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104TH CONGRESS *2d Session*	SENATE	REPORT 104–351

FAMILY PRIVACY PROTECTION ACT OF 1995

R E P O R T

OF THE

COMMITTEE ON GOVERNMENTAL AFFAIRS UNITED STATES SENATE

TOGETHER WITH

ADDITIONAL AND MINORITY VIEWS

TO ACCOMPANY

H.R. 1271

TO PROVIDE PROTECTION FOR FAMILY PRIVACY

AUGUST 2, 1996.—Ordered to be printed

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AUGUST 2, 1996.—Ordered to be printed

Mr. STEVENS, from the Committee on Governmental Affairs, submitted the following

REPORT

[To accompany H.R. 1271]

The Committee on Governmental Affairs, to which was referred the act to provide protection for family privacy, having considered the same, reports favorably thereon without amendment and recommends that the bill do pass.

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I. SUMMARY AND PURPOSE

The Family Privacy Protection Act requires that a parent or guardian give written consent prior to a minor child participating in a survey or questionnaire that solicits responses on topics of a sensitive, personal nature when that survey or questionnaire is funded in whole or in part by the Federal government. There are seven specific topics identified for privacy: (1) parental political affiliations or beliefs, (2) mental or psychological problems, (3) sexual behavior or attitudes, (4) illegal, antisocial, or self-incriminating behavior, (5) appraisals of other individuals with whom the minor has a familial relationship, (6) relationships that are legally recognized

as privileged, including those with lawyers, physicians, and members of the clergy, and (7) religious affiliations or beliefs.

This legislation will protect the privacy rights of parents and families from unwelcome government intrusion, and it protects minors from being required to divulge personal and sensitive information without prior written consent.

II. BACKGROUND AND NEED FOR LEGISLATION

H.R. 1271 will expand to all federal agencies and programs family privacy protections similar to those that currently apply to federal education assistance programs.

Legislation protecting the privacy of minors from Federally sponsored questions originated in the General Education Provisions Act (GEPA). (Public Law 90–247, January 2, 1968, as amended).

Originally enacted as Title IV of the Elementary and Secondary Education Amendments of 1967 (P.L. 90–247), GEPA codified Federal education statutes into one document. Since 1970, most major acts extending Federal education programs' authorization for appropriations, have amended GEPA in some significant way. Three of those changes were designed to enhance the protection of the rights and privacy of parents and students.

The "Protection of the Rights and Privacy of Parents and Students" was established by Congress when it adopted the Kemp amendment, entitled, "Family Educational Rights and Privacy Act of 1974." (P.L. 93–380, August 21, 1974). This provision, in part, "required the Secretary of the former Department of Health, Education, and Welfare to adopt appropriate regulations to protect the rights of privacy of students and their families in connection with any surveys or data-gathering activities conducted, assisted, or authorized by the Secretary or an administrative head of an education agency." The law states further that, "No survey or data-gathering activities shall be conducted by the Secretary, or an administrative head of an education agency under the applicable program, unless such activities are authorized by law." An applicable program is one which receives federal aid.

The 1974 Kemp amendment also established the "Protection of Pupil Rights" which required parents of students participating in Federally assisted educational "research or experimentation program[s] or project[s]" be provided access to the instructional materials. A "research or experimentation program or project" was defined as an instructional activity using "new or unproven teaching methods or techniques."

In 1978, Congress adopted the Hatch amendment to the section entitled, "Protection of Pupil Rights" (P.L. 95–561, November 1, 1978). This provision prohibited requiring pupils to participate in certain forms of testing as part of a Federally assisted education program, without the prior written consent of the pupil's parent or guardian in the case of a minor or prior consent of the pupil if he or she is an adult or emancipated minor. The Hatch amendment applied to non-scholastic examinations set forth as "psychiatric or psychological" tests or treatments.

Psychiatric or psychological examination or test is defined as "a method of obtaining information, including a group activity, that is not directly related to academic instruction and that is designed to

elicit information about attitudes, habits, traits, opinions, beliefs or feelings." Psychiatric or psychological treatment is defined as "an activity involving the planned, systematic use of methods or techniques that are not directly related to academic instruction and that is designed to affect behavioral, emotional, or attitudinal characteristics of an individual or group."

The statute required that prior written consent of a parent or guardian be obtained before a minor was required to submit to "psychiatric examination, testing, or treatment, or psychological examination, testing, or treatment, in which the primary purpose is to reveal information concerning: (1) political affiliations; (2) mental and psychological problems potentially embarrassing to the student or his family; (3) sex behavior and attitudes; (4) illegal, antisocial, self-incriminating and demeaning behavior; (5) critical appraisals of other individuals with whom respondents have close family relationships; (6) legally recognized privileged and analogous relationships, such as those with lawyers, physicians, and ministers; or (7) income (other than that required by law to determine eligibility for participation in a program or for receiving financial assistance under such program)."

The Grassley amendment (P.L. 103–227, Goals 2000, March 31, 1994) modified the 1978 Hatch provision to broaden the scope of the parental consent requirement. The Grassley amendment no longer limited the informational requirements on instructional materials to research or experimentation programs or projects, and it expanded the scope of the parental written consent requirement to "a survey, analysis, or evaluation" the revealed information on the seven privacy topics set forth previously in the 1978 Hatch amendment.

H.R. 1271, the Family Privacy Protection Act of 1995 was introduced to expand the parental consent requirements provided for in programs under the Department of Education to all federal agencies. While a large portion of surveys and questionnaires are administered in the school setting, they may have originated and been funded through various departments and agencies within the Federal government. This legislation is needed to apply a uniform standard throughout the Federal government for research surveys and questionnaires administered to a minor child soliciting responses on certain issues of a private and personal nature.

III. LEGISLATIVE HISTORY

House of Representatives

In the House of Representatives, on March 16, 1995, the Subcommittee on Government Management, Information, and Technology of the Government Reform and Oversight Committee held a hearing to solicit comments from interested parties on Title IV of H.R. 11, the Family Reinforcement Act. H.R. 1271, the Family Privacy Protection Act of 1995 was subsequently introduced in the House of Representatives on March 21, 1995. It was referred to the Government Reform and Oversight Committee. The Committee adopted an amendment in the nature of a substitute and ordered the bill, as amended, favorably reported by voice vote on March 23, 1995, (H. Rpt. 104–94).

On April 4, 1995, the House of Representatives passed H.R. 1271 by recorded vote of 418 yeas and 7 nays after adopting by voice vote the committee amendment in the nature of a substitute; adopting by a recorded vote of 379 yeas and 46 nays, an amendment by Representative Souder which required parental consent to be "written" rather than "informed", removed the $500 limit on monetary damages that an individual can claim, and clarified the exemption for tests intended to measure academic performance applied except to the extent that questions in such tests would require a minor to reveal information on any of the seven sensitive topics; and rejecting by recorded vote of 131 yeas and 291 nays, an amendment by Representative Dornan which sought to prohibit all surveys or questionnaires being administered to minors.

H.R. 1271 as passed by the House of Representatives was received in the Senate and referred to the Senate Committee on Governmental Affairs on April 5, 1996.

Senate hearing

A hearing was held by the Senate Committee on Governmental Affairs on November 9, 1995. Testimony was presented by Senator Charles Grassley of Iowa; Wad Horn, Ph.D., Director of the National Fatherhood Initiative; Art Mathias, President of Christian Coalition of Alaska; Robert Knight, Director of Cultural Studies for the Family Research Council; Sally Katzen, Administrator, Office of Information and Regulatory Affairs, Office of Management and Budget; Felice Levine, Ph.D., American Sociological Association; and Lloyd Johnston, Ph.D., Program Director of the Survey Research Center at the University of Michigan; and prepared testimony was submitted for the record by Sue Rusche, Executive Director of National Families in Action.

In addition, written testimony was submitted by the U.S. Department of Health and Human Services; the U.S. Department of Justice; Dr. Linda A. Teplin, Professor, Department of Psychiatry, Northwestern University; Thomas Gleaton, Ed.D., the President of the Parents' Resource Institute for Drug Education (PRIDE); Shirley Igo, President for Legislation, National PTA; and the American Academy of Pediatrics.

Senator Grassley, the sponsor of the 1994 Goals 2000 amendment requiring prior written parental consent for Department of Education surveys and questionnaires, testified in support of H.R. 1271. Grassley noted his disappointment with the draft regulations issued by the Department of Education to implement his amendment. He noted that he "was extremely disappointed in those regulations because . . . they gut the intent of the law to protect children and families from privacy intrusions without prior written consent." Section 6 of H.R. 1271 exempted the Department of Education in the belief that the 1993 amendment had established the written parental consent requirement for surveys and questionnaires on privacy topics. However, Senator Grassley indicated his support for striking that exemption and his strong support for the language contained in H.R. 1271. The distinction Senator Grassley was making is pivotal in the debate on H.R. 1271. The draft regulations required only informed consent rather than written consent as stated in the statute. Senator Grassley made his views clear in

stating: "It was with deliberate intent that I required written parental consent. It is not enough to get implied consent. . . . These are adult decisions to make. That is why my amendment left the decision specifically and deliberately in the hands of parents. Unfortunately, this is the biggest flaw with the Department of Education regulations on my original amendment. They simply leave the decision in the hands of the child. . . . This defeats the intent of my amendment."

Dr. Horn testified in favor of the legislation. His testimony indicated that parents need to be adequately informed of the nature of surveys and questionnaires that are given to their children. He believes that requiring prior written consent is the best way to ensure parents are properly notified. Dr. Horn also noted that in his "experience as a researcher that parental consent is fairly easily obtained except in cases where the investigation comes into conflict with the sensibilities or closely held belief of the parents." Further, it is precisely when the investigation comes into conflict with such belief that parental consent is the most important.

Mr. Mathias provided several examples of events occurring in the Alaska school system that parents found objectionable. His testimony also cited specific questionnaires and surveys that had been brought to his attention by Lorraine Ferrell, a member of the Anchorage School Board. Her minor children were given the questionnaires without her knowledge or prior consent.

In relation to the Alaska cases cites, Chairman Steven noted that in addition to the 1994 Grassley amendment to Goals 2000, the State of Alaska has a law that prohibits the administration of any survey or questionnaire in a public school "that inquires into private family affairs of the student not a matter of public record or subject to public observation unless *written* permission is obtained from the student's parent or guardian." (Emphasis added)

Mr. Knight testified that parents are the people "most equipped to discern the needs of their children." He also indicated that the loss of the ability of parents to determine their children's education needs is an unacceptable cost to pay for surveys and questionnaires. He also noted that repeated surveys and questionnaires can desensitize children to sensitive issues. "Through sheer repetition of reference, harmful activities can lose their power to inspire natural resistance." Thus, surveys and questionnaires can lead to the behavior that is being investigated.

Mr. Hilton noted the similarity between the language in H.R. 1271 and Utah law. He testified that he believes that there should be a uniform consent form for all federally funded surveys. As a civil rights attorney, Mr. Hilton provided details of litigation on parental rights and various court rulings. He urged that the right of private action be made stronger.

Ms. Katzen testified on behalf of the administration in opposition to H.R. 1271. She indicated that while the administration supports parental involvement with respect to research involving children, the administration is opposed to the "written" consent requirement. She noted that various forms of affirmative consent and passive consent consent should not be ruled out and referenced the current practices in social science research protocols for "informed" consent. Ms. Katzen also noted the potential negative impact of the written

consent requirement citing reduced response rates which lead to unreliable results. She also pointed out that the information collected by these surveys and questionnaires is an important policy making tool.

Dr. Levine testified in favor of alternative forms of consent. She noted that "a face-to-face interview or a telephone call might make much more sense or be more appropriate when illiteracy rates of parents are high." She also noted that the bill, by requiring written consent, is contrary to Congressional efforts to decrease unnecessary paperwork. Dr. Levine also stressed the importance of using the results of such surveys and questionnaires in understanding high risk behavior such as smoking, drug abuse, and violence.

Dr. Johnston's testimony explained his objection to an absolute written consent requirement. He urged the committee to consider alternative methods of achieving consent and made some suggestions in providing parents with options to respond when informed of a survey or questionnaire when they objected to their minor child being included in a study. He also noted the importance of the information being collected in these studies.

Sue Rusche submitted her written statement reflecting the need to utilize surveys and questionnaires to combat drug abuse and to create effective drug abuse prevention programs.

In written testimony, Dr. Gleaton noted the experience of PRIDE's of surveys in addressing high risk behavior. He indicated that the loss of the ability to collect reliable data on adolescent drug use would cut off access to understanding important health indicators among children.

Dr. Teplin referred to her research on child psychiatric disorders. She indicated in her written testimony that her studies identify the psychiatric needs of children in the juvenile justice system and are vital to understanding the needs of these children and to helping them. She also noted that in many cases, parental consent is not only unfeasible but unnecessary because there is "minimal risk" of harm by researchers.

Shirley Igo submitted written testimony in opposition to the Family Privacy Protection Act. She noted alternative methods of informing parents and the importance of research for all levels of decision making, both parental and scholastic.

The Department of Health and Human Services and the Department of Justice both expressed opposition to the written consent requirement stating that it could jeopardize the ability of studies to provide Federal, state and local policy makers with useful, quality information.

Senate committee vote

On April 18, 1996, the Committee on Governmental Affairs ordered H.R. 1271 favorably reported by a recorded vote of 7 yeas; Senators Stevens, (Roth by proxy), Cohen, Thompson, Cochran, McCain, Smith, and Brown, to 5 nays; Senators Glenn, Nunn, Levin, (Pryor by proxy), (Lieberman by proxy), Akaka, and Dorgan after rejecting an amendment in the nature of a substitute offered by Senator Glenn by a recorded vote of 6 yeas; Senators Glenn, Levin, (Pryor by proxy), Lieberman, Akaka, and Dorgan, to 7 nays;

Senators Stevens, (Roth by proxy), (Thompson by proxy), (Cochran by proxy), (McCain by proxy), Smith, and Brown.

IV. SECTION-BY-SECTION ANALYSIS

Section 1. Short title

Family Privacy Protection Act of 1995.

Section 2. Family privacy protection

Section 2(a) establishes a requirement that administrators of Federally funded surveys and questionnaires obtain written parental consent prior to asking seven kinds of sensitive questions. The seven subject areas requiring written parental consent are: (1) parental political affiliations or beliefs, (2) mental or psychological problems, (3) sexual behavior or attitudes, (4) illegal, antisocial, or self-incriminating behavior, (5) appraisals of other individuals with whom the minor has a familial relationship, (6) relationships that are legally recognized as privileged, including those with lawyers, physicians, and members of the clergy, and (7) religious affiliations or beliefs.

Section 2(b) creates general exceptions to this policy. The exceptions include the seeking of information for the purpose of a criminal investigation or adjudication, a good faith inquiry into the health, safety, or welfare of an individual minor, the seeking of information required by law to determine eligibility for participation in a program or for receiving financial assistance, and for purposes of administration of the immigration, internal revenue, or customs laws of the United States.

Section 2(c) excludes any test intended to measure academic performance, unless the test includes questions in any of the seven sensitive subject areas.

Section 3. Notification procedures

Section 3 requires the head of any Federal agency or department conducting a survey or questionnaire involving minors to establish procedures for the department or agency to notify minors and their parents of the protections of this act. The procedures shall also provide for advance public availability of each questionnaire or survey to which a response from a minor is sought.

Section 4. Compliance

This section requires the head of each Federal department or agency to establish such procedures as are necessary to ensure compliance with the Act.

This section also provides that the Act should not be construed to foreclose any individual from obtaining judicial relief otherwise available.

Section 5. Minor defined

The terms "minor" and "emancipated minor" will be defined under the laws of the State in which the individual resides.

Section 6. Application

Section 6 exempts programs and activities which are subject to the General Education Provisions Act (20 U.S.C. 1221 et seq.). This section effectively removes the Department of Education from the Family Privacy Protection Act. The General Education Provisions Act, as amended by Senator Grassley in 1994 as discussed above, was thought to have provided for a written parental consent requirement for the participation of minors in surveys and questionnaires on privacy matters.

Section 7. Effective date

The Act shall take effect 90 days after being signed into law. The Act applies to grantees of departments and agencies on that date, not just future recipients of Federal funds.

V. CBO COST ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, May 2, 1996.

Hon. TED STEVENS,
Chairman, Committee on Governmental Affairs,
U.S. Senate, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has reviewed H.R. 1271, the Family Privacy Protection Act of 1995, as ordered reported by the Senate Committee on Governmental Affairs on April 18, 1996. CBO estimates that H.R. 1271 would result in increased costs of between $2 million and $3 million a year in most years to administer certain federally funded surveys, assuming appropriation of the necessary funds. The act would not affect direct spending or receipts; therefore, pay-as-you-go procedures would not apply.

Bill purpose: H.R. 1271 would require that administrators of certain surveys or questionnaires obtain written parental consent prior to surveying a minor on certain topics, such as parental political affiliation, sexual behavior, and illegal activities. The act would apply to surveys or questionnaires that are part of a program or activity funded in whole or in part by the federal government. The act's provisions are similar to those contained in the Goals 2000: Educate America Act (Public Law 103–227), which requires written parental consent for surveys funded through the Department of Education.

Federal budgetary impact: Based on information provided by federal agencies and by private researchers, CBO estimates that enacting this legislation would increase—in some cases, dramatically increase—the costs to conduct federal surveys of minors.

The Federal Regulations for the Protection of Human Subjects (45 CFR part 46) currently require that federal studies obtain informed parental consent. In many cases, this involves the use of a passive written consent process—that is, parents can object to their child's inclusion in a survey by returning a form of disapproval. H.R. 1271 would change this to require written parental consent.

According to a study by the Rand Corporation, a written consent requirement could increase the cost of acquiring consent (not the

cost of the whole survey) by more than 15-fold to maintain a comparable response rate. The study found that only 40 percent of the individuals sampled responded to the initial consent form, with 60 percent requiring telephone follow-ups. As a whole, the costs to obtain written consent were 15 times greater than that for passive consent, and still yielded a lower response rate (86 percent as compared with 93 percent). The Survey Research Center at the University of Michigan, which conducts the Department of Health and Human Services' (DHHS) teen drug-use surveys, indicated that if this ratio were applied to a school-based survey of 50,000 students that it conducted last year, the written consent requirement would have added $0.75 million to the $4 million cost of the study—a 20 percent increase. For the data collection effort, which alone cost $1.6 million, written consent would have increased the costs by nearly 50 percent.

In sum, CBO expects that the requirement of written parental consent could add nearly 50 percent to the data collection costs of some surveys directed at respondents under the age of 18. At DDHS, surveys of minors are conducted by the Centers for Disease Control (CDC), the Substance Abuse and Mental Health Services Administration (SAMSHA), the National Institute for Child Health and Human Development (NICHD), and other agencies. SAMSHA, for example, conducts a survey with an average cost of about $7.5 million of which about $5 million is for collecting data. About one-quarter of the respondents are minors. Using the estimates from the University of Michigan, written consent would add up to $0.6 million annually to the cost of this survey. Likewise, the Bureau of the Census has estimated that a written consent requirement would add about $2 per interview to the National Crime Victimization Survey—an in-person survey—or about $140,000 in total.

Thus, depending on the survey administered in any particular year, CBO estimates that requiring written consent would add between $2 million and $3 million annually to the costs of federally funded surveys.

Impact on State, local, and tribal governments: H.R. 1271 contains no intergovernmental mandates as defined by Public Law 104–4. State, local, or tribal governments are likely to face additional costs to administer certain programs or activities that are funded in part by the federal government. Such costs, however, would result from conditions of federal financial assistance and not from mandates as defined by the law.

Impact on the private sector: The legislation would impose no new private sector mandates, as defined by Public Law 104–4. All provisions within H.R. 1271 that might impose requirements on the private sector would be considered a condition of federal assistance.

Previous CBO estimate: On March 28, 1995, CBO provided a cost estimate for H.R. 1271, as ordered reported by the House Committee on Government Reform and Oversight on March 23, 1995. CBO estimated that the House-reported bill would have no significant impact on the federal budget because that bill would not change the current requirement that agencies obtain "passive" parental consent. This version of the bill would impose a stricter consent process, as did the House-passed version.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contacts are Paul Cullinan, and John R. Righter.

Sincerely,

JUNE E. O'NEILL, *Director.*

VI. REGULATORY IMPACT

Paragraph 11(b)(l) of rule XXVI of the Standing Rules of the Senate requires that each report accompanying a bill evaluate "the regulatory impact which would be incurred in carrying out the bill."

The enactment of this legislation would not have a significant regulatory impact on the public, nor would it constitute an undue regulatory burden on the departments or agencies. The Department of Education has had similar regulations since 1978. In addition, most other departments and agencies have adopted the regulations and practices of the Department of Health and Human Services covering research surveys and questionnaires. Existing regulations require written parental consent for minors prior to their participation in research surveys and questionnaires, but also contain certain waivers of this requirement. H.R. 1271 would eliminate the waivers.

VII. ADDITIONAL VIEWS OF SENATOR COHEN

The Family Privacy Protection Act has a worthy goal—to ensure that parental consent is obtained before minors may participate in federally funded research projects that touch upon sensitive, private matters. This bill passed the House by a 379–46 vote last year and, in 1994, similar legislation relating to research funded by the Department of Education passed the Senate 93–0. It is a topic deserving of consideration by the full Senate.

Nonetheless, I am concerned that the legislation in its current form may hinder important research on drug and alcohol addiction, juvenile delinquency, teenage pregnancy, child abuse, smoking by minors, and the spread of communicable diseases. The problematic aspect of the legislation is its inflexible requirement that written parental consent must be obtained before any minor may participate in a research project addressing any one of seven enumerated "sensitive" topics. This requirement will have two effects on federally funded surveys and questionnaires. First, it will substantially increase the cost of research projects. More importantly, however, it will undermine the reliability of research into youth behavior by lowering participation rates and biasing the sample set of research subjects. One national study demonstrated that 50% of parents failed to respond to a request for written consent, although follow-up phone calls indicated that only 1% of the parents objected to their child's participation. Moreover, the written consent requirement is likely to skew survey results because children from dysfunctional families are far less likely to obtain consent to participate in a survey than children from functional families. Without reliable data on critical issues of our day such as juvenile crime, substance abuse, and teenage pregnancy, I fear that efforts to address these problems will be compromised.

Supporters of H.R. 1271 do not refute that requiring written consent will degrade important research efforts, but argue that the privacy interests of parents outweigh any incidental impacts the legislation might have. I do not concur. It is important to keep in mind that even under current law, federal researchers must obtain some form of parental consent before conducting a survey of minors. The manner in which consent must be objected is determined by "institutional review boards," which are comprised of scholars and community representatives from the university or organization conducting the research. In some instances a board will require written consent, but it may also determine that parental rights are sufficiently protected if parents are notified about the subject matter of a survey and informed that they have a right to prohibit their child from participating (otherwise known as "informed consent"). Through the institutional review board process, the level of consent can be calibrated to the sensitivity of the survey at issue. If the current institutional review board process is not providing

sufficient protection to parental rights, perhaps legislative changes should be made to ensure that institutional review boards give greater weight to parental concerns. But regardless of whether changes to the current system are in order, in my view, the incremental enhancement of parental rights that would be obtained by requiring written consent for all surveys, as opposed to a more flexible system that only requires written consent when necessary, is not worth the detrimental effects that this legislation will have on important research into youth behavior.

To be sure, informed consent is not perfect. In a limited number of instances, parents will not receive the notices the researchers send to them and may be upset that their children participated in surveys without their prior knowledge. One way to minimize the frequency that this occurs would be to increase the role of school administrators and other local officials in reviewing surveys involving minors. We may want to consider legislation mandating that local officials have the opportunity to review surveys and prohibit the children for which they are responsible from participating if they do not approve the types of questions that are being asked. In this way, local officials accountable to the community can serve as surrogates for parents by ensuring that any materials distributed to children conform with community standards. Those who run the schools or other youth-oriented institutions make dozens of decisions on a day-to-day basis, without the written consent of parents, that have far more important effects on children than do surveys and questionnaires. Certainly, administrators with responsibility for hiring teachers, developing curriculum, establishing school safety policies, and imposing discipline can also be entrusted to decide whether the content of a survey is consistent with community norms. The combination of notice to parents plus review by school or other administrative officials should be sufficient to protect parents' legitimate concern that their children not be exposed to inappropriate research materials.

Although I believe this set of policies will provide sufficient protection to parents, federal law should be sufficiently flexible to allow states and localities to set more stringent consent standards. If any state decides that children should not be surveyed without written parental consent, then federally funded researchers choosing to work in that state should be required to abide by state law. It would be a mistake, however, to create a federal mandate that applies the most stringent state law to the entire country, which is what the legislation reported by the Committee would do.

In light of the debate that took place on this legislation in the Governmental Affairs Committee, it appears that all members share the goals of empowering parents while maintaining local autonomy. I am hopeful that legislation acceptable to a broad majority of the Senate can be crafted as this bill moves to the floor.

BILL COHEN.

SUMMARY

VIII. MINORITY VIEWS OF SENATORS GLENN, LEVIN, PRYOR, LIEBERMAN, AND AKAKA

We strongly oppose H.R. 1271 for the following reasons:

1. It is unnecessary. It seeks to fix a problem that simply does not exist.
2. It would seriously impair research and evaluation crucial to identifying and addressing life-threatening problems facing America's children.
3. It would create an unnecessary layer of Federal regulation that would burden local schools and communities at a time when we are asking them to do more with less.
4. Its broad and uncertain scope would impose significant burdens on local schools and communities, lead to increased litigation, and hurt, not help the health and safety of our nation's children.

While the stated goals of H.R. 1271 are to protect children and strengthen the family, what it would really do is cripple our ability to respond to the problems that confront families and their children every day. It would make reliable research and evaluation too expensive, and it would create a mountain of unnecessary paperwork along the way.

H.R. 1271 is opposed by doctors and nurses, health and social science researchers, teachers, counselors, State public health officials, community groups, and parents. Over two dozen national organizations dedicated to the health, safety, and well-being of America's children have written the Committee opposing H.R. 1271. Here are some comments these organizations have made about the effects that H.R. 1271 will have on children.

> From the American Academy of Pediatrics, an organization of 50,000 pediatricians: "This legislation is yet another case of style over substance, with a title that is deceiving to the public. * * * Parental consent should be the standard, but written mandates go too far. A code of ethics already exists for research surveys, including the rights of adults and minors to refuse participation."
>
> From the National PTA: "H.R. 1271 is too extreme and would hamper the ability of researchers to provide reliable and valid data that not only Congress, but organizations such as the National PTA, heavily rely on to take positions and urge various statutory and regulatory measures."
>
> From the Association of State and Territorial Health Officials: "State public health officials agree that children should not be surveyed without parents' knowledge. However, this permission is already obtained. Further requirements are unnecessary and will ruin the random methodology of a survey."

> From the American Sociological Association: "H.R. 1271 ostensibly enhances parental involvement and control over questions or information directed to a minor, but the bill actually undermines critical research on youth health behaviors and provides no significant additional protection to the privacy of families. Ironically, while this bill purports to help parents, it is more likely to harm their interests by jeopardizing their access to essential and valid information on high risk health behaviors such as drug and alcohol use, tobacco use, violence, and the like."

Other opponents of the bill include the National Council on Alcoholism and Drug Dependence, the America Public Health Association, the Community Anti-Drug Coalitions of America, Partnership for a Drug-Free America, National Families in Action, the Child Welfare League of America, and dozens of America's top experts in child and adolescent research.

The Department of Justice, the Department of Health and Human Services, and the Office of Management and Budget also oppose the bill. In a November 14, 1995, letter to the Committee, Andrew Fois, Assistant Attorney General, U.S. Department of Justice, stated:

> Many issues from drug abuse to child abuse have been informed by studies that will no longer be feasible or representative if H.R. 1271 is enacted in its current form. Requiring prior written parental consent is likely to exclude minors who are in trouble with the law or abused at home from studies because parents are not available or willing to provide that consent. Impeding the collection of critical information about the problems affecting children is damaging. Policy makers and law enforcement officials need accurate information about trends affecting children in order to mount appropriate responses to protect child victims and punish young criminals.

The Secretary of Health and Human Services, Donna Shalala, wrote to the Committee on April 7, 1996, and said:

> The requirement that parental consent be in writing, and in advance, could seriously jeopardize the ability of these studies to provide Federal, State and local policy makers with useful and reliable information. Further, in programs such as those serving runaway youths, the requirement for written consent, prior to otherwise, may be logistically impossible to meet or may even be incompatible with the best interests of the children receiving services.

H.R. 1271 IS UNNECESSARY

Existing Federal regulations provide ample protection for children participating in Federally-sponsored survey research. Through these regulations, a reliable and sophisticated system for obtaining informed parental consent for children participating in survey research has been created. The requirement of across-the-board written consent imposed by H.R. 1271 undermines the current system, which satisfactorily addresses the diverse needs of individual communities by allowing for local flexibility in the choice of consent

procedures while providing strong safeguards for children who participate in survey research. In short, H.R. 1271 is a solution in search of a problem.

In 1991, seventeen Federal agencies, which together sponsor the vast majority of Federal research involving children, adopted a common set of regulations, 45 CFR, Part 46, Subpart A, to protect research participants. These regulations require that researchers obtain informed consent from parents whose children will participate in survey research. Procedures for obtaining informed consent must be carefully scrutinized and approved by a local review committee, an Institutional Review Board (IRB), whose sole purpose is to protect human research subjects.

In order to ensure that consent procedures accurately reflect the level of risk to children, the Federal regulations require a case-by-case evaluation of proposed surveys. In instances where there is sufficient risk, the regulations require written parental consent. However, in cases where an IRB concludes that the research poses "less than minimal risk of harm" to children, an alternative consent procedure may be used instead.

This does not mean that researchers do not have to obtain informed parental consent, but rather that the consent procedures used can be less stringent than written consent. Examples of alternative consent procedures include oral consent, where a parent must give affirmative consent over the phone or in person, and implied (or passive) consent, where researchers send a first-class mailing to parents describing the research and give the parents an opportunity to decline participation, either orally or in writing. In the latter case, if parents do not decline participation, it is assumed that they consent to their child's participation.

If mechanisms outlined in a research proposal for obtaining informed parental consent are insufficient, an IRB will disapprove the research project or require that the consent procedure be strengthened to reflect more adequately the degree of risk involved. Institutional officials, such as school administrators, may also disapprove research proposals and decline participation in any survey if they disagree with the protections provided for children. They are also barred from approving any survey that has not received IRB approval.

By law, IRBs must be broadly representative. They must consist of at least five members and must include at least one scientist, one non-scientist, and one person who is not affiliated with the institution conducting the research. On the Federal level, IRBs are governed by the Office for Protection From Research Risks at the National Institutes of Health, which provides guidance on research conduct and investigates claims of inappropriate research practices.

The current Federal regulations do not preempt state or local laws that would require more stringent consent procedures than those approved by a relevant IRB. Under 45 CFR 46.101(f), the Federal regulations state that "this policy does not affect any state or local laws or regulations which may otherwise be applicable and which provide additional protections for human subjects." For example, if an IRB approved an oral consent procedure for obtaining informed consent, a state or locality would be free to impose a more demanding consent standard, such as written consent. The only in-

stance where Federal regulations would override state or local authority would be if the state or locality established a less stringent consent requirement than that mandated by the Federal policy.

By imposing a rigid across-the-board requirement for written consent, H.R. 1271 would eliminate any possibility of using an alternative consent procedure in cases where research poses little or no risk to children. This one-size-fits-all approach does not take into account the differing needs of individuals and communities that will participate in and benefit from survey research. It would also destroy the flexibility permitted by the Federal regulations that ensure efficient research while safeguarding children. A number of ongoing Federal surveys that explore such issues as drug and alcohol use and child violence have been carefully designed to minimize risk to children and use lower cost parental consent procedures.

At the hearing on H.R. 1271 on November 9, 1995, proponents of the bill failed to provide examples of problems with Federal surveys or consent procedures that would be addressed by imposing the rigid written consent requirement of this bill. In fact, the only example using a Federal survey was one in which a Utah school tested a child after written consent had been given and then rescinded. In this case, the problem was not the parental consent process, but rather subsequent follow-through by the school. This local school enforcement problem is not addressed by H.R. 1271.

HURTING RESEARCH, HURTING CHILDREN

If we are to develop viable solutions to the host of problems that confront our children and their families today, we must continue to collect meaningful data on the behaviors and attitudes of children and adolescents. Parents, educators, counselors, researchers, and policy-makers all require access to reliable information about young people in order to craft sound responses to a growing array of social ills that affect our children every day, such as adolescent drug and alcohol abuse, youth violence, and the spread of AIDS.

At the local community level, doctors, teachers, school nurses, drug treatment counselors all depend on survey data to learn about emerging problems and evaluate the effectiveness of ongoing programs:

Thomas L. Conlan, Jr., a member of the Board of Directors for Hamilton County, Ohio, Alcohol and Drug Addiction Services (ADAS) expressed his concern about H.R. 1271, stating "We depend on information obtained from federally funded surveys to help measure the effectiveness of our drug and alcohol prevention programs."

According to Evelyn Martinez, Executive Director of the Los Angeles Alliance for a Drug Free Community: "Over the past two decades, survey data on youth substance use and abuse have served as an early warning system for parents, families and communities, allowing us to target our prevention efforts where they are needed most as well as to measure program outcomes fairly."

The Wood County Partnership Council of Marshfield, Wisconsin, reports that it relied on survey data to prioritize planning and help develop effective strategies that have signifi-

cantly lowered the number of teens who drive after drinking. One important effort was "prevention training for over 1,000 adults, including school personnel, clergy, parents and grandparents, who then develop prevention action plans for their communities."

"Abuse and neglect and other 'potentially embarrassing' family problems often constitute the reasons that youth run away from home [said the HHS Administration for Children and Families]. Obtaining information about these problems is critical in order for service providers to address these problems and to facilitate a youth's return home or placement in an alternative living arrangement."

At the other end of the process, Congress routinely uses survey research data to set Federal policy in a number of areas that affect children and families. For example, a 22-year ongoing school-based survey called Monitoring the Future, run by the University of Michigan's Institute for Social Research, has alerted Congress time and again to changing trends in adolescent drug use and has been instrumental in guiding national drug prevention efforts.

In the late 70's, Monitoring the Future called attention to the sharp rise in daily marijuana use among young people, leading to more Federal research on the consequences of marijuana use.

In the late 80's, it helped spotlight and quantify the levels of cocaine and crack use, leading to a Federal media campaign aimed at communicating the dangers of these drugs.

In the early 90's, the study identified the sharp increase in inhalant use among young teenagers, leading to a full-scale media ad campaign against inhalants.

The survey has been used in all White House National Drug Control Strategy documents since the creation of the drug czar's office in the 80's.

The Monitoring the Future survey and others like it continue to assist Congress in crafting national drug prevention policies. Indeed over the last several months, several Senators have referred to the results of these studies on the Senate floor in debate on Federal drug policy.

In a statement about youth drug use, Senator Kyl noted that, "the University of Michigan's Institute for Social Research [the Monitoring the Future Survey] found that, after a decade of steady decline, drug use by students in grades 8, 10, and 12 rose in 1993."

During the same debate, Senator Abraham pointed out that, "according to the 1994 'Monitoring the Future' study, drug use in three separate categories—used over lifetime, use in past year, use in past month—has shown a remarkable surge during the last 2 years, for young people in particular."

In the following excerpt from a speech on drug smuggling, former Senate Majority Leader Dole cited statistics from several drug surveys, including Monitoring the Future, the National Household Survey on Drug Abuse, and the Youth Risk Behaviors Study.

I will point out a few statistics. These are not Senator Dole's facts. These are facts given to use by people who are experts in the area [of adolescent drug use]. The number of young people between 12 and 17 using marijuana has

> increased from 1.6 million in 1992 to 2.9 million in 1994. That has probably increased a lot more since the end of 1994. And the category of "recent marijuana use" has increased a staggering 200 percent among 14- to 15-year-olds. About one in three high school students uses marijuana, and 12- to 17-year-olds who use marijuana are 85 percent more likely to graduate to cocaine than those who abstain from marijuana. Juveniles who reach age 21 without ever having used drugs almost never try them later in life. If you make the first 21 years without using drugs, then you are probably not going to be addicted.

These statements underscore the value to Congress of sound information on adolescent behaviors. In order to conduct enlightened debate and develop effective policies to address the problems facing our young people and their families, as well as apply effective strategies at the community level, we must preserve our ability to collect and analyze reliable data.

If enacted, H.R. 1271 would devastate the quality of survey research that provides valuable insights into the lives of our young people. While requiring written parental consent in all cases may sound innocuous, it is not. Such a requirement would lower response rates dramatically and thereby render useless most, if not all, of the data obtained from a given survey. Moreover, because of the extensive paperwork and follow-up efforts that would be needed to achieve high response rates, the costs of research would skyrocket, making it likely that many important research projects would not be funded.

Dr. Johnston, Director of the Monitoring the Future Survey at the University of Michigan, described how H.R. 1271's written consent requirements sounds reasonable until one takes into account that:

> Requiring researchers to secure written parental permission in advance makes one survey into two surveys, because parents must first be surveyed to obtain their written permission, and only then can the students be surveyed. This might be acceptable, assuming that the substantially greater costs to the government were tolerable, were it not for the fact that the non-response rates from parents are debilitatingly high. I say debilitatingly, because the resultant response rates for the young people would be so low in most cases as to render the data useless at worst, highly misleading at best. * * * In sum, the introduction of a written parental consent requirement—as contrasted to advance notification and description with a convenient method for the parent to decline—will result in virtually unusable data from practically all in-school and phone surveys of youth.

The detrimental effects of written parental consent on response rates are well-documented. When passive consent procedures are used, one can expect response rates of 90% and above. In contrast, when written parental consent is employed, response rates drop precipitously, often to around 50% or less. When response rates

plummet to those levels, survey data becomes unreliable and unusable.

A study by the RAND Corporation comparing active written consent versus passive consent estimated that obtaining written consent was at least 15 times more expensive than passive consent. The author of the study, Phyllis Ellickson, has stated:

> A decade ago, it cost $25 per child to get signed forms from most of the parents; now it costs about $45 per child. For a large-scale study involving 20,000 children, the consent process alone could cost nearly a million dollars—probably considerably more if the children come from geographically dispersed areas. And even then, there is no guarantee that the effort will be successful.

A portion of the Monitoring the Future survey seeks written parental consent as part of a home follow-up of students who had previously been surveyed at school. Fewer than half (48.7%) of the parents returned the consent form in this case. When the remainder were contacted by phone, another 35% gave oral consent and only 1% declined participation. The balance of families could not be located. These results clearly indicate that a parent's failure to return a consent form does not necessarily indicate an objection to a child's participation, and that obtaining affirmative consent requires much effort for little apparent benefit.

This follow-up study tracked four groups of students, classified by the likelihood that they would drop out of school. The response rate to the initial written consent request was approximately 30% lower in the highest risk group compared to the lowest risk group, indicating that the written consent provision would lead to results that under represent the students most at risk. Consistent, with this conclusion, at one inner-city school with a high population of at-risk students, the written response rate was an abysmal 17%.

In a similar New York state survey the same results were found. One school had to be dropped from the study because only 20 of 224 signed parental consent forms were returned. Of the remaining schools, a comparison was made of those which required that written parental consent forms be returned with those which required that parents be given advanced notification of the study and given the opportunity to decline their child's participation.

The participation rate was 67.8% when written consent forms had to be returned, and 95% when just advanced notification was provided. In the schools with high risk populations where written parental consent forms were required, student participation was lowest. Other studies reported in journals such as Addictive Behaviors provide further evidence that parents of students who are most at-risk are less likely to return signed consent forms even though they do not, after repeated follow up, object to their child's participation.

If researchers hope to attain reasonable response rates under H.R. 1271, they will have to do extensive mail and phone follow-ups, as described in the example above. These additional efforts will require tremendous time and resource commitments from the participating schools, since schools are prohibited from releasing parents' phone numbers and addresses to researchers. Therefore,

school employees will be forced to write follow-up letters or make intrusive follow-up phone calls (often several calls per parent). In most cases, researchers will have to shoulder the cost burden of follow-up by reimbursing schools for labor and materials costs out of limited research grants. The result is that the cost of reliable research will skyrocket, potentially to the point where many valuable projects could not be funded. Dr. Johnston, Director of the Monitoring the Future Survey, estimates that across-the-board written consent would add approximately $500,000 annually to the cost of that survey alone.

In some cases, local school districts may have to bear the brunt of the increased costs associated with research and evaluation without reimbursement. For example, in order to qualify for Safe and Drug Free School Funds, local schools are required to conduct a periodic needs assessment. In the State of Michigan, this requirement is met through the Michigan Alcohol and Other Drugs School Survey (MAOD), a study that provides local information on adolescent drug use. The survey is also used to evaluate the effectiveness of local drug prevention efforts. Without this survey, many communities in Michigan would have no way to gauge the extent of drug use among their children. Dr. Thomas Van Valey, Director of the MAOD survey, concludes that the added requirements of H.R. 1271 would "put the cost of the survey completely out of range for many school districts, especially the smaller ones."

During the markup of H.R. 1271, Senator Stevens alluded to the possibility of allowing for affirmative oral consent rather than requiring written consent in all cases. While oral consent may elevate response levels marginally compared to the very low levels expected under a written consent requirement, it would not achieve the response rates necessary for reliable data analysis. The intrusive and expensive follow-up efforts outlined for the written consent method would also be required for affirmative oral consent. Dr. Van Valey writes that, "affirmative consent (either oral or, even more stringently, written) requires extraordinary (and costly, both in time and money) measures to be followed in order for adequate samples to be obtained. Even when a carefully designed sampling approach can be used, such restrictions can easily increase costs by a substantial percentage."

The following excerpt from a Congressional Budget Office cost estimate corroborates the claims of researchers regarding probable cost increases under H.R. 1271. "Based on information provided by Federal agencies and by private researches, CBO estimates that enacting this legislation would increase—in some cases, dramatically increase—the costs to conduct Federal surveys of minors. * * * In sum, CBO expects that the requirement of written parental consent could add nearly 50 percent to the data collection costs of some surveys directed at respondents under the age of 18."

Because of the dramatic cost increases associated with written consent, many important Federal surveys would be significantly curtailed or even eliminated because of H.R. 1271.

The Crime Victimization Survey by the Department of Justice interviews parents by telephone and, if they consent orally, also interviews their children. This low-cost telephone survey

that provides valuable information on rape and sexual attacks, would be impossible under H.R. 1271.

An ongoing survey of the largest school-based program to prevent youth violence, the "Resolving Conflict Creatively Program" in New York City, depends upon surveying a large, representative sample of participating children. The survey director has stated flatly that, "Active written consent would make this [survey] impossible."

The Youth Risk Behavior Survey, run by the Centers for Disease Control, provides data to health professionals and educators regarding the health behaviors and attitudes of high school students. Cost increases under H.R. 1271 would likely cripple the ability of this survey to provide usable data.

The Drug Use Forecasting (DUF) survey is widely used to assess drug use trends. According to Andrew Fois, Assistant Attorney General, U.S. Department of Justice, "The written consent provision in H.R. 1271 would effectively eliminate the DUF. A key indicator of drug use and enforcement effectiveness would be lost."

Runaway and Homeless Youth Act program evaluations, overseen by HHS' Administration for Children and Families and supported at the State and local levels, question youth on their reasons for seeking help. Questions often relate to "mental or psychological problems which are potentially embarrassing to the minor or his family" and "parental consent is not appropriate in this situation since abuse and neglect and other family problems often lead the youth to run away from home."

The information provided by these studies and evaluation efforts are critically important to protecting the health and safety of America's children. As a nation we must ensure that we learn the extent of problems facing our children and what responses can be taken by families, communities, States, and the Federal government.

Again, this is not merely an academic concern. As Sue Rusche, Executive Director of National Families in Action said in her testimony to the Committee:

> Statistics that charted the horrifying rise in drug use in the 70s provided the fundamental impetus for parents to act. Parents were outraged by drug paraphernalia, alarmed by decriminalization, and dumbfounded by "responsible use" messages, but their response would have been "so what? That won't affect my child." We couldn't have motivated them if we hadn't been able to show them that these factors were affecting *all* children, and it was only going to get worse unless we banded together and took action to change it.

Sue Rusche helped organize a parents' campaign, and worked with other community-based groups such as the National Parents Resource Institute for Drug Education (PRIDE) and the National Federation of Parents for Drug-Free Youth (now the National Family Partnership). These parents, working together, got results. For example, in 1978 they got the Georgia Legislature to pass the nation's first State law banning the sale of drug paraphernalia.

MORE PAPERWORK IN A TIME OF FEWER RESOURCES

Our Committee has spent much of this Congress pushing for reforms to make government work better and cost less and to create systems that are more flexible and responsive to individual needs. Today, if a parent wants to exempt a child from a Federal survey a parent finds intrusive, all the parent has to do is call his or her local school. It's quick, it's cheap, and it works. Replacing that system with one creating costly and burdensome new paperwork requirements would take government in exactly the opposite direction from the one this Committee has traditionally followed.

The written consent requirement of H.R. 1271 will result in a flood of paperwork since schools must compile, analyze, and save the consent forms for the tens of thousands of students who participate in research surveys. The burden of this avalanche of paperwork will not fall on researchers, but rather on local school employees who help administer the surveys. Schools, in the interest of protecting personal privacy, are generally prohibited from giving researchers information about parents, such as their addresses and phone numbers. Therefore, schools, not researchers, would have to spend considerable staff time contacting parents by phone or mail to encourage them to respond to the written consent request or following up with them if they do not respond initially. Because of the increased burden on school staff, many schools would be unable to participate in the research, thereby lowering the representativeness of the response pool.

The increase in local paperwork is all the more notable, and unnecessary, given existing Federal controls. As has already been discussed, current regulations insure that research is designed to safeguard the privacy and sensitivities of minor research subjects. Additionally, Federally-sponsored information collection activities are also required to go through review under the Paperwork Reduction Act. The Committee originated this Act, and most recently strengthened that Act through the Paperwork Reduction Act of 1995 (Public Law. 104–13). The Act established the OMB paperwork clearance process to ensure that Federally-sponsored information collection activities are not unduly burdensome to the public and are necessary for the proper performance of agency functions.

A witness testifying in favor of H.R. 1271 at the Committee's hearing cited a controversial survey as evidence of the need for the legislation. The facts show, however, that the survey's review under the Paperwork Reduction Act actually argues to the contrary against H.R. 1271, showing how well the current process is working. This witness described a controversial survey on teen sexual behaviors proposed by HHS. This study, known as the American Teenage Study, was stopped in the development stages during the OMB paperwork clearance process because of the sensitive nature of its questions, and was never administered to students. Thus, the existing Federal process worked to stop the study and no additional requirements would have affected it, or would have been needed to halt it.

That H.R. 1271 both ignores the current Federal process controls, and imposes new paperwork requirements on localities is evidence of its burdensome and costly impact.

H.R. 1271'S BROAD AND UNCERTAIN SCOPE

Regardless of the intended purpose of H.R. 1271, its explicit language would apply written consent requirements to a broad and unprecedented array of community and school activities. As currently worded, the bill would cover any "program or activity funded in whole or in part by the Federal government". This could include many activities unrelated to school-based research surveys or questionnaires. For example, a church that receives Federal funds to operate a homeless shelter could be required to obtain written consent for children to participate in otherwise unrelated and independent Sunday school activities.

Another example of the uncertain scope of the term "activity" was provided by a witness at the Committee's hearing who was testifying in favor of the legislation. The individual described a classroom exercise called "Are You a Liberal or a Conservative" that was given in a junior high social studies class in Anchorage, Alaska without obtaining parental consent. The questions were not part of a Federally-funded research effort. Rather they were contained in a supplement to a political science unit in a textbook called "Introduction to the Social Sciences," used citywide in the Anchorage school district. Nonetheless, the witness stated, in answer to a post-hearing question, that H.R. 1271 would prohibit the use of such an exercise without prior written parental consent because of Federal support for the school.

The claim that classroom teaching is a covered activity under the legislation is also suggested by the legislation's qualified exemption of "tests intended to measure academic performance except to the extent that questions in such tests would require a minor to reveal information listed [in the seven listed areas]" (sec. 2(c), emphasis added). This limitation effectively nullifies the exemption and clearly subjects classroom testing to the terms of the legislation, to the extent there is any Federal support.

The bill's very broad and very vague terms extends to the seven listed sensitive subject areas. It covers any questions that are intended to or have the consequence of eliciting information about such undefined general topics as parental political beliefs, psychological problems, sexual behavior, antisocial or self-incriminating behavior, comments about family members, or religious beliefs. These vague provisions, coupled with the clear intentions of proponents, declared at the Committee hearing, to attempt to enforce the legislation through judicial review, point to a future under H.R. 1271 of harassed local community and school officials, repeated litigation over even the most basic educational curriculum decisions, and the steady loss of critical information needed to inform program and policy decisions to protect the health and welfare of our nation's children.

This Committee has gone on record repeatedly about the need to perform cost-benefit analyses for new Federal requirements. The costs here are high in terms of paperwork requirements, burdens on school personnel, increased expense and compromised research and evaluation. The benefits have yet to be established, since the bill's proponents have been unable to document any instance of inadequate protection of children involving a Federal survey, much

less a national problem justifying the prohibitive paperwork, cost and research burdens that would be imposed.

GLENN SUBSTITUTE

We firmly support the use of parental consent procedures in all research involving children. H.R. 1271 targets Federally-sponsored surveys and questionnaires which contain questions in seven categories, but there is no reason to limit parental involvement to these seven categories. While the current regulatory scheme has worked well, Congress could strengthen existing policy for all Federally-sponsored research, while not eliminating the flexibility that has been achieved at the local level. The Glenn substitute, which was offered during the markup, did just that, allowing for local flexibility, while strengthening existing safeguards for children participating in survey research.

The Glenn substitute bill would have required that, prior to the participation of a minor in any Federally-sponsored survey or questionnaire:

(1) At least one parent or guardian is provided with advanced notification of the survey;

(2) At least one parent or guardian is provided with information on the purpose of, and the subjects to be covered in, the survey;

(3) At least one parent or guardian is informed of his or her right to have access to the survey as a condition of consenting to the minor's participation;

(4) At least one parent or guardian has provided consent for the minor's participation in the survey (the type of consent required would be determined by the appropriate IRB);

(5) At least one parent or guardian is notified of the means for declining a minor's participation;

(6) The minor is informed that participation is voluntary and that they will not be penalized for declining to participate;

(7) The minor is provided with the opportunity to decline participation;

(8) Information is provided about whom to contact for additional information about the survey;

(9) The parent, guardian, and minor are provided with an explanation of the procedures used to protect respondents, the confidentiality procedures to protect the information collected, and the extent to which any identifier information will be maintained;

(10) The chief administrative officer or designee consents to the administration of the survey or questionnaire in the institutional setting.

The Glenn substitute bill would provide for adequate, advance notification to parents before a child can be invited to participate in any Federally-sponsored survey, and a convenient method for parents to decline their child's participation. The substitute bill would eliminate the single, rigid parental consent mechanism in H.R. 1271 and allow flexibility at the local level to decide the method by which parents may give consent.

CONCLUSION

In an era of tightening Federal budgets, we need to make our research and evaluation dollars go farther. We need programs that work better and cost less, not the other way around.

Without many of the surveys affected by H.R. 1271, it will be difficult for families, educators, and policy makers to make informed decisions about the safety and welfare of children. Accurate research is needed on important issues, such as substance abuse, violence, and adolescent pregnancy. Parents have a right to know what challenges children face in school and in their neighborhoods, and public officials have a responsibility to ensure that this information is readily available to them. Reliable information is needed to alert parents and community leaders as well as policy makers when children face serious social or health problems. As elected officials, we should guarantee that this information is available to those who need it most. If this bill is implemented, the access to much of this information by parents, service providers and policy makers will be impeded or lost.

Burdening children's research with paperwork that costs more, slows down schools, intrudes on parents, and leads to less reliable research just does not make good sense. We all want to protect American families and their children, but H.R. 1271 represents exactly the wrong approach.

JOHN GLENN.
CARL LEVIN.
DAVID PRYOR.
J. LIEBERMAN.
DANIEL K. AKAKA.

IX. CHANGES IN EXISTING LAW

In compliance with paragraph 12 of rule XXVI of the Standing Rules of the Senate, requires that Committee reports indicate the changes in existing law of the proposed legislation. The bill as reported makes no change in existing law. It provides new authority for the parents or guardians to decide whether to consent to the participation of a minor child in federally funded surveys or questionnaires.

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