

Privacy Protection or Poor Policy? Some things you may not know about the ESEA

February 22, 2002

For the first three quarters of 2001, only two pieces of legislation received much attention on Capitol Hill. The first was the president's budget – no surprise there. The second was the Elementary and Secondary Education Act (ESEA), called "Leave No Child Behind." This was to be the centerpiece of the administration's domestic policy agenda, and news about the development and progress of this legislation made headlines. Both the House and Senate passed their respective versions of the bill before the August recess, and the stage was set for the differences to be hammered out in a conference committee.

The conference committee received a bill that was over 1,200 pages of text, with literally hundreds of amendments. The issues which received the most press were funding, state control of funds, and "failing" schools. Yet tucked away under the monetary battles and the donnybrooks over federal and state jurisdiction lay an amendment that was, and now is, a real threat to behavioral science.

Before the ESEA was passed by the House of Representatives last spring, an amendment was attached by Rep. Todd Tiahrt, R-KS, that would have required written parental consent before a child took part in any survey of any kind, if the survey involved "mental or psychological problems potentially embarrassing to the student ... sex behavior or attitudes ... illegal or self-incriminating behavior ... appraisals of other individuals with whom the minor has a familial relationship." Failure to comply with this amendment would mean a loss of federal funds for the non-complying school.

Tiahrt stated on the House floor that he introduced this amendment "in support of parental rights." The amendment, passed by the House, purports to protect children – but it is the endangered research and the knowledge it provides that will truly protect children from the dangers of drug abuse, domestic violence, and disease. This requirement for active consent, if instituted, would dramatically reduce student participation in school surveys, particularly among the most at-risk sectors of society, even though the vast majority of parents usually have no objection to their teenager's participation. In addition, students who live in homes where alcoholism or abuse are problems are less likely to receive permission to participate in studies on those subjects, which means that we would not receive the input of the population that is most relevant.

The Senate version of ESEA did not go so far as to require active parental consent before every survey given to a student, but it too was troublesome. Introduced by Sen. Tim Hutchinson, R-WY, it required that "a state or local education agency ... shall develop and adopt guidelines regarding arrangements to protect student privacy that are entered into by the agency with public and private entities that are not schools. ... " The provision went on to say that parents needed to be advised of the adopted guidelines at least once per school year.

The surveys that would be subject to these amendment help scientists garner valuable knowledge, which

in turn can be used to develop policies and programs to can keep children healthy and protected from the many dangers they face everyday, including drug and alcohol abuse, violence, and diseases such as cancer and AIDS. The amendments described above would have an impact on almost all research involving school children, especially longitudinal studies. If these studies are not allowed to continue with a true representative sample, years of progress and millions of dollars invested in these studies would be lost.

Of course, the surveys are approved by accredited Institutional Review Boards, and every precaution is taken to protect the privacy of the subjects. But when dealing with children as subjects, it inevitably means dealing with parents. Very few will disagree that parental consent is necessary before children are allowed to participate in research surveys, especially when sensitive topics are involved. But the process used to obtain consent could mean the difference between a groundbreaking survey and one that is devoid of a true representative sample. For all of these reasons, APS joined with many other science and education groups to actively oppose the Tiahrt and Hutchinson amendments.

After September 11, ESEA was understandably put on hold. Once the atmosphere in Washington regained some equilibrium, the conference committee went about forging the final legislation. In the end, the final language more closely represented the Hutchinson amendment:

...a local educational agency that receives funds under any applicable program shall develop and adopt policies, in consultation with parents, regarding the following:

The right of a parent of a student to inspect, upon the request of the parent, a survey created by a third party before the survey is administered or distributed by a school to a student; and (ii) any applicable procedures for granting a request by a parent for reasonable access to such survey within a reasonable period of time after the request is received.

The amendment in the final version of the legislation is intended, for the most part, to regulate commercial surveys in the classroom. Often, corporations will conduct surveys in schools, while they gather marketing data and the schools receive compensation. Scientific research was not the intended target. However, because the legislation does not distinguish between the types of surveys it applies to, behavioral science has been caught in crossfire.

Behavioral scientists rely heavily on research involving children, which naturally leads them to schools. Conducting surveys on behavior would be seriously undermined if some segments of the population are not allowed to participate in surveys, skewing the representative sample. Many schools that currently allow their students to be involved in research surveys use a form of parental consent known as passive consent. Parents are told of the survey and nature of research, and can opt to hold their children out if they so please. Active dissent is required. There is a strong possibility, however, that local education agencies will begin to implement active consent rules, requiring written consent before a child participates.

Even though an active parental consent requirement is not required by the ESEA, this final compromise is far from innocuous. When local education agencies do develop their own guidelines for allowing consent, most will do so with no knowledge of the benefit of surveys for scientific research, which could

end up subject to several forms of scrutiny. Because local agencies now have free reign to institute their own policies, an active consent requirement is likely to pop up in more than a few places.

Lloyd Johnston of the University of Michigan, whose Institute for Social Research oversees “Monitoring the Future,” is very concerned with the potential impact of the legislation. “I think this is simply an example of legislation that seems reasonable on its face, but that creates far more problems than it solves,” Johnston said. “Since school surveys provide perhaps the best window into a number of problem behaviors among the nation’s young people, these unintended consequences are not insignificant.”

In addition, the result can be a patchwork of local policies on the consent issue, leaving those who conduct research in more than one locality to navigate a myriad of different regulations. Johnston added, “The inclusion of a requirement in the ESEA that schools establish policies for the protection of student privacy carries the distinct risk that it will give rise to a crazy-quilt of differing policies, many of which will raise serious obstacles to national or even statewide scientific surveys in the schools. In particular, the proliferation of active parental-consent requirements, which the Congress specifically chose to leave out of the federal legislation, and for good reason, would seriously harm the representativeness of survey samples.

“Active consent procedures have the effect of suppressing overall response rates,” Johnston said, “because many parents simply fail to answer and must be counted as refusals, even though they have no objection to their child’s participation. Such under-representation tends to be particularly high among certain at-risk and minority groups, skewing the results in undesirable ways.”

The research at stake, much of which is funded by the federal government – through the National Institutes of Health, Department of Education, and National Science Foundation – is conducted for no other purpose than to ensure the well being and health of the nation’s children. The knowledge produced from this research has the potential to lead to treatment and prevention programs to address the problems of our youth. This amendment will make it harder to base treatment and prevention programs on good information. The federal government spends millions of dollars every year on studies such as these, and will continue to do so.

Longitudinal studies such as “Monitoring the Future” – funded by the National Institute on Drug Abuse – and The National Longitudinal Study of Adolescent Health, or “Add Health” – funded by the National Institute of Child Health and Human Development – are just two examples of the type of research our country needs to assure that our children lead safer lifestyles. Their benefits, as well as the benefits of countless other research activities, are unquestionable: “Monitoring the Future” has tracked illicit drug use among adolescents since 1975. “Add Health” provides over 800 researchers with access to its data, and approximately 300 scientific presentations, reports, and articles have been produced to date. One message, and a strong one at that, which came out of early findings of “Add Health,” is the continuing importance of families during the adolescent years in protecting against risky behaviors. “Add Health” research also suggests that parental behaviors and parenting practices have an important effect on adolescent risk behavior. Policy makers and scientists will not be well served if localities promulgate policies that hinder the surveys and research generated by these and similar studies.

President Bush signed the legislation in January, and we have this to report: Maybe no child was left

behind, but behavioral science research might be.