House of Representatives passed the FY 1997 Agriculture and Rural Development Appropriations bill by a vote of 351-74. The House defeated a number of amendments to the bill, including one, that lost by two votes, which would have ended subsidy payments to tobacco farmers. Thus, the bill that emerged from the House resembled the legislation that emerged from the appropriations committee a few days earlier.

In the research area of the bill, there were mixed results. It provides the National Research Initiative Competitive Grants (NRI) program with \$97 million, the same figure as last year, but \$33 million below the administration's request. The Farm Bill included a \$100 million Fund for Rural America (see *Update*, May 27), at least one-third of which is supposed to go for research funding. Thus, the House could have assumed that the \$33 million shortfall from the budget request in their appropriation for NRI would be made up by the Fund for Rural America. The Appropriations Committee report, includes language that these funds should be used "primarily to supplement appropriated funds..." The Markets, Trade and Rural Development component of the NRI was allocated \$4 million, the same as FY 1996 funding, but \$2.5 million below the request.

As usual, Congress continued to fund Special Grants well above the administration's request of \$5.6 million. The House allocated \$44.2 million, slightly under FY 1996's \$47.8 million for these grants for specific projects usually requested by constituents.

The Rural Policies Institute received \$644,000, same as in FY 1996. Funds for the project improving geographic information systems were reduced from \$939,000 to \$750,000.

The Economic Research Service received \$54.2 million in the House appropriation. This is a slight \$1 million increase over FY 1996 funding. The additional money will support the agency's role in the Department's integrated pest management initiative. The National Agricultural Statistics Service received a large \$19.1 million increase over FY 1996 to \$100.2 million. Most of this increase, \$17.5 million, covers the transfer of the Census of Agriculture from the Department of Commerce. The rest of the increase goes to integrated pest management data collection.

The House reduced formula payments under the Hatch Act by \$5.1 million from FY 1996, leaving it at \$163.7 million at this stage of the appropriations process.

The Senate is expected to take up the bill in July.

NIH RELEASES PEER REVIEW REPORT *AS*

The Report of the Committee on Rating Grant Applications issued by the National Institutes of Health lists ten "principal" recommendations to improve "the process by which scientific review groups rate grant applications."

NIH Deputy Director Wendy Baldwin is seeking comments on the report from the extramural research community. "Changes to so critical an element of peer review as the system of rating grant applications should not be implemented without the participation and contributions of the scientific community that they will affect," the report states.

An outgrowth of Vice President Gore's National Performance Review, the report is one of many reinvention activities underway at NIH. Some of the activities are new and respond to the mandate to reinvent the federal government; others are part of ongoing efforts to improve the way NIH operates.

The report examined the grant applications rating process and made recommendations for improvement.

These recommendations were made "in light of the contemporary thinking in the behavioral sciences as it relates to psychological measurement and decision-making."

The committee "operated from the starting point that the rating system currently used by NIH scientific review groups works reasonably well; no one appears to believe that poor quality science is consistently being given good scores nor that exceptionally good science is consistently being given poor scores....[I]t becomes increasingly important to ensure that scores are as reliable as they can be, and that program staff have the maximum amount of useful information on which to base their funding decisions." The major issues addressed were: "the review criteria and how they are used by the reviewers, the scale on which reviewers make their quantitative ratings, statistical manipulation of reviewer ratings to derive a score that would maximize comparability of scores across reviewers and review groups, and the necessity of pilot testing all new procedures before they are adopted or rejected."

Recommendations:

According to the report, the following ten recommendations will be the "basis for discussion about possible changes in the scoring system." NIH is seeking comments regarding the "merit and feasibility of piloting" each of the recommendation individually.

Review Criteria Recommendations

1. The proposed, reformulated review criteria should be adopted for unsolicited research project grant applications. The reformulated criteria are:

Significance: The extent to which the project if successfully carried out, will make an original and important contribution to biomedical and/or behavioral science.

Approach: The extent to which the conceptual framework, design..., methods, and analyses are properly developed, well-integrated, and appropriate to the aims of the project.

Feasibility: The likelihood that the proposed work can be accomplished by the investigators, given their documented

experience and expertise, past progress, preliminary data, requested and available resources, institutional commitment, and (if appropriate) documented access to special reagents or technologies and adequacy of plans for the recruitment and the retention of subjects.

2. Reviews should be conducted by criterion, and the reviewer's written critiques should address each criterion separately.
3. Applications should receive a separate numerical rating on each criterion.
4. Reviewers should not make global ratings of scientific merit.

Rating Scale Recommendations

5. The rating scale should be defined so that larger scale values represent greater degrees of the characteristic being rated and the smaller values represent smaller degrees.
6. The number of scale positions should be commensurate with the number of discriminations that reviewers can reliably make in characteristics being rated. An eight-step scale (0-7) is recommended on the basis of the psychometric literature; however, a maximum of 11 steps (0-10) are acceptable.
7. The rating scale should be anchored only at the ends. The performance of end-anchors should be evaluated and other approaches to anchoring should be investigated as needed.

Calculation, Standardization, and Reporting Scores Recommendations

8. Scores should be standardized on each criterion within reviewer and then averaged across reviewers. The exact parameters for this standardization should be defined by an appropriately constituted group.
9. Scores should be reported on the eight-point scale used by reviewers in making the original ratings. Scores should be reported with an implied

precision commensurate with the information contained in the scores. Two significant digits are recommended.

10. If a single score is required that represents overall merit, it should be computed from the three criterion scores using an algorithm that is common to all applications. The Committee favors the arithmetic average of the three scores; however, an appropriately constituted group should test and choose the algorithm to be used.

The report also contains comments from the committee "on the way it sees the recommendations relating to each other." It noted that some of the recommendations can "proceed independently of the others." Additionally, the committee urged the implementation of revised review criteria "as soon as possible," while noting that "at a minimum, the revised criteria could simply be substituted for the current criteria with little retraining of reviewers necessary."

The complete 32-page report is available for downloading on the NIH's home page: <http://www.nih.gov/grants/rpa.htm>. Decisions on the implementation of any of these recommendations will need to be made by January, 1997 if they are to be in place for the review of grant applications to be funded in Fiscal Year 1998. Comments on the report's recommendations may be sent to DDR@NIH.GOV until October 1, 1996.

EXCHANGE AMENDMENT ADDED TO SENATE BILL

An amendment sponsored by Sen. Paul Simon (D-IL) has been added to the Defense Authorization bill in an attempt to save the National Security Education Program. *MS*

Simon's amendment would repeal a House-passed provision that would require NSEP grantees to serve in a defense or intelligence capacity. The amendment would target the service payback, but in a more flexible manner. Prior to the House action, NSEP recipients could fulfill program requirements by working in any branch of the federal government or in education for a set period of time.

NSEP, which supports area studies programs from a trust fund drawn from money that had been allocated for defense and intelligence, has survived significant legislative and bureaucratic obstacles since its 1991 creation.

Other components of the defense bill are likely to produce a presidential veto.

FORGIONE TO HEAD EDUCATION STATISTICS OFFICE

On June 4, the United States Senate confirmed Pasqual (Pat) Forgione as the new Commissioner of the National Center for Education Statistics (NCES). Forgione replaces Emerson Elliott who retired last August. Jeanne Griffith had been Acting Commissioner in the interim.

Forgione had served, since 1991, as Chief State School Officer of Delaware. Previously he had directed the Connecticut Education Department's research, evaluation and assessment. He was also the first executive director of the National Education Goals Panel. He has a doctorate in Administration and Policy Analysis and a master's in urban history from Stanford.

Position Overlaps Administrations

The NCES Commissioner's position is a four year appointment from a fixed date. This was done in 1987 to have the position overlap presidential terms in attempt to make it non-partisan and remove NCES from political interference. Unfortunately, the White House was six months late in announcing Forgione's appointment and the Senate took another six months to confirm him. His current appointment expires in June 1999.

URBAN INSTITUTE TO EVALUATE DEVOLUTION

With major support from the Annie E. Casey Foundation, the Urban Institute has launched a project to assess the devolution of responsibility for social programs from the federal government to the states. The \$19 million project, extending from 3 to 5 years, will monitor the impact of these changes on children, families, and the communities in which they live.

Assuming that Congress has convincingly asserted that the current system of federal categorical support programs is broke, the project anticipates the ultimate passage of block grants that will move to the states the protection of the safety net programs for the poor in the areas of health care, income security, education and training, and social services. Recognizing that these block grants will include substantial reductions in Federal funds, the Urban Institute effort seeks to determine what difference this will make in people's lives.

The project will pursue "rigorous" evaluation data to replace "anecdotes masquerading as evidence." It will develop a 50 state data base to include aggregate measures of budget growth or decline, tradeoffs among major spending categories, discretionary tax increases and decreases, and certain indicators of programmatic change. Additional information for 25 states will be obtained through telephone interviews and limited site visits to talk with state officials. In 10 to 14 states, a survey of 1,800 households with children will collect more detailed data on individual outcomes and program administration. This survey should provide contrasts among states as to access, utilization, and outcomes for the different strategies they will pursue. Comparisons with Current Population Survey and Health Interview Survey results will provide historical trend information. The study will also produce qualitative case studies in this 10 to 14 state sample.

Are the States Prepared?

The research will also attempt to ascertain the validity of a current perception that the states are summarily unprepared for the responsibilities that are about to be handed to them. One form of technical assistance, under development at the University of Maryland's Block Grant Institute, is to provide the

states with micro-simulation policy models to track development in these social policy areas.

Steven Gold and Lawrence Thompson of the Urban Institute are the co-directors of the project. Isabel Sawhill, former Associate Director of the Office of Management and Budget and a former COSSA

Board member, now at the Urban Institute, and Richard Thornburgh, former U.S. Attorney General and Pennsylvania Governor, are co-chairing the project's oversight policy board. Although Annie E. Casey is the major funder, and support from the Henry Kaiser Foundation and others has been procured, the project is still seeking more funds to reach its goal.

SOURCES OF RESEARCH SUPPORT: DEPARTMENT OF HEALTH AND HUMAN SERVICES

COSSA provides this information as a service and encourages readers to contact the agency for further information or application materials. Additional application guidelines and restrictions may apply. KC

Administration for Children and Families National Center on Child Abuse and Neglect

The Administration on Children, Youth and Families (ACYF) administers national programs for children and youth, works with States and local communities to develop services which support and strengthen family life, seeks out joint ventures with the private sector to enhance the lives of children and their families, and provides information and other assistance to parents, public and private agencies, States and local communities, and other entities.

The National Center on Child Abuse and Neglect (NCCAN) announces the availability of FY 1996 funding for university-based doctoral or medical student and faculty fellowships in child abuse and neglect. Funds from NCCAN are for research on the causes, prevention, identification, treatment and cultural distinctions of child abuse and neglect; for research on appropriate, effective and culturally-sensitive investigative, administrative and judicial procedures with respect to cases of child abuse; and for demonstration or service programs and projects designed to prevent, identify and treat child abuse and neglect.

Application Procedure: To obtain materials, contact: Administration on Children, Youth and Families, Operations Center, 3030 Clarendon Blvd., Suite 240, Arlington, VA 22201, 1-800-351-2293.

Eligible Applicants: Eligible applicants are institutions of higher education, including medical schools, teaching hospitals, and Historically Black colleges and Universities on behalf of qualified students, medical students, residents, house officers, or fellows enrolled in the institution and faculty employed by the institution.

Restrictions on Awards: NCCAN proposes to award funds for fellowships in blocks to eligible institutions. Each institutional block would contain up to four students and one faculty member. The students and faculty member may pursue their own individual research or work on coordinated projects on child abuse and neglect. The length of the project may not exceed 17 months. The maximum Federal share of the project is not to exceed \$75,000 per university or institution to fund up to four student-candidates at \$13,750 each and \$20,000 for the faculty candidate. There is no matching requirement. It is anticipated that three sites will be funded.

Deadline: August 16, 1996

Contact: The ACYF Operations Center Technical Assistance Team at 1-800-351-2293.

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