

Congressional Record -- Senate

Thursday, April 2, 1992;
(Legislative day of Thursday, March 26, 1992)

102nd Cong. 2nd Sess.

138 Cong Rec S 4708

REFERENCE: Vol. 138 No. 49

TITLE: NATIONAL INSTITUTES OF HEALTH REVITALIZATION AMENDMENTS

SPEAKER: Mr. ADAMS; Mr. BRADLEY; Mr. COATS; Mr. DOLE; Mr. DURENBERGER;
Mr. FORD; Mr. GORE; Mr. GORTON; Mr. HARKIN; Mr. HATCH; Mr. HATFIELD;
Mr. HELMS; Mr. JEFFORDS; Mr. JOHNSTON; Mr. KENNEDY; Mr. KOHL; Mr.
LAUTENBERG; Mr. LEAHY; Ms. MIKULSKI; Mr. MITCHELL; Mr. SIMON; Mr.
SIMPSON; Mr. WELLSTONE

.....

AMENDMENT NO. 1755 TO AMENDMENT NO. 1754

Mr. SIMON. Mr. President, I will speak on the secondary amendment that I have offered that is pending. First, I will describe what our bill does in regard to the sex survey research, which is a sensitive area. It would simply allow the Secretary to fund human sexual behavior research that has first been approved and reviewed through the existing scientific peer review process.

This means the project has been reviewed by applicable local ethics review panels, and that it has been reviewed by scientific panels. And then it has been approved by the Director of the Institute that is involved. Then, the Secretary is to fund the surveys on sexual behavior, or the Secretary can appoint an ethics advisory board to determine if there are ethical grounds for withholding funding.

The provision -- I would like to underscore this -- does not require or mandate that such studies be done.

In addition to these qualifications, what my amendment does is add another qualification. And that is that the Secretary has to determine that this survey -- there are two surveys involved -- will assist, first, in reducing the incidence of sexually transmitted diseases, the incidence of infection with the human immunodeficiency virus, or the incidence of any other infectious disease; or second, in improving reproductive health or other conditions of health.

And on the survey that is the teen sex survey, it is voluntary on the part of the teens, and it requires parental consent. The adult survey was initially developed by the National Institute of Child Health and Development, being concerned about what was happening in the whole AIDS problem.

At one point, it was approved by Secretary Sullivan and Assistant Secretary of Health, Mason. On the teen survey, let me quote from Mr.

Bernadine Healy, the appointee of President Bush, who is now the director of NIH.

She said the following about the teen sex survey:

It will be a wonderful survey. I knew it would be controversial, and I reviewed it personally. I read the whole thing myself, and it is an excellent study.

The amendments that we have offered, Senator Kennedy's primary amendment and my secondary amendment, were approved by the House of Representatives 283 to 137. My colleague, who is the Presiding Officer now, Senator Breaux, will recall that Congressman Roy Rowland, from Georgia, who is a physician, and with whom I had the opportunity of serving in the House and for whom I have great respect, and Congressman McDermott, who is also a physician -- and I do not believe I served in the House with Congressman McDermott -- but these two physicians led the fight on this.

And my colleague who is the Presiding Officer will tell you Congressman Rowland has his feet on the ground. He is a very conservative Democrat. And Congressman Rowland said this is essential if we are going to protect the health of people in this country, and I think we ought to be listening to him.

It is interesting who has endorsed this. The American Medical Association and the various public health associations, psychological associations, and so forth, and let me add one other. I cannot remember -- maybe it is just my faulty memory -- I cannot remember the American Red Cross ever getting involved and endorsing amendments, but the American Red Cross says this is important because of the health of our population.

At one point the administration strongly supported the surveys, but under pressure, frankly, from those who misunderstood the Secretary of HHS either voluntarily or was forced to overrule them and backed off on this. What we want to do is open the door. This does not mandate it. But it allows it and it encourages us to move forward.

We have huge problems. We have not had a teen survey, sex survey, or adult survey since the late forties and [*S4730] early fifties. Why do we have some of the problems that we have? Well, they vary so much -- births to unmarried women -- and, incidentally, we have the highest teenage pregnancy rate in any industrialized country in the world -- births to unmarried women. Whites in Hartford, CT, 50 percent of the births are to unmarried women, and in Detroit it is 32 percent. Why this differential? In New Mexico, on the white population, it is 27 percent, and in Alabama it is 10 percent. Among blacks, in Wisconsin it is 76 percent, in Illinois, 75 percent, in Hawaii 15 percent.

Why the huge differences no matter which ethnic group you pick? We ought to know. Ignorance does not protect us, I say to my friends. That is the most fundamental thing that we have to recognize. We have a choice of ignorance or knowledge in this field. Let us not choose the route of ignorance.

For example, among teenagers, the rate of AIDS has gone up 20 percent in the last 2 years. That ought to be of concern to all of us. Two million Americans now suffer from gonorrhea. There is a whole series. Syphilis has gone up 85 percent since 1985; Chlamydia, 4 million American women are suffering from this. AIDS is going to cost - these estimates vary, and I do not know who is right on these estimates -- AIDS is going to cost this Nation, in terms of government and private expenditure, somewhere between \$4 and \$13 billion this year, totally aside from the humanitarian problem that that causes. Over 130,000 Americans have died of AIDS. What we want to do is let us find out how we can prevent some of this needless tragedy.

It is interesting that USA Today has an editorial, which I shall read:

A handful of politically potent prigs are treating a major public health problem like a dirty joke.

Secretary of Health and Human Services Louis Sullivan gave in to ideologies who objected to questions about sexual practices in a five-year survey of adolescent sexual behavior and killed funding for this worthwhile effort.

He may have killed more than a study. Ignorance about the risks our young people are taking can cost lives.

The goal of this study was to discover not just what teens are doing, but why. Why are they putting themselves in danger of AIDS, sexually transmitted diseases and unwanted pregnancy at younger ages and in greater numbers? What influences do family values have on their decisions? What part do school, peers and the community play?

If this misplaced prudery prevails, we'll never know. Many, like the writer across the page, think that's just fine. They're content with the current state of knowledge and don't want to spend government money to learn more.

This is a dangerous advocacy of ignorance.

Many questions that raised objections had been dropped from an early draft. Three-quarters of the questions were not about sexual practices. Each of the 24,000 teens answering the survey would do so with parental consent. Parents would answer separate questionnaires.

These days, a teen who is careless with sex risks far worse consequences than parental disapproval.

AIDS cases among teen-agers in the United States have increased about 40 percent in two years, which means that there are now thousands infected with the deadly virus. Other data tells us that awful number is bound to grow:

Half of girls have had sex by age 17; half of boys by 16.

Only one-third of boys always use condoms.

Nearly 80 percent of boys and 50 percent of girls age 18-19 switch partners within 12 months.

That's a recipe for disaster for our young people.

AIDS is just one of the diseases that can wreck their lives; they're also in danger of infections that can cause sterility and pregnancy that can put them on welfare. Fifty-nine percent of women who were receiving welfare in 1988 were age 18 or younger when they first gave birth.

If these grim facts are going to change, we have to learn more about teen behavior. What encourages teens to take such risks? What would persuade them to avoid those risks?

Secretary Sullivan should heed the House vote late Thursday affirming such surveys. What better use for public money than buying a tool to save young lives?

What we choose not to know can ruin their lives -- or kill them.

We have spent, I do not know how much time, Mr. President, in this body and in the other body on the whole question of abortion. One of the major causes of abortion is teenage pregnancy. We have about a million teenage pregnancies each year, 400,000 of which end up in abortions. If through this survey, we can reduce the numbers of teenage pregnancies, we will, in fact, then reduce the number of abortions. Those who are interested in reducing the numbers of abortions should be supporting the amendment which Senator Kennedy and I have offered.

If this survey goes ahead, will it add one more teenage pregnancy to this Nation? I cannot believe it. If this survey goes ahead, can we get knowledge that can prevent teenage pregnancies? I cannot stand here and guarantee it, but there is at least a strong possibility that we can.

Let us not move under a cloak of darkness. Let us find out what is going on.

Ignorance is going to cost lives. Education can save lives, and if particularly we know some of the ties and some of the reasons for some of the problems we face, everyone is going to be ahead.

For those who say you cannot do anything in the way of education and prevention, I say to my friends, smoking ordinary cigarettes is a much different thing today than it was not too many years ago. I was just thinking this morning I do not think we have 10 Members of the United States who smoke cigarettes anymore. I am sure that 20 years ago or 30 years ago, probably at least half of the Members of the United States did. Education does work.

How can this survey find out anything? Well, we can maybe find out how teenage pregnancy may be tied in with alcohol, with peer pressure, with other problems, with a whole question of educational attainment.

I think, by all means, we ought to move ahead on this, Mr. President, and I hope we do the rational thing, the compassionate thing, and the thing that is going to save lives, and that is to say

that we are going to make a decision that we are not going to act out of ignorance. We are going to act because we have accumulated the kind of knowledge that we ought to have.

Mr. President, if no one else seeks the floor, I suggest the absence of a quorum.

The PRESIDING OFFICER. The clerk will call the roll.

The legislative clerk proceeded to call the roll.

Mr. SIMON. Mr. President, I ask unanimous consent that the order for the quorum call be rescinded.

The PRESIDING OFFICER. Without objection, it is so ordered.

Mr. SIMON. Mr. President, I request the yeas and nays on the amendment that we have offered.

The PRESIDING OFFICER. Is there a sufficient second?

There is not a sufficient second, the Chair observes, at the present time.

Mr. KENNEDY. Yeas and nays, Mr. President.

The PRESIDING OFFICER. Is there a sufficient second?

There is a sufficient second.

The yeas and nays were ordered.

Mr. SIMON. Mr. President, as far as I am concerned, we can proceed to the vote. The managers of the bill may have more knowledge that there are others who wish to speak on it. If there are none, we can go ahead with the vote.

Mr. KENNEDY. Mr. President, I suggest the absence of a quorum.

The PRESIDING OFFICER. The clerk will call the roll.

The legislative clerk proceeded to call the roll.

.....

Mr. KENNEDY. Mr. President, on behalf of the majority leader and, as I understand, with the support of Senator Dole, I ask unanimous consent that the pending amendments be withdrawn; that Senator Simon be recognized to offer an amendment on the subject of sexual behavior; that his amendment be immediately laid aside; that Senator Helms be recognized to offer his amendment that is provided for in the consent agreement dealing with the same subject; that there be 2 hours for debate on both the Simon and the Helms amendments to run concurrently and be divided between Senators Simon and Helms, or their designee; that neither the amendments nor possible language proposed to be stricken by the amendments be subject to amendment; that at the

conclusion or yielding back of the time, the Senate, without any intervening action or debate, vote on the Simon amendment to be followed immediately, without any intervening action or debate, by a vote on the Helms amendment.

The PRESIDING OFFICER. Is there objection?

Mr. LEAHY. Reserving the right to object. Would it be possible before this 2 hour starts that the Senator from Vermont may be able to have a total of, say, 6 minutes for a statement on the bill, no more than that, if that can be part of the request?

Mr. SIMON. Mr. President, if my colleague will yield, I have no objection to that. I am in the awkward situation of having this amendment on the floor and we are marking up the budget. The Budget Committee does not permit proxies. If he could withhold while I offer the amendment, then I would be pleased to agree to that.

The PRESIDING OFFICER. Is there objection to the unanimous-consent request? Without objection, it is so ordered.

The two amendments requested are withdrawn.

The amendments (Nos. 1754 and 1755) were withdrawn.

AMENDMENT NO. 1756

(Purpose: To impose certain requirements with respect to surveys of sexual behavior)

Mr. SIMON. Mr. President, I send an amendment to the desk.

The PRESIDING OFFICER. The clerk will report.

The assistant legislative clerk read as follows:

The Senator from Illinois [Mr. Simon] proposes an amendment numbered 1756.

Mr. SIMON. Mr. President, I ask unanimous consent that the reading of the amendment be dispensed with.

The PRESIDING OFFICER. Without objection, it is so ordered.

The amendment is as follows:

At the appropriate place, insert the following new section:

SEC. . REQUIREMENTS REGARDING SURVEYS OF SEXUAL BEHAVIOR.

With respect to any survey of human sexual behavior proposed to be conducted or supported through the National Institutes of Health, such survey may not be carried out unless --

(1) the proposal for such survey has undergone review in accordance with the applicable requirements of sections 491 and 492 of the Public Health Service Act; and

(2) the Secretary, in accordance with the provisions of Title II of this Act, will make a determination that the information expected to be obtained through the survey will assist --

(A) in reducing the incidence of sexually transmitted diseases, the incidence of infection with the human immunodeficiency virus, or the incidence of any other infectious disease; or

(B) in improving reproductive health or other conditions of health.

.....

Mr. KENNEDY. Mr. President, we are waiting for the Senator from North Carolina to come to the floor to present his amendment and give him an opportunity to address this subject matter. Senator Simon and I have spoken about the importance of his amendment, and I will take just a few more minutes to address it in just a short time.

.....

Mr. HELMS addressed the Chair.

The PRESIDING OFFICER. The Senator from North Carolina.

AMENDMENT NO. 1757

Mr. HELMS. I thank the Chair for recognizing me. I send an unprinted amendment to the desk and ask for its immediate consideration.

The PRESIDING OFFICER. The Chair would note that under the previous order amendment No. 1756 is set aside.

The Senator from North Carolina is authorized to offer his amendment.

Mr. HELMS. That is correct.

The PRESIDING OFFICER. The clerk will report.

The assistant legislative clerk read as follows:

The Senator from North Carolina [Mr. Helms] proposes an amendment numbered 1757.

On page 115, strike lines 1 through 17 and insert the following:

"SEC. 1010. -- PROHIBITION AGAINST SHARP ADULT SEX SURVEY AND THE AMERICAN TEENAGE SEX SURVEY.

The Secretary of Health and Human Services may not during fiscal year 1992 or any subsequent fiscal year conduct or support the SHARP survey of adult sexual behavior or the American Teenage Study of adolescent sexual behavior. This section becomes effective April 15, 1992."

Mr. HELMS. Mr. President, have the yeas and nays been ordered on the Simon amendment?

The PRESIDING OFFICER. I believe they have. The Chair is incorrect; they have not. The yeas and nays on the Simon amendment have not been ordered.

Mr. HELMS. I ask for the yeas and nays on the Simon amendment.

The PRESIDING OFFICER. The Chair must advise the Senator that that is not in order because it is not the pending question.

Mr. HELMS. Mr. President, the amendment at the desk would strike section 1010 of the underlying bill and insert language to prohibit forcing the American taxpayers to provide an estimated \$25 million to fund two national sex surveys that the Secretary of the Department of Health and Human Services [HHS] has already rejected as being improper, but which Secretary Sullivan would nevertheless be required to fund under the bill as amended by Senator Simon.

Section 1010 requires the Secretary of Health and Human Services, whether he likes it or not, to provide money for these two sex surveys -- proposed by research bureaucrats on the Federal payroll. Funding for these projects is required even though the Secretary has made the judgment that the surveys are not in the public's best interest and, by the way, the Senate already rejected these two sex surveys last September by a margin of 2 to 1.

Mr. President, the pending amendment strikes out this outrageous mandate in section 1010 -- and that is what it is, a mandate -- because it interferes with the ability of the Secretary of HHS to run his department. HHS and the Justice Department, by the way, justifiably object to this provision because it clearly intrudes upon the constitutional power of the executive branch as provided by the separation of powers provisions of the Constitution.

Just for the purpose of emphasis, I will reiterate that on September 12 of last year, the Senate voted 66 to 34 in support of my amendment to strike what was then a \$10 million, 1 year appropriation designated for these two sex surveys, and to shift that \$10 million into what is called the adolescent family life programs to encourage teenagers to abstain from sexual activity. I have placed copies of that roll call vote on the desks of my colleagues, so that each Senator can recall his or her position of last year.

At this time, I ask unanimous consent that the roll call vote of September 12, 1991, be printed in the Record immediately prior to today's vote on the Helms amendment.

The PRESIDING OFFICER. Without objection, it is so ordered.

Mr. HELMS. Mr. President, despite the overwhelming vote by this Senate on this issue last fall, some elements in Congress have not yet gotten the message. Their resurrection of the sex survey issue in section 1010 is just another example of an unceasing effort to fund their warped social and political agenda with millions of dollars of taxpayers' money.

I resent that, I object to it, and that is why I am on this floor this afternoon with this amendment.

The amendment last September 12 presented Senators with a clear-cut choice between supporting title XX -- the only federally funded sex education program that counsels our children to abstain from having sex until they are married -- or supporting the reprehensible sex surveys that the sexual liberation crowd is pushing, the real purpose of which is to cook the scientific facts to legitimize homosexual and other sexually promiscuous lifestyles.

No other face can be put on it. The Senate had a clear choice last September between support for sexual restraint or support for homosexuality and sexual decadence.

So, Mr. President, the pending amendment will disclose whether Senators will keep faith with their earlier votes. Once again, the issue is whether we are going to permit the use of the American taxpayers' money to pay for sex surveys deliberately designed and staffed to produce preordained results ostensibly showing that promiscuous, perverted, sexual practices are normal and, therefore, socially acceptable.

Mr. President, the Senate must reject this cruel hoax.

The truth is clear, Mr. President. Children are engaging in sex at younger and younger ages as the so-called sex education agenda moves into the elementary schools -- an agenda often camouflaged as so-called AIDS education. But the real intent and real effect of these programs unmistakably desensitizes children at younger and younger ages to immoral and deadly sexual lifestyles.

Mr. President, I am persuaded that the majority of Americans clearly understand that the real purpose behind the current sex survey proposals is not to stop the spread of AIDS. The real purpose is to compile supposedly scientific and Government-sanctioned statistics supporting ultra-liberal arguments that homosexuality is normal behavior.

Bullfeathers. There is nothing normal about it, Mr. President. I believe the majority of the American [*S4738] people know that. I believe that the majority of the American people resent the use of their money to promote and legitimize this immoral lifestyle.

The handwriting is on the wall. These so-called scientific surveys will be used time and time again to confer acceptability, if not respectability, upon homosexuality by portraying it implicitly or explicitly as normal sexual behavior. However, it is precisely these homosexual practices that account for at least 85 percent -- perhaps more -- of America's AIDS cases.

In short, the results of the sex surveys will be used -- and you can see it coming -- to legitimize the very behavior that accounts for the overwhelming majority of AIDS cases in this country.

Mr. President, from a scientific perspective, sex surveys, by their very nature, are neither objective nor scientific. On average, 40 to 60 percent of the people asked to participate in a sex survey will say: Forget it, I am not participating. The Centers for Disease Control will tell you that any refusal rate higher than 15 percent will skew any survey's results by at least 50 percent.

The participation rates, Mr. President, are so low because most Americans resent even being asked to answer questions about how often they engage in sex, with whom, their preferences for sexual partners, and which sex act they prefer.

Well, that raises the question of who does participate in there purportedly scientific surveys? Only those with the desire to share the graphic details of their sexual intimacies, real or imagined -- people who obviously favor lewd or perverse sexual behavior.

Ask yourself, Mr. President, what kind of parents would even consider allowing their teen-aged child or children to answer questions contained in the NIH's proposed teenage sex survey.

At this point, Mr. President, I am in somewhat of a dilemma because of the repulsive nature -- the repulsive nature -- of the questions. I shall not read them in the Record. However, I do ask unanimous consent that a photostat copy of some of the questions from the American Teenage sex study be placed on each Senator's desk.

The PRESIDING OFFICER (Mr. Lieberman). Without objection, it is so ordered.

Mr. HELMS. Mr. President, the unacceptable nature of these NIH questions makes it obvious why 40 to 60 percent of Americans refuse even to participate in sex surveys. All the same, this does not deter the avidly pro-homosexual members of the scientific community. They know that sexual deviants, perverts, and homosexuals will be disproportionately represented in every one of these sex surveys. In fact, they count on it because they want to buttress their political and social pretense that homosexuality is not deviant behavior, and of course, Mr. President, it is deviant behavior.

Such deception and misrepresentation have been endemic in such sex surveys from the very beginning. Look back at Alfred Kinsey's sex survey in the 1940's. It was the original source for the often cited phony statistic that 1 out of 10 people is a homosexual.

Now, Dr. Kinsey knew before he started what he wanted his survey to prove. So he never -- never -- disclosed the fact that he had surveyed mostly homosexuals, prisoners, and college students -- a sample obviously non-representative of the American people as a whole.

It was, and it was intended to be, a monumental falsehood.

Mr. President, Senators may also wish to know that the Government's supposedly objective research investigators for the proposed survey of adult sexual behavior are absolutely biased.

Let me give you some examples. One of the 3 investigators is a fellow named Stuart Michaels, a former chairman, now get this, of the American Sociological Association's Lesbian and Gay Caucus. Oh, what an objective guy he is going to be. And then there is a John Gagnon, who has been adviser or board member of organizations such as the National Organization for the Repeal of Marijuana Laws, the National Sex And Drug Forum, and the Institute for the Advancement Of Human Sexuality. I have never laid eyes on John Gagnon, but I do not want him in my living room, I do not think the majority of the American people would.

But let us consider a rather revealing quote from Mr. Gagnon's 1977 book entitled "Human Sexualities." I want to be very slow in reading the following quote because I want Senators to understand what the man said. I quote:

The horror with which society views the adult who has sexual contact with young children is lessened when one examines the behavior of other mammals.

OK. We are going to compare humans with mammals. Then Mr. Gagnon asserts:

Sexual activity between adult and immature mammals is common and appears to be biologically normal.

I think, Mr. President, most Americans will not agree with Mr. Gagnon's premise that the same standard be used for judging human sexuality as is used for animals.

Most civilized people would in fact agree, I think, that any adult who has sexual contact with children is -- absolutely -- an animal.

I commend Dr. Sullivan, the Secretary of Health and Human Services, for recognizing the absurdity of the NIH's proposal to spend \$18 million -- \$7.1 million this year alone -- on a national sex survey of American teenagers. Even though Dr. Sullivan canceled this project last year, and God bless him for doing so, section 1010 of this bill proposes to revive it, and Senator Simon's amendment merely adds to those provisions in section 1010.

Mr. President, NIH also proposes to spend another \$3 million on a so-called SHARP survey of adult sexual behavior that the Office of Management and Budget and the House Appropriations Committee rejected in 1989. See, those projects have been rejected, rejected and rejected. And, here it is again popping up in this bill.

The fact is that despite the administration's commendable past efforts to stop both surveys, the sex liberation crowd is still pushing, pushing, pushing for them.

So, I close for the moment, Mr. President, but let me reiterate -- at the risk of being repetitious -- that the Senate considered this matter last September 12 when it voted 66 to 34 to strike the funding for these sex surveys. I fervently hope that Senators will do so again by supporting the pending Helms amendment.

I reserve the remainder of my time.

The PRESIDING OFFICER. Who yields time?

Mr. KENNEDY. How much time does the Senator wish? I yield 4 minutes.

The PRESIDING OFFICER. The Senator from Vermont Mr. Jeffords, is recognized.

Mr. JEFFORDS. Mr. President, as we all know, a little knowledge is a dangerous thing and we have far too little scientific knowledge on the topic of human sexual behavior, however sensitive and private a topic it may be. It is for this reason that I stand before you in support of the provisions in section 206 of the NIH reauthorization bill that deals with the issue of sexual behavior research.

I also support the Simon amendment which will assist us in making sure that that proceeds in the kind of way that should not lead us into difficulty.

The street knowledge, or ignorance, that typified sexual awareness in my generation, is perpetuated today in the attitudes that prevent a forthright approach to scientific research into human sexual behavior. This cannot continue.

The emergence, in epidemic proportion, of major social ills such as unintended pregnancy and sexually transmitted diseases including AIDS cry out for knowledge. We need data to tell us, not only what is happening, but why and where it is happening.

It is my belief that only through federally funded research can we gain this critical knowledge

David Landers, a Vermonter with a Ph.D. in educational counseling, and who is director of the student resource center at St. Michaels College in Vermont, has devoted his life to counseling young people. He urges me to support section 206 and sexual behavior research because he has come to know [*s4739] how terribly difficult it can be to convince young people, not only that they are at risk, but to take precautions to reduce or eliminate risk.

The only solution is to confront them with firm, indisputable, indeed sometimes shocking evidence. And such evidence can only be rooted in the irrefutable statistical reports that emerge from broad-based, carefully organized, scientific studies.

Mr. President, our young people are at risk. Our younger generation, future generations are at risk. The facts of life, or death, are that AIDS is not going to be cured in the immediate future. We must accumulate, as fast as possible, the behavioral knowledge upon which to base our defenses in order that our children can survive. That is why we need this bill now.

First of all, there is absolutely no evidence that asking adults or teenagers about sexual behavior research will promote or encourage sexual behaviors. Surveys do not give messages about moral or ethical values; they are designed to measure behavior and attitudes. We ask

questions about crime in public surveys but these surveys are not alleged to promote crime.

There is also a significant misunderstanding about who will be surveyed about these behaviors. Only persons who have agreed to participate will be asked any questions. They will be told up front what the survey is about and given every opportunity not to participate or to stop if somewhere along the way they find that they do not wish to proceed.

Finally, and in some ways most importantly, it has been suggested that section 206 of this bill directs HHS to conduct sexual behavior research. That just is not the case.

Section 206 does not in any way mandate the conduct of sexual behavior research by the Department of Health and Human Services. Rather, it levels the field for studies of human sexual behavior by directing Secretary Sullivan to give another look at supporting such research. Under this bill Secretary Sullivan would be directed to convene an ethics advisory board that would include at least 50-percent membership from the general public, to review sexual behavior research studies that have been denied funding in the last several years.

Moreover Senator Simon amendment is to the effect that before any survey of human sexual behavior can be undertaken through NIH, the projects must be reviewed for scientific and ethical considerations. I am cosponsoring this amendment, supporting this further precaution.

I urge that we defeat any amendments that prohibit or otherwise restrict the sexual behavior research provisions in this bill in order that we can undertake the research we so desperately need. I urge Senators to support the Simon amendment.

Mr. President, I yield back the remainder of my time and yield the floor.

The PRESIDING OFFICER. Who yields time?

Mr. KENNEDY addressed the Chair.

The PRESIDING OFFICER. The Senator from Massachusetts.

Mr. KENNEDY. Mr. President, I yield myself such time as I may use.

Mr. President, I strongly oppose the amendment of the Senator from North Carolina.

The NIH reauthorization bill is designed to put the genius of this nation behind prospects for saving lives and improving the quality of life for all of our citizens -- through rigorously reviewed scientific research that is at the cutting edge and foremost in the world.

The Senator's amendment would politicize the scientific process and undermine our ability to deal with urgent health and social problems, and in so doing, may actually cost us American lives.

As a nation, we face many vitally important public health challenges, among them the skyrocketing rates of teenage pregnancies and sexually transmitted diseases, including HIV, that threaten the health and productive future of our youth.

Numerous prominent scientific and public health panels, including the Institute of Medicine.

Mr. President, I have an Institute of Medicine study here from 1991 where it points out that:

The epidemic of HIV infection and AIDS is both a biological and a behavioral phenomenon and efforts to contain its spread must look to both biomedical and behavioral sciences for interventions.

It continues:

Lack of knowledge regarding patterns and determinants of sexual and drug-using behaviors in the general public, as well as in groups at particular risk for HIV infection, has hampered public health efforts to develop health education interventions for the prevention of AIDS. The committee considers increased attention and funding to be warranted, given the lack of scientific data on behaviors related to HIV infection, the seriousness of the HIV/AIDS epidemic, available research opportunities in the field, and the potential public health benefits such research could realize.

And then it points out:

Data are scarce on initiation into early sexual activities and the influence of family and peer groups on sexual behavior and contraceptive use. It is also unclear how much of the sexual activity of adolescence is motivated by sexual desire and how much results from the desire for peer acceptance and other nonsexual motives.

This is typical of the opinion put forward by the Institute of Medicine and others in the scientific community who believe that developing sound public policy is dependent on this kind of information. The National Academy of Sciences, the National Research Council, and the National Commission on AIDS have all issued reports documenting the need for reliable behavioral research data critical to designing and evaluating effective prevention strategies.

As we approached this debate, organizations such as the American Medical Association, the American Public Health Association, the American Psychological Association and many other medical and public health associations have urged the Senate in clear and unequivocal terms to put sound science and public health principles first. We should remember that today as we consider this amendment. In this case, putting America first means putting public health first.

The real issue is who determines what specific research projects the NIH pursues -- research scientists with decades of experience -- or the Congress.

The substitute amendment offered by Senators Simon, Jeffords, and myself responds to concerns that Members have about federally funded

behavioral research, and at the same time, supports the integrity of the scientific process.

The substitute would require that any proposed study of sexual behavior would be authorized for potential funding only after three specific restrictions had been met:

First, the project would have to be reviewed by the applicable local ethical review panel, in order to ensure that high ethical standards have been met.

If a university makes a request for funding for a study, they have to establish an ethical panel, who will review the request in terms of its ethical and scientific value.

Second, the project would have to be reviewed by the applicable scientific peer review panels in order to ensure that rigorous scientific standards had been met.

Those panels will actually be named by the Secretary himself or herself. They set up these panels. And they are in the best position to determine the scientific validity.

And finally the project would have to be reviewed by the Director of the relevant Institute of the NIH in order to assure that the study would assist in the prevention of infectious diseases -- or the improvement in health status. What we are talking about is the need for data critical to our ability to develop appropriate educational materials to prevent the spread of infectious disease -- and to improve our health status.

The Simon-Kennedy amendment protects both the public interest and the public health.

There is a long standing tradition of Members on both sides of the aisle standing on this floor to defend the NIH and the peer review process from political whim.

We should continue that tradition today and reaffirm our commitment to sound science and the integrity of the NIH.

[*S4740] If we are to protect the public health and remain in the forefront of medical knowledge and expertise, we must ensure that health-related decisions are made by those who possess the information and the tools necessary to save lives and reduce suffering.

When presented with the same set of amendments, the House of Representatives refused to put politics before public health and voted by a veto-proof majority of 283 to 137 to support the substitute.

I urge my colleagues to vote for science by opposing the Helms amendment and to supporting the substitute.

I reserve the remainder of my time.

The PRESIDING OFFICER. Who yields time?

Mr. HELMS addressed the Chair.

The PRESIDING OFFICER. The Senator from North Carolina.

Mr. HELMS. Mr. President, I am sorry Senator Jeffords has left the floor. He repeatedly referred to section 206. For the Senator's information, section 206 in this bill has become section 1010, as the bill has been modified by Senator Kennedy.

Now, I am going to ask my friend from Massachusetts if he would mind reading -- and I am going to send it down to him -- the questions in this photostat from one of the proposed surveys. Would the Senator just read them for the Senate's edification.

Mr. KENNEDY. Will the Senator yield for a response?

Mr. HELMS. Sure.

Mr. KENNEDY. All I am saying is we tried to get the various material. If the Senator thinks I am going to pick up a piece of paper from the Senator from North Carolina that I have not had a chance to examine and the authenticity of which I do not know, basically, which I do not know -- --

Mr. HELMS. Mr. President, I do not yield for that.

Mr. KENNEDY. The Senator is mistaken.

Mr. HELMS. Regular order, Mr. President.

Mr. KENNEDY. So I reject that request.

Mr. HELMS. Regular order.

The PRESIDING OFFICER. The Senator from North Carolina has the floor.

Mr. HELMS. You bet.

No, the Senator does not want to read the questions because they are so rotten that he would lose his case on the spot. That is his problem.

Now, these questions may be all right for a nightclub in Miami or Palm Beach at 2 o'clock in the morning on Saturday night, but they are not fit for young children to be asked in their own homes. That is the point I am making.

I am tempted to ask the clerk to read them into the Record since Senator Kennedy is unwilling to do so. He pretends that he does not know what these questions are. He knows what they are.

Mr. President, I have two letters from the Department of Health and Human Services and the Department of Justice, that object to the provisions of title II -- in section 202 to be exact -- that require the Secretary of HHS to convene a special ethics advisory board before he can withhold funding from any project the Government researchers at NIH decide they want to fund -- like these sex surveys.

More importantly, not only does title II require the Secretary to convene such an advisory board before he can withhold funding, but the Secretary must absolutely fund the project if a majority of that so-called advisory board approves the project. Since at least a third and perhaps as many as half of the board will have to be these same researchers who are pushing this garbage, can there be any serious doubt whether a majority of the board will approve the projects, over the Secretary's objections to them?

I reiterate: Secretary Sullivan, bless his heart, has already rejected these surveys. I think he knows a little bit more than Senator Kennedy, or Senator Jeffords, or Senator Simon, or Jesse Helms, or anybody else about what is and what is not appropriate in this field.

So to pretend that this advisory board is going to work out fine, as I heard one Senator say, is nonsense. It will take away from the Secretary his constitutionally derived responsibility and authority.

Mr. President, how can the board be called an advisory board when Secretary Sullivan will be compelled to abide by whatever this board decides? Think about that. That is why the Departments of Justice and Health and Human Services say that this provision violates the appointments clause of the Constitution, and is, therefore, an infringement on the separation of powers provisions set up by the Founding Fathers.

Section 1010 -- which I would say to Senator Jeffords, if he were still here, used to be section 206 in title II before Senator Kennedy modified the underlying bill -- takes this unconstitutional process yet another step. That section says that the two sex surveys at issue -- and NIH, by the way, says these are the only two research projects affected by section 1010 -- "shall be considered to have been recommended for approval" by such a newly required, so-called ethics advisory board as soon as this bill is enacted into law.

So let us not engage in legerdemain or obfuscation. Let us cut through the legal shenanigans, Mr. President.

Section 1010 says that Secretary Sullivan must fund these two sex surveys once this bill is enacted into law. It is as simple as that. And anybody who can read the English language knows not only what this section purports to do, they also know what it is afoot.

I reiterate for purposes of emphasis: Secretary Sullivan has already turned thumbs down on these two surveys. I think he is absolutely right, and I think the vast majority of the American people agree with him.

I reserve the remainder of my time.

The PRESIDING OFFICER. Who yields time?

Mr. KENNEDY. Mr. President, I suggest the absence of a quorum.

The PRESIDING OFFICER. The clerk will call the roll.

The bill clerk proceeded to call the roll.

Mr. KENNEDY. Mr. President, I ask unanimous consent that the order for the quorum call be rescinded.

The PRESIDING OFFICER. Without objection, it is so ordered.

Mr. KENNEDY. Mr. President, I yield myself such time as I require.

Mr. President, I want to point out for the Record, I do not intend to get into a debate about particular questions in the survey here on the floor of the Senate.

The basic issue in question to be resolved in this legislation is, are we going to meet the ethical and scientific standards I outlined earlier, at the local community and university level, as well as at the NIH. And having done that, we will allow valid and important research to proceed.

That is the way the procedure ought to work. There are some of those who would rather, perhaps, not know what is happening among the young people in this country. But there are certainly some strong public health challenges that beckon our attention.

Each year, more than a million teenagers 19 and under become pregnant; over 10,000 babies are born to girls under 15 years of age. The implications are staggering. We know that adolescents who have children before the age of 20 are more likely to drop out of school and become dependent on welfare. Ninety percent of the teenagers who have children, who do not graduate from high school, will be on welfare 10 years from the time they have their babies.

In 1989 the Federal Government spent over \$21 billion for health and welfare services to families of teenage mothers. Sound public policy is cost effective. It saves money. Effective education efforts require an understanding of the context in which decisions about early sexual activities and risky behavior are to be made, and this information is desperately needed.

Sexually transmitted diseases among youth have been skyrocketing in recent years. Fifty-five percent of high school students become sexually active before graduation. More than 2.5 million adolescents contract a sexually transmitted disease each year; and 86 percent of the sexually transmitted diseases occur in people under age 29. These figures highlight an urgent public health concern, and the longer we delay the worse the problem becomes.

These diseases are a major cause of infertility, especially when they are [*S4741] undiagnosed and untreated. Up to 30 percent of all fertility may be due to past sexually transmitted disease infection. Over \$2 billion is spent every year on health care costs associated with infertility and the heartache to women and families is immeasurable.

STD's cause painful and costly infections. They cause ectopic pregnancies, fetal deaths and disabling illnesses. Over 7,000 infants

were born with syphilis last year, the highest rate in 40 years, with an estimated medical cost of \$128,000 per child.

Prevention and education efforts are essential to halt this tragedy. But our programs will not succeed without strong grounding in behavioral research.

We can no longer afford to proceed in the dark as we attempt to deal responsibly with these serious health problems. The Nation's public health experts have sounded the alarm. They have done so virtually unanimously with virtually no dissent.

Hundreds of years ago in medieval times, men feared witches and burned women. And now in the United States some who fear AIDS want us to burn research.

I want to include in the Record the profile on those individuals who were on the Committee to Study the AIDS Research Program of the National Institutes of Health. It was chaired by William Danforth, the chancellor of the Washington University at St. Louis, MO, the brother of our distinguished colleague.

I also include Linda Aiken who is a professor of sociology, University of Pennsylvania; Marshall Becker, associate dean, School of Public Health at the University of Michigan; Victoria Cargill, professor of medicine, University Hospitals of Cleveland, Case Western Reserve University; John Coffin, professor of the Department of Molecular Biology, Tufts University in Boston; R. Gordon Douglas, senior vice president, Medical and Scientific Affairs, Merck, one of the important pharmaceutical companies; James Eigo from New York, Herman Eisen who is the Whitehead Institute, professor of immunology at MIT; Melvin Grumbach who is the professor of pediatrics at the School of Medicine, University of California; Don Hopkins who is a consultant on the worldwide Global 2000; Max Lang who is professor, chairman, Department of Comparative Medicine at Penn State; Curtis Meinert, professor of epidemiology, Johns Hopkins; Neil Nathanson, chairman of microbiology at the University of Pennsylvania; Philip Schein, president and chief executive officer of U.S. Bioscience; Arthur Silverstein, professor emeritus, Institute of the History of Medicine, Johns Hopkins.

Hardly a very inflammatory group. Anyone can look through this group and recognize these are men and women who are distinguished in their professions and who are attempting to provide a valuable public service -- and I think they have.

Mr. President, all of us can effectively demagog particular kinds of questions, statistics, pictures and the like. What we are attempting to do in the amendment is ensure that research which can have an important and positive impact on the spread of infectious diseases is permitted.

It is the overwhelming conclusion of those who have the expertise and responsibility for the development of public health policy, that there has to be sound behavioral research. Some people might not like that, and some people might be offended by the questions presented by the Senator from North Carolina. There may be questions that offend me and offend other Members here, but it seems to me that given the

seriousness of the problem, we ought to do all we can to ensure sound public health policy. That is what the Simon amendment, that I am a cosponsor of, would do. I yield 5 minutes to the Senator from Illinois.

Mr. HELMS. The Senator may yield for a question.

The PRESIDING OFFICER. The Senator from Massachusetts does control time.

Mr. HELMS. I will not have the clerk read back what the Senator from Massachusetts said, but it is a violation of the rules. But that is all right. Let Senator Simon continue.

Mr. KENNEDY. The Senator from Massachusetts does not need a lesson from the Senator from North Carolina. I saw my colleague and friend from Illinois, the prime sponsor of the amendment, and I thought he ought to be entitled to speak. I am sure he will wait his turn. I will yield to him at such time when the Senator from North Carolina finishes.

Mr. HELMS addressed the Chair.

The PRESIDING OFFICER. The Senator from North Carolina.

Mr. HELMS. The Senator may need some instruction from somebody on a lot of things, but I still say that he yielded to the Senator from Illinois. Now if the Senator from Illinois will seek recognition, he will get it. But I think we ought to abide by the rules.

Mr. SIMON. Parliamentary inquiry, Mr. President. My understanding was that we divided the time between the two sides, and my understanding was the Senator from Massachusetts yielded to me part of the time that has been allotted to those of us who are in favor of my amendment. Is that correct?

The PRESIDING OFFICER. The Chair advises the Senator from Illinois that the time has been divided as under the control of the Senator from Massachusetts and the Senator from North Carolina.

Mr. SIMON. And the Senator from Massachusetts yielded me and I certainly do not want to cut off the Senator from North Carolina -- --

The PRESIDING OFFICER. It is the Chair's understanding that the Senator from Massachusetts had yielded, from the time allocated to him, to the Senator from Illinois.

Mr. HELMS. Mr. President, that is not the question. I am perfectly willing for the Senator from Illinois to go ahead, but I think the rules of the Senate ought to be abided by. The Senator has sought recognition and he may have it, as far as I am concerned.

The PRESIDING OFFICER. The Senator from Illinois has the floor and is using the time allocated by the Senator from Massachusetts.

Mr. SIMON. Mr. President, I strongly support, obviously, my own amendment and, with all due respect and I respect the sincerity of my

friend from North Carolina, but I think he is dead wrong on this. When I say dead wrong, I think there are lives at stake here.

We are not going to protect ourselves through ignorance. It is just very simple. We ought to know what is happening -- what is happening among young people, what is happening among adults -- so we can stop the scourge of some of the social diseases that are plaguing our society. And on the teenage matter, parental consent is required, I underscore again, as well as voluntary efforts by the teenagers themselves.

But let us find out what is happening. That is why the American Medical Association, the American Psychological Association, American Psychiatric Association, even the American Red Cross which rarely gets involved in any of these things, the American Red Cross -- I would point out that on the House side, the amendment which we have offered, carried the House 283 to 137, by more than a 2-to-1 majority. On the House side, there are two physicians, Representative Roy Rowland from Georgia and Representative McDermott from the State of Washington.

Those two physicians helped lead the fight for this. I would point out for any Senators who do not know Congressman Rowland is one of the most conservative Members of the House of Representatives, but he is a physician and he knows we do not protect ourselves through ignorance, through a cloak of silence about what is happening.

Will we find out some things we would sooner not know are happening in our society? Maybe we will. I do not know. Will we can find out what the patterns are, why some cities have a much higher rate of teenage pregnancy in terms of ethnic groups? Why do whites in Hartford, CT, have a much higher teenage pregnancy rate than whites in Detroit? Why do Wisconsin and Illinois have a much higher rate of births to unmarried black women, 76 percent, compared to 15 percent in Hawaii? Why the difference?

Will it hurt us to find out, to see what we can do to protect our young people? When the rate of AIDS among teenagers has gone up 40 percent in [*S4742] the last 2 years, are we just going to pretend that this has not happened?

I hope we do the sensible thing, Mr. President, and say let us find out the facts. Let us listen to the physicians of this Nation who advocate finding out the facts. Let us have this survey, conducted, I might add, by the University of North Carolina. Let us find out the facts and then maybe we can save lives. We are certainly not going to save lives through ignorance, by pretending we live in a day and age that we perhaps like when I grew up and the Presiding Officer grew up. Things have changed, some of them for the better, some of them for the worse. But let us find out where we are. Let us find out how we can protect people in our society.

Totally apart from the humanitarian side of it, this year -- and the estimates vary -- the estimates are that AIDS is going to cost our society \$4 to \$13 billion. Can we do something to try to prevent the spread of it? Let us find out. Let us have these surveys.

I hope we do the humanitarian thing. I hope we do the fiscal common sense thing by approving the amendment that I have offered and disapproving the amendment offered by my friend from North Carolina.

I respect his sincerity, but he is wrong on this one, dead wrong.

Mr. President, I yield the floor. If no one seeks the floor, Mr. President, I question the presence of a quorum and would ask that the time be allocated evenly to both sides during the quorum call.

The PRESIDING OFFICER (Mr. Lautenberg). Is there objection? The Chair hears none, and it is so ordered. The clerk will call the roll.

The legislative clerk proceeded to call the roll.

Mr. HELMS. Mr. President, I ask unanimous consent that the order for the quorum call be rescinded.

The PRESIDING OFFICER. Without objection, it is so ordered.

Mr. HELMS. May I inquire, Mr. President, as to how much time I have remaining?

The PRESIDING OFFICER. The Senator from North Carolina has 34 minutes remaining.

Mr. HELMS. Thirty-four. I thank the Chair.

Mr. President, I am almost amused at some of the statements being made here. When my friend from Illinois -- and he is my friend -- says that I am wrong, he is also saying that Secretary Sullivan is wrong. He is saying that Secretary Sullivan was wrong last year. He is saying that the Senate was wrong when it voted 2 to 1 in support of my amendment that banned this pair of surveys.

I will stand with Secretary Sullivan and the Justice Department and by the will of the Senate last September. But, is it not odd that the very same people who oppose my amendment insist that we should treat AIDS as a disease all of a sudden, while in every other area -- I would point out -- these same opponents insist that we treat AIDS as a social condition. They oppose disclosure of names. They oppose treating AIDS as we do other infectious diseases with respect to immigration, and they oppose each and every effort to stop the spread of AIDS as we do with all other infectious diseases.

I believe the Senator from Utah is not on the floor. Would somebody check in the Cloakroom and see if he is there, because I want to ask him a question.

Until Senator Hatch can come, I suggest the absence of a quorum, with the time being charged equally.

The PRESIDING OFFICER. Without objection, it is so ordered. The clerk will call the roll.

The legislative clerk proceeded to call the roll.

Mr. KENNEDY. Mr. President, I ask unanimous consent that the order for the quorum call be rescinded.

The PRESIDING OFFICER. Without objection, it is so ordered.

Mr. KENNEDY. Mr. President, I would like to read from an editorial - I yield myself 3 minutes -- from the Chapel Hill Herald:

If ignorance is bliss, Health and Human Services Secretary Louis Sullivan wants the United States to live in nirvana.

Sullivan recently canceled a study of teen-age behavior, stating that certain questions on the survey might lead people to underestimate the harm of casual sex. Other conservatives have objected to what they consider distasteful questions on the survey.

The study was designed to roll back the clouds of myth that surround our perceptions about teen-age behavior, especially sexual activity. It would give public health officials valuable information about what types of risky activities teen-agers engage in. That, in turn, would allow health workers to find ways to combat those risky behaviors and prevent the spread of disease.

The study is based on a logical premise. You can't fight an enemy you don't know anything about. And you can't prevent diseases from creating tragedy and even death if you don't know the extent to which those diseases may be spread.

But Secretary Sullivan, who is supposed to look after the health of the nation, apparently has another item higher on his agenda: politics. In the name of morality, Sullivan and Co. have canceled the study. But their "moral" action reveals cynicism and utter lack of high principles. They've allowed partisan, petty politics to interfere with legitimate scientific research. They have placed a higher priority on self-importance and self-righteousness than on the lives that the survey's results could help save.

I ask unanimous consent that the full editorial be printed in the Record.

There being no objection, the article was ordered to be printed in the Record, as follows:

POLITICS HIDING BEHIND MORALITY

If ignorance is bliss, Health and Human Services Secretary Louis Sullivan wants the United States to live in nirvana.

Sullivan recently canceled a study of teen-age behavior, stating that certain questions on the survey might lead people to underestimate the harm of casual sex. Other conservatives have objected to what they consider distasteful questions on the survey.

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allow health workers to find ways to combat those risky behaviors and prevent the spread of disease.

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As U.S. Representative David Price, D-4th, said this week before Congress, sing a public health issue as a political football is "the very antithesis of morality." We couldn't agree more.

Fortunately Price and other members of Congress succeeded in injecting some common sense into the sex-study debate. Price sponsored an amendment to an appropriations bill that would allow the federal funding of sex studies that had been approved by an expert panel. The successful amendment forestalled an opposite measure that would have banned the use of federal money for any sex survey.

It's unclear how the congressional action will affect the teen-age behavior study already canceled through the Health and Human Services Department. The amendment would still have to be passed by the Senate to become law.

But perhaps Secretary Sullivan, who appears to be a better observer of politics than he is of scientific method, will see the light that Congress is shining in his eyes and reconsider his decision.

U.S. health workers need the information that could be gleaned from a scientific survey of teen-age behavior, including sexual behavior. We hope this important research won't continue to fall victim to politics hiding behind the skirts of morality.

Mr. KENNEDY. Mr. President, I would also like to include in the Record an article from the Salt Lake Tribune by Linda Ellerbee. I will include that in the Record. It has this one particular paragraph:

What problem, you ask? Teen-age sexual activity, teen-age pregnancy and teen-age sexually transmitted diseases (such as AIDS) are at an all-time high in this country, or, to put it in words even a pointy-headed bureaucrat can understand: More youths are "doing it," and youths are "doing it" more. More children are having babies. More children are dying. More children (and their babies) will be dying. If this doesn't bother you particularly, remember that all this costs taxpayers a whole lot of money.

Mr. President, I ask unanimous consent this article along with two others be printed in the Record.

[*S4743] There being no objection, the articles were ordered to be printed in the Record, as follows:

[From the Salt Lake Tribune, July 27, 1991]

"JUST SAY NO" JUST BREEDS IGNORANCE, WON'T STOP TEEN SEX

(By Linda Ellerbee)

What's the difference between healthy people and ignorant people? None at all, if you ask our government. This is the government that has "Healthy People" as a stated goal for the year 2000. This is the government that admitted that the reasons for and consequences of early sexual behavior are poorly understood. This is the government that now is canceling plans for a comprehensive survey on the sexual behavior of teen-agers because -- surprise, surprise -- conservatives don't want to give the kiddies any dirty ideas.

Well, that sure ought to fix the problem.

What problem, you ask? Teen-age sexual activity, teen-age pregnancy and teen-age sexually transmitted diseases (such as AIDS) are at an all-time high in this country, or, to put it in words even a pointy-headed bureaucrat can understand: More youths are "doing it," and youths are "doing it" more. More children are having babies. More children are dying. More children (and their babies) will be dying. If this doesn't bother you particularly, remember that all this costs taxpayers a whole lot of money.

These are called facts, which are good things to know, especially if one wants to change them. But sometimes, in order to change facts, even more facts are required, such as "which children?" "just how often?" and "why?"

The study, which had been approved by the Public Health Service, would have asked these questions and more of some 24,000 teen-agers in grades seven through 11. Precautions against invasion of privacy would have been taken. Consent of the teen-agers would have been required. Parental consent would have been required, and parents would have been interviewed also. In the end, we might have learned a thing or three. But this week Health and Human Services Secretary Louis Sullivan scrapped the study because, he said, it might detract from efforts to discourage sex among teen-agers. In other words, asking youths if they're "doing it" would encourage them to "do it."

The way asking somebody if they use drugs would encourage them to use drugs?

Excuse me, but is anyone else in this fair land as tired of the "Just Say No" mentality in our government as I am? Here's another fact. "Just Say No" doesn't work. Not when it's based on ignorance. It hasn't worked with drugs. It won't work with sex. Thinking people need reasons to make decisions, and even a teen-ager is a thinking person now and then.

If drug use is beginning to slow down among our young people these days, it's because of widespread and intensive educational efforts being made to teach children about drugs, about why people use them and what happens to people who use them, not because Nancy Reagan told children to "Just Say No."

This is all so very silly. Ignorance teaches nothing but ignorance. Most people believe they see the world as it is, but most of us really see the world as we are. You don't get people to change by telling them you're right and they 're wrong. You don't get people to change by telling them they ought to. You don't get people to change by bullying them or by shouting at them. The only way you change somebody's mind is to walk over to where they're standing and say, "Oh, now I see what it looks like from here. Now I understand you. Now let's work from here."

You give them a reason to change.

But first, you've got to get to where they are. That's what this study was about. Getting to where teen-agers are. Getting inside their hearts and minds. Getting answers. Getting facts.

Getting truth.

And showing a little respect for the truth. That, I think, is what bothers me most. What we have now is a government that has little or no respect for the truth, a government that thinks sex education invariably leads to sex, a government that thinks sticking one's head in the sand will make the bad things go away. What a shame we don't live in Disneyland. There days, you stick your head in the sand, somebody's likely to do dirty things to the end sticking up in the air.

But don't tell our leaders about that either. When it comes to truth they don't like, they just say no. And we keep on paying. And so it goes.

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'NAUGHTY!' IS NOT ENOUGH

How long will the Bush administration keep reflexively dropping, like a hot burrito, any project about which the far right cries "Naughty, naughty!"? This week, all it took to halt a major federal study of adolescent sexual behavior and factors influencing it was a complaint or two from groups that included the Rev. Pat Robertson's Christian Coalition.

Instantly, Health and Human Services Secretary Louis W. Sullivan put the study on hold pending further review. A bare 24 hours later he canceled it outright.

That response betrays both political cowardice and absence of thought. Two UNC-Chapel Hill professors have spent two years designing this planned five-year survey of 24,000 randomly chosen 7th through 11th graders across the country. The federal Public Health Service approved the project, and it was sponsored, for \$18 million, by the National Institute of Child Health and Human Development.

Most important, this study aimed to pin down some actual facts about teen sexual activity and contraceptive use, and to put those facts in context. These researchers are not idle snoops or gossipmongers. Prof. Richard Udry, of the university's respected Department of Maternal and Child Health is director of the Carolina Population Center, Prof. Ronald Rindfuss is a reputable sociologist. They say the study is needed because no previous research has inquired into how teens' social world, including not only peers but family, school and church, affects their sexual lives and vice versa.

That makes sense. And it exposes the knee-jerk shallowness of those who praise Mr. Sullivan's ban on the grounds that we already know all we need to know about teen sex, *** not enough to know if we want to help teens. It is only enough if we want to live in never-never land.

No questionnaire is perfect -- and no one knows that better than a good survey researcher. That's why Drs. Udry and Rindfuss spent years trying to frame questions right and organize the questionnaire to skip what wasn't relevant. A girl who told interviewers she wasn't sexually active, for example, wouldn't be asked other questions about sexual practices.

What shows most clearly their responsible, careful planning is that no teen-ager would have been interviewed without parents' consent -- and parents would have been interviewed too.

Mr. Sullivan said the survey could send "inadvertent" messages "counterproductive to his commitment to better communicate the message against casual sex." That is classic doublespeak. Asking for the reasoning behind some questions would have been fine. But to stop the project cold is pandering to those who prefer to deal with difficult reality by sticking their heads in the sand and hoping it'll go away.

On this subject, a nation as concerned about "family values" as this administration and the American people profess to be could certainly use a little hard, factual data -- a few answers to the agonized "whys" in the minds of millions of parents and damaged or heartbroken teens. Like it or not, in this day and age, "Naughty, naughty!" is not enough.

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RECONSIDER, MR. SULLIVAN

Evidently, when it comes to teen-age sexual behavior, Louis Sullivan would rather not know the facts.

Sullivan, the secretary of Health and Human Services, has cancelled an \$18 million, 45-month study of teen sexual mores -- a study that would have been led by researchers from the University of North Carolina at Chapel Hill.

Sullivan claimed the study might send an "inadvertent message" to young people, undermining the administration's efforts to persuade teens to say no to casual sex.

Despite Sullivan's careful rhetoric, the thumbs-down was clearly political -- an easy way to throw a bone to conservatives and religious fundamentalists who had objected to the study.

One of the study opponents, Gary L. Bauer, president of the conservative Family Research Council, had said the study would be a waste of money because everybody already knows that too many teens are having sex too early with too many partners. Said Bauer: "We ought to be spending \$18 million to figure out how to divert them from that conduct instead."

Bauer and the other critics missed the point.

According to Ronald R. Rindfuss, a professor of sociology at UNC and a member of the university's Population Center, the study was an attempt to understand the ways in which schools, families, churches, friends and communities influence teen attitudes and behavior.

The picture that would emerge from such a study might have helped to explain why the United States has such a high rate of teen-age pregnancies. It might have shed light on the factors that lead so many young people to risk exposure to the virus that causes AIDS.

These are problems that cannot be solved in a knowledge vacuum. Simply telling young people to abstain from casual sex isn't going to make the problems go away.

In the interests of science, Sullivan should look for a graceful way to reconsider this hasty and unwise decision.

The PRESIDING OFFICER. Who yields time?

Mr. SIMON addressed the Chair.

The PRESIDING OFFICER. The Senator from Illinois.

Mr. KENNEDY. I yield 3 minutes to the Senator from Illinois.

The PRESIDING OFFICER. The Senator from Illinois has 3 minutes.

Mr. SIMON. Mr. President, if I may respond to the remarks of my colleague and friend from North Carolina -- and as he said before we are friends. We are neighbors over in the [*S4744] Dirksen Building, and I respect his sincerity.

No. 1, I was over in the Budget Committee in a markup in the Budget Committee at the same time I have had to be here on the floor.

But on the survey questions, my understanding is those specific questions are no longer part of any survey proposed. But there will be an ethical review board appointed by the Secretary to review all of this if the Secretary so desires. I assume that Secretary Sullivan will appoint a good ethical review board.

Second, when the Senator from North Carolina -- if I may have his attention here -- says that Secretary Sullivan was wrong, as a matter of fact Secretary Sullivan has been on both sides of this issue.

Mr. HELMS. I did not say the Secretary was wrong.

Mr. SIMON. No. The Senator said by implication that I am saying the Secretary is wrong. And the fact is I am saying the Secretary was right first when he said these were OK, and he was wrong later when he turned them down.

When you say the Senate was wrong, I think the Senate was wrong in its first vote. I do not think the Senate was aware of what was going on. I hope we do the right thing here today.

Finally, I would just say to my friend from North Carolina, and to my colleagues in the Senate, ignorance is not a shield. It is like we are on a train track, and there is a train coming down, and someone says put a bandanna on your eyes so you do not see the train, plug your ears so you do not hear the train, and then maybe the train will stop on its own. That is not what is going to happen.

We better find out what is going on. Ignorance is not going to protect us. We better find out.

If I have any of my time remaining, I yield it to the Senator from Massachusetts.

Mr. HELMS. Mr. President, I yield myself such time as I may require.

Mr. President, since the chairman of the Health and Human Resources Committee raised doubts as to the authenticity of the photostated survey questions, I want to ask the Senator from Utah [Mr. Hatch], the ranking member on that committee, if indeed these questions are authentic and taken from NIH's proposed American teenage study of sexual behavior?

Mr. HATCH. I can tell the distinguished Senator from North Carolina that this draft entitled: "The American Teenage Study, School Administrator Questionnaire; Teenage American Study," sponsored by National Student Child Health and Human Development, constituent of the U.S. National Institutes of Health, Department of Health and Human Services -- the particular information as I understand it the Senator wants verified, verify this whole study, as being a study. But the particular pages that the distinguished Senator has asked to have verified are section 5 entitled "Homosexual Behavior," pages 116 and 117, I believe. They are the pages within the study. They are 2 pages of the study of 124 pages.

Mr. HELMS. I thank the Senator.

Let me say to my good friend from Illinois, Mr. Simon, that he suggested these questions are no longer relevant because they are not applicable. He is wrong about that, too.

What he is talking about are the questions from the adult survey which have been modified in response to the public outcry over the questions that survey initially proposed to ask. The questions I have put on Senator's desk are still the questions proposed to be asked, as the Senator from Utah has just authenticated as part of the American

teenage study of adolescent sexual behavior. These questions are from NIH's proposed teenage sex survey, and the questions in that survey have never been changed, I say to my friend from Illinois. As I said, some questions in the adult survey have been changed, but I would note that even after being changed the adult questions are still utterly disgusting.

Mr. President, I invited the Senator from Massachusetts to read the questions, and I am glad he did not because I do not think we ought to embarrass the public with the nature of these disgusting questions.

Moreover, I do not want these questions to appear in the Congressional Record, and I ask unanimous consent that at any place they may have been included they be stricken.

The PRESIDING OFFICER. Is there objection? Without objection, it is so ordered.

Mr. HELMS. Mr. President, a lot of Senators what to get away from here. I think we have ventilated this thing accurately.

I do not believe we are going to change any minds one way or the other. So, like my friend Albert G. Edwards, former pastor of the Presbyterian Church in Raleigh used to say: "You do not save any souls after 12 o'clock." It is not 12 o'clock. It is 5:25.

But before I yield back the remainder of my time, assuming Senator Simon and Senator Kennedy will yield back their time, I think I should reiterate that the Simon amendment will merely direct that the two outrageous sex surveys at issue go through the process set out in section 202 of this bill. The Secretary of HHS and the Department of Justice object to that process because it infringes on the ability of the Secretary of HHS, Dr. Sullivan, to reject such programs when he determines -- as he is charged by the President of the United States to do -- that such projects are not in the public's best interest.

Now, I am willing to yield back the remainder of my time, if Senators Kennedy and Simon will do likewise, so we may vote on the two amendments.

Mr. KENNEDY. Mr. President, I would make a very brief comment, and clarification.

I ask consent to be able to include procedures which are followed in the utilization of this survey. Any young person to be questioned in this survey would have to have parental permission. In addition, other procedures were also built into the study design.

I will include those in the Record at an appropriate place.

There being no objection, the material was ordered to be printed in the Record, as follows:

National Commission on Acquired Immune Deficiency Syndrome,
Washington, DC, March 30, 1992.

Hon. Edward M. Kennedy, Chairman, Committee on Labor and Human Resources, Dirksen Building, U.S. Senate, Washington, DC.

Dear Mr. Chairman: As the Senate considers H.R. 2507, the NIH Revitalization Amendments of 1991, we wish to express our strong support for research related to obtaining information about behaviors that place an individual at risk for contracting HIV. While the National Commission on AIDS has not taken a formal position on any particular research study, the Commission does believe behavioral and social research has been poorly funded thus far in the HIV epidemic, and research on sexual and drug-using behaviors deserve much greater emphasis if there is to be hope for altering the course of the epidemic. This is particularly true for adolescents.

In March of last year, the National Commission on AIDS devoted an entire day of public hearings to the issues surrounding adolescence and HIV disease. Repeatedly, the Commission was told that we needed to develop more effective ways of getting the prevention message to teenagers who, according to numerous studies and the testimony of our witnesses, frequently engage in high risk behaviors. The development of more effective prevention programs will depend a great deal on what we can learn about when, how and why teenagers engage in behaviors that put them at risk for HIV disease. We desperately need this information. Our children's lives depend on it.

Sincerely,
David Rogers, M.D.,
Vice-Chairman.
June E. Osborn, M.D.,
Chairman.

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American Medical Association, Chicago, IL, March 31, 1992.

Re Surveys of human sexual behavior.

Hon. Edward Kennedy, U.S. Senate, Dirksen Senate Office Building, Washington, DC.

Dear Senator Kennedy: The American Medical Association urges the Congress to provide the National Institutes of Health with the funds necessary to conduct human sexual behavior surveys.

These studies are designed to provide current and reliable information crucial to our efforts to fight the HIV epidemic. With accurate estimates of the number of people currently engaging in behaviors that put them at risk of HIV infection, public health officials can better predict future patterns of the spread of HIV and develop appropriate prevention and control programs. This data will also be useful for developing public [*S4745] health measures to reduce sexually transmitted diseases.

Our present lack of up-to-date and accurate data in this area is a compelling reason for funding national surveys.

We recognize that these surveys deal with a very sensitive subject and that some political objections to them have been raised. However, their development has involved an impressive scholarly and scientific approach. Moreover, extensive review procedures have been designed to assure that impartial scientific experts and government officials will review every step of these projects.

As our nation continues to spend large amounts of scarce resources on combatting AIDS and HIV infection, it is imperative that public health officials should base their efforts on the knowledge that can be gained by sexual behavior surveys.

Sincerely,
James S. Todd, MD,
Executive Vice President.

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Organizations for Research on

Health and AIDS Risk Behavior, Washington, DC, June 20, 1991.

Hon. Louis Sullivan, M.D., Secretary, Department of Health and Human Services, Washington, DC.

Dear Dr. Sullivan: We, the undersigned research, medical, and education organizations, are writing to express our concern about the long delay in HHS approval of the Survey of Health and AIDS Risk Prevalence (SHARP). This survey, which reflects significant revisions to an earlier and widely-discussed version, will provide much-needed national data on sexual behavior related to the contraction and transmission of AIDS and other sexually transmitted diseases (STDs). It is our understanding that the SHARP project has passed review by the Assistant Secretary for Health and awaits a final decision by you. We urge your prompt review and approval of the survey.

Study after study attests to the increasing need for better knowledge about the circumstances under which people engage in sexual behaviors that put them at risk of contracting dangerous diseases and spreading them to others. This knowledge is necessary for developing effective public health and education strategies to stem the spread of HIV/AIDS and other STDs, now afflicting hundreds of thousands of Americans. But we never have gathered comprehensive national data on sexual behavior representative of all groups in our society, even though numerous reports and commissions have recommended such an effort.

Just this past March, the Institute of Medicine issued a report on the state of the AIDS research program at NIH calling for "increase[d] support for behavioral research, especially for basic behavior research ... on behaviors relevant to the transmission of HIV, including but not limited to human sexual development and practices." The report specifically addressed continued HHS delay in approving the revised SHARP instrument, and recommended that "the pretest questionnaire for the [NICHD's] National Survey of Health and AIDS Risk Prevalence should be finalized and released, and the study should be allowed to proceed immediately" (p.70).

This recommendation mirrors others made over the past few years from equally eminent bodies. In 1988, the President's Commission on the Human Immunodeficiency Virus Epidemic recommended that HHS work with NICHD and CDC and "continue to fund national baseline data collection activities with longitudinal components that would permit a better understanding of sexual practices ..., attitudes, and risk behavior of adults and adolescents ..."

Similarly, the National Academy of Sciences in its 1989 report, "AIDS: Sexual Behavior and Intravenous Drug Use," urged support for the collection of data that estimate "the prevalence of the sexual risk-taking behaviors associated with the acquisition and spread of HIV infection in various populations, including those at higher and lower risk," with a high priority on "studies of the social and societal contexts of sexual behaviors.

Further delay of the SHARP study should not be permitted. The survey instrument has been developed under the guidance of NICHD by researchers with outstanding scientific credentials, and is sensitive to the delicate nature of questions about sexuality. It was reviewed through the NIH peer review process. Furthermore over the past two years, the original survey instrument has been revised to address concerns raised about the propriety of asking deeply personal questions. All information requested in the revised survey is directly relevant to STD/AIDS epidemiology or prevention. The data collected through SHARP will be used to develop accurate estimates of the number of people currently engaging in behavior that puts them at increased risk of STD infection, to predict future patterns of the spread of AIDS, and to provide a base for AIDS prevention and control programs.

There have been almost 79,000 AIDS related deaths since the effort to conduct this survey began, and it is expected that over 40,000 new HIV infections will occur this year alone. We must use every tool at our disposal to prevent the further spread of this disease and others similarly transmitted. We strongly urge your immediate approval of SHARP, so that the feasibility phase of the study can begin without further delay.

For reply purposes, please contact Judith D. Auerbach, Ph.D., Government Liaison, Consortium of Social Science Associations, 1522 K Street, N.W., Suite 836, Washington, D.C. 20005.

Sincerely,

The Alan Guttmacher Institute, American Academy of Pediatrics, American Anthropological Association's Task Force on AIDS, American Association for the Advancement of Science's Committee on Scientific Freedom, American College of Obstetricians and Gynecologists, American Educational Research Association, American Fertility Society, American Federation for Clinical Research, American Psychiatric Association, American Psychological Association, American Psychological Society, American Social Health Association, American Sociological Association, Association of American Universities, Association of Schools of Public Health, Consortium of Social Science Associations, Council of Professional Associations on Federal Statistics, Federation of Behavioral, Psychological and Cognitive Sciences, National Association

of State Universities and Land-Grant Colleges, Population Association of America, Society for Research in Child Development.

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American Academy of Pediatrics, Washington, DC, January 16, 1992.

Hon. Louis Sullivan, M.D., Secretary, Department of Health and Human Services, Humphrey Building, Washington, DC.

Dear Mr. Secretary: As you begin the fiscal 1993 budget process, I am writing to urge you to reconsider your decision to suspend the American Teenage Study.

Our primary concern is the impact of your action on the merit-based scientific review process that has long been a singular strength of the National Institutes of Health (NIH). This study is a research project grant which was thoroughly and extensively reviewed through the usual NIH peer review process and by various officials of your department including Dr. James Mason, Assistant Secretary for Health, and Dr. Bernardine Healy, director of the NIH. It is our understanding that these higher levels of review included a careful evaluation of the social and ethical implications of the proposed research. Suspending a research grant that has been awarded after such extensive review sets a harmful and dangerous precedent.

In addition, we are concerned about the effect this decision will have on teens and young adults. Today, adolescents live in a complex environment, and we need to better understand that environment. There are increasing numbers of young adolescents who become parents; sexually transmitted diseases are on the rise; and the adolescent population is expected to have the greatest increase in the rate of HIV infection. As you well know, this is especially true for minorities and children in poverty. These are not trivial problems; their consequences will profoundly affect the lives of an extraordinary number of teenagers and tomorrow's adults as well.

The Academy supports research in the area of human sexuality and recognizes in particular the need for studies designed to improve insights into sexual attitudes and practices of adolescents. We believe the American Teen Study will do this. It is designed to obtain vital information about adolescent behaviors that contribute to the risk of AIDS, other sexually transmitted diseases, and unintended pregnancy. Its results will be used to better identify high-risk groups and improve intervention mechanisms. This research is not a threat to our adolescents, but not undertaking this study will be, as well as imperil the integrity of the federal research process.

Sincerely,
Daniel W. Shea, M.D.,
President.

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AMERICAN PUBLIC HEALTH ASSOCIATION

(Interim policy statement adopted by the Governing Council, Nov. 13, 1991)

LB2: HUMAN SEXUAL BEHAVIOR RESEARCH

The American Public Health Association

Acknowledging that the incidence of HIV (human immunodeficiency virus) infection and other sexually transmitted diseases affects almost 12 million Americans each year, 86 percent of whom are aged 15 through 29; n1 and that half of the six million pregnancies which occur in the United States each year are unintended; n2 and

n1 Healthy People Year 2000: National Health Promotion and Disease Prevention Objectives: Sexually Transmitted Diseases: Washington, DC: US Department of Health and Human Services, 1990, pp. 494-495.

n2 Harlap S. Kost K. Forrest JD: Preventing Pregnancy, Protecting Health: A New Look at Birth Control Choices in the United States. New York: Alan Guttmacher Institute, 1991. 66-70.

Recognizing that current projections about likely trends and patterns of the incidence of these diseases and unintended pregnancies are being made without basic information about the behaviors that determine them; and

Noting that the projections of the Centers for Disease Control of the number of people in the United States who engage in high-risk sexual behavior are still dependent on data from the 1940s; and

Further noting that several important reports have strongly recommended that research on sexual behavior be conducted in order to address these crises, including a 1991 Institute of Medicine report that stated "these protracted delays have had an injurious effect on the scientific process and [*S4746] on the progress of behavioral research on sexual behavior;" n3 and

n3 The AIDS Research Program of the National Institutes of Health. Washington, DC: Institute of Medicine, 1991. pp. 66-70.

Recognizing that this information is essential for designing educational efforts and intervention strategies; and

Acknowledging that the United States Public Health Service's (PHS) targeted reduction in unintended pregnancies to no more than 30 percent of pregnancies (a 46 percent decrease) in the Year 2000 Objectives for the Nation; n4 and

n4 Healthy People Year 2000: National Promotion and Disease Prevention Objectives: Family Planning. Washington, DC: US Department of Health and Human Services, 1990, p. 193.

Acknowledging further that the PHS's goal for containing HIV infection is no more than 800 per 100,000 people by the Year 2000; n5 and

n5 Op. Cit: HIV Infection, 479.

Knowing that survey research, with informed consent and in the case of minors with parental approval, is an acceptable method of obtaining information; and

Knowing that the Scientific Review Committees and Advisory Council of the National Institutes of Child Health and Human Development has approved two proposals for funding with high priority scores, the American Teenage Study of the Population Center, University of North Carolina, and the Social Demography of Interpersonal Relations Study, of the National Opinion Research Center, University of Chicago; and

Observing that, in July 1991, Department of Health and Human Services (DHHS) Secretary Louis Sullivan withdrew the NIH-approved contract for the American Teenager Study; n6 and

n6 Rich S: HHS Cancels Teen Survey after Conservatives Complain. The Washington Post, July 24, 1991.

Observing that in October 1991 the NIH staff indefinitely postponed the Social Demography of Interpersonal Relations Study; n7 and

n7 Another Survey on Sexual Behavior Shelved by HHS: The Nations Health, November 1991, p. 5.

Recognizing that the above mentioned studies are but two highly publicized examples of attempts by the Administration to quash important and needed research related to human sexual behavior; and

Observing that in November 1991 the Congress of the United States agree to delete funding for two approved surveys of human sexual behavior from the appropriations legislation for DHHS; n8 therefore

n8 Congressional Record. September 12, 1991, 12890.

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1. Views with alarm and deplores the attack on academic freedom and independence of scientific inquiry in the area of human sexual and fertility related behavior;

2. Strongly opposes the unprecedented and egregious action of rescinding and indefinitely deferring approved grants;

3. Urges Congress to direct DHHS to conduct and fund research on the health aspects of human sexual behavior, and that such research should be supported on an ongoing basis if a determination is made by appropriate experts at NIH that the knowledge gained from such research

will assist in reducing the incidence of HIV or other sexually transmitted diseases, or unintended pregnancy, or in improving reproductive health or other conditions of health; and

4. Urges DHHS to proceed with such research based on the scientific merits of each proposed project rather than with regard to political considerations.

REFERENCES

ORGANIZATIONS SUPPORTING SEXUAL BEHAVIOR RESEARCH

[As of December 13, 1991]

AIDS Action Council.

Alan Guttmacher Institute.

American Academy of Pediatrics.

American Anthropological Association, Task Force on AIDS.

American Association for the Advancement of Science, Committee on Scientific Freedom and Responsibility.

American Association of University Professors.

American College of Obstetricians and Gynecologists.

American Educational Research Association.

American Federation of Clinical Research.

American Fertility Society.

American Foundation for AIDS Research.

American Home Economics Association.

American Medical Association.

American Public Health Association.

American Psychiatric Association.

American Psychological Association.

American Psychological Society.

American Red Cross, Office of HIV/AIDS.

American Social Health Association.

American Sociological Association.

Association of American Medical Colleges.

Association of American Universities.
Association of Reproductive Health Professionals.
Association of Schools of Public Health.
Center for Population Options.
Child Welfare League of America.
Consortium of Social Science Associations.
Council of Professional Associations on Federal Statistics.
Federation of Behavioral, Psychological and Cognitive Sciences.
Girls, Incorporated.
Human Rights Campaign Fund.
National Association of Social Workers.
National Association of State Universities and Land Grant Colleges.
National Council of Family Relations.
National Leadership Coalition on AIDS.
Population Association of America.
Population Resource Center.
Society for Research in Child Development.
Society for Research on Adolescence.
Society for the Scientific Study of Sex.
Transnational Family Research Institute.

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INSTITUTE OF MEDICINE

(Report of a Study -- The AIDS Research Program of the National
Institutes of
Health -- 1991)

BEHAVIORAL RESEARCH

The epidemic of HIV infection and AIDS is both a biological and a behavioral phenomenon, and efforts to contain its spread must look to both biomedical and behavioral sciences for interventions. Since the discovery of the virus and its modes of transmission, there have been significant advances in treatment for HIV disease. Historically, however, the discovery of effective chemotherapies and vaccines has not guaranteed success in controlling sexually transmitted diseases (STD)

or other types of infection. For example, although penicillin has been an important and effective part of the campaign against syphilis for more than 40 years, this sexually transmitted disease persists and in fact today is on the rise (Rolfs and Nakashima, 1990). Outbreaks of childhood measles also still occur, despite the availability of a safe, effective vaccine. Disease prevention, then, often requires more than biomedical technologies. HIV infection is an example of an incurable but preventable disease that is amenable to behavioral intervention.

The committee believes NIH has neglected AID-related behavioral research, the results of which are inadequate funding and an underdeveloped knowledge base (compared with such disciplines as immunology and virology), absence of a behavioral research infrastructure (including a paucity of Ph.D.-level professionals), and lack of understanding of the behaviors central to the transmission of HIV. Lack of knowledge regarding patterns and determinants of sexual and drug-using behaviors in the general public, as well as in groups at particular risk for HIV infection, has hampered public health efforts to develop health education interventions for the prevention of AIDS. The committee considers increased attention and funding to be warranted, given the lack of scientific data on behaviors related to HIV infection, the seriousness of the HIV/AIDS epidemic, available research opportunities in the field, and the potential public health benefits such research could realize.

In fiscal year 1989 the Office of the Assistant Secretary for Health (OASH) reported that NIH spending for behavioral research was \$5.7 million. Of this amount, funding for human behavioral research was \$4.6 million (0.76 percent of the total NIH research budget); the remaining \$1.1 million went to the Animal Resources Program in the Division of Research Resources to support the use of chimpanzees in studying HIV infection. OASH estimates for behavioral research in fiscal years 1990 and 1991, respectively, are \$3.4 million and \$3.2 million, or 0.45 and 0.39 percent of the total NIH research budget. Thus, funding for human behavioral research has decreased since fiscal year 1989 both in total amount and as a percentage of the total NIH AIDS research budget.

Behavioral research spans a broad spectrum. It can include the use of epidemiological techniques to identify the distribution of behavioral risk factors, and basic research designed to understand the etiology, or underlying determinants, of behavior. Such research may include; for example; studies of the physiological, psychological, and social mediators that influence and modify behaviors relevant to the transmission of HIV. It also includes efforts to evaluate the effectiveness of interventions intended to modify behaviors. This may include design and assessment of strategies to prevent the imitation of high-risk behaviors, reduce recidivism, or test the efficacy of culturally specific behavioral strategies to reduce risk behaviors for HIV infection.

Significant research opportunities exist in the field of behavioral research. For example, very little is known about the prevalence of sexual behaviors, especially in minority groups, the adolescent population, women, the over-50 age group, and prostitutes (male and female); even less is known about their etiology. As an illustration of a significant data deficit, estimates of the number of men who engage

in same-gender sex figure prominently in calculations of HIV prevalence; yet the figures used by the PHS in those calculations were derived from Kinsey's studies on male behavior from the period 1938-1948 (Turner, 1990). The precision of two methods currently used to forecast the AIDS epidemic, trend analysis and back calculation, is also hampered by a lack of information about the basic determinants [*S4747] of HIV incidence; for example, little information is available about the average number of sexual contacts within certain population groups and the probability that these contacts are made with uninfected individuals (Hellinger, 1990). Data are scarce on initiation into early sexual activities and the influence of family and peer groups of sexual behavior and contraceptive use (CDC, 1990b). It is also unclear how much of the sexual activity of adolescence is motivated by sexual desire and how much results from the desire for peer acceptance and other nonsexual motives (Turner et al., 1989).

Significant gaps also exist in understanding intervention strategies. It is known that, for behavior to change, individuals must recognize a problem, be motivated to act, and have the knowledge and skills necessary to perform the action. However, data of how best to present information, instill and maintain motivation, and inform individuals remain incomplete. For example, studies have shown that information is necessary but often insufficient by itself to effect behavioral change; the association between knowledge and attitudes on one hand, and behavior on the other, however, remains unclear (Turner et al., 1989). The effectiveness of fear as a motivating element in AIDS prevention messages also is not well understood; nevertheless, PHS-sponsored information and prevention and treatment programs for sexually transmitted diseases often employ fear-evoking messages. Research has shown that, to be effective, information must be delivered in a manner that is comprehensible, convincing, and relevant to the audience it is intended to reach. Achieving this goal will require a much greater understanding of the perspectives and culture of the various ethnic, racial, social, age, and sexual orientation groups that currently make up the national population (Turner et al., 1989). Also necessary is a better understanding of the effects of different intervention strategies among different populations. For example, although some strategies have been effective in certain populations (i.e., gay men), it is not known whether the same approaches would successfully solicit cooperation and motivate change in other populations such as adolescents, minorities, women, or prostitutes.

The public health consequences of continued neglect and inadequate funding of behavioral research could be severe. Effective interventions require an understanding of the behaviors that place a person at risk for acquiring HIV/AIDS, especially in view of the fact that modification of risky behavior is the only currently available way to prevent HIV infection. Getting ahead of the epidemic requires foresight to limit the spread of infection in populations and regions that currently have a low prevalence of AIDS and HIV infection; such opportunities should not be overlooked, for, once lost, they cannot be recaptured. Adolescents are generally recognized as a population for which prevention activities could have a great impact. The large and growing middle-age and older segments of the population also deserve attention to forestall any possibility that the epidemic may become established in the more than 60 million people aged 50 and older. Currently, women of childbearing age still have a low HIV prevalence

rate overall and also represent an excellent opportunity to avert the spread of HIV infection. Yet before intervention strategies can be designed to prevent the spread of HIV to those who are not yet infected, it is essential to know which behaviors to target, in whom they occur, and how they can be modified.

Given the lack of understanding of behaviors related to HIV infection and of ways to change them, the committee believes that there is a role for ADAMHA, CDC, and NIH in supporting behavioral research. All three agencies currently conduct behavioral research, but the type and focus vary significantly according to each agency's respective mission. ADAMHA's mission is to find scientifically based solutions to alcohol, drug, and mental health problems and to promote effective strategies to deal with the health problems associated with the abuse of alcohol and drugs and mental illness (ADAMHA, 1990). The agency sponsors research that principally addresses the neuropsychological changes encountered after HIV infection occurs and the etiology and role of drug abuse (including alcohol) in HIV infection. The ADAMHA HIV/AIDS program has a unique focus in that the agency combines research on the biological, behavioral, and psychological aspects of HIV infection with intervention research and the provision of clinical services. In contrast, CDC's mission is to prevent unnecessary disease, disability, and premature death, and to promote healthy lifestyles (CDC, 1990a). To this end CDC supports mainly applied behavioral research that is directly related to the implementation and assessment of broad-scale education and prevention programs. NIH's mission is to conduct and support research on the causes, diagnosis, prevention, and cure of diseases in humans (NIH, 1987). In keeping with this mission, NIH supports a small amount of basic behavioral research on the determinants of HIV-related behaviors based on the institutes' specialized constituencies and research interests. For example, investigators at NICHD are studying developmental components of sexual behavior, whereas NIAID researchers are incorporating intervention behavioral research into clinical research on sexually transmitted diseases. Thus, ADAMHA supports basic and applied research; CDC focuses on programs of disease surveillance and control, with mainly applied research examining behavioral change interventions (particularly in high-risk groups) as part of specific efforts in disease prevention and health promotion; and NIH supports mostly basic research, whose findings provide the basis for the design of actual interventions by CDC and other public health agencies.

As the government's principal biomedical research organization, NIH sponsors behavioral research in areas other than AIDS in which the disease burden to society is significant, such as cancer and heart disease. For example, NCI's Cancer Prevention and Control Program supports behavioral research on a range of topics from nutrition to smoking cessation. In fiscal year 1990, NCI spent 5 percent of its budget on behavioral research. NHLBI also devotes substantial funding to behavioral research and interventions in areas such as hypertension and cardiovascular disease; the institute spent approximately 3.3 percent of its budget on behavioral research. Overall, NIH devotes approximately 3.1 percent of its funding to behavioral research (Raub, 1988). The comparable figure for AIDS behavioral research was 0.45 percent. (This is not to say that the proportion of NIH resources devoted to behavioral research has been optimal; indeed, the Senate Committee on Appropriations directed NIH to establish a comprehensive

10-year plan for steadily increasing its funding of health and behavioral research [U.S. Congress, Senate, 1989].)

CDC has been making a large investment in applied behavioral sciences research with regard to AIDS. This fact, however, does not relieve NIH of its responsibility to support and conduct such research; indeed, other committees (e.g., Turner et al., 1989) have noted particularly pressing needs for behavioral research on AIDS and strongly recommended an NIH role. This committee believes that, similar to its work in heart disease and tobacco use, NIH can play a key role in supporting basic research to understand the etiology of sexual and drug-using behaviors and in initiating demonstration projects to evaluate intervention strategies. This research may also benefit efforts to prevent transmission of other sexually transmitted diseases and the initiation and continuation of illicit drug use. The committee commends present NIH efforts (i.e., NIAID's efforts to integrate behavioral research with biomedical research through its Sexually Transmitted Diseases Cooperative Research Centers and NICHD's research on adolescents) but considers more research to be needed.

(Recommendation 3.9: The NIH AIDS program should increase its support for behavioral research, especially for basic behavioral research (e.g., research designed to understand the etiology or underlying causes of behaviors and evaluate the effectiveness of interventions to modify particular health-related behaviors) on behaviors relevant to the transmission of HIV, including but not limited to human sexual development and practices and (in coordination with ADAMHA) drug addiction and abuse.)

As behavioral research becomes a greater part of the NIH and PHS research portfolio, it will require careful planning and coordination to develop appropriate research agendas and clearly define agency roles. At present PHS has mechanisms in place to designate responsibility for research areas and prevent unproductive duplication; these include agreements between NIH institutes, clearance of proposed RFAs through the NIH Office of Extramural Programs, posting of proposed RFAs on a computerized bulletin board for review by other NIH and ADAMHA components, and informal discussion among researchers. These mechanisms, however, do not provide for early-stage coordination and lack high-level PHS oversight. At one point, the PHS Executive Task Force on AIDS had several subcommittees focusing on specific components of behavioral research (e.g., addiction and behavior), but these committees have been disbanded in preparation for a reshaping of all task force committee structures. This committee believes that the PHS should sponsor conferences, involving appropriate NIH, CDC, and ADAMHA officials and behavioral scientists, to identify promising areas of behavioral research, develop a PHS behavioral research agenda, and make recommendations on methods to improve coordination among PHS agencies sponsoring behavioral research.

As noted earlier in this section, the AIDS epidemic has highlighted the need for current data that are representative of the general population to guide the design of behavioral interventions on sexual behavior. To fill this data gap, NICHD proposed a national survey of health behaviors and AIDS risk prevalence that included questions on sexual relationships, partner characteristics, sexual behaviors with partners, and behaviors such as drug use that put people at risk for

AIDS. The survey was also intended to provide a research basis for designing, implementing, and evaluating education and intervention programs to stop the spread of HIV. Despite the value of such information, however, the survey has not as yet been performed. NICHD sought to conduct a pretest to refine the questionnaire and identify possible design problems and sent the pretest [*S4748] survey questionnaire to OMB in December 1988. Since then it has undergone multiple reviews by OMB, the NIH Director's Office, the Office of the Secretary of Health and Human Services, and OASH, which has been holding the revised pretest since July 1989. Currently, negotiations continue regarding the content and design of the questionnaire, and the future of the full survey is uncertain. The committee believes that these protracted delays have had an injurious effect on the scientific process and on the progress of behavioral research on sexual behavior. The committee believes that the National Survey of Health and AIDS Risk Prevalence will provide invaluable information for efforts to prevent the spread of AIDS and HIV infection and should go forward as soon as possible.

(Recommendation 3.10: The pretest questionnaire for the National Institute of Child Health and Human Development's National Survey of Health and Aids Risk Prevalence should be finalized and released, and the study should be allowed to proceed immediately.)

NURSING RESEARCH

High-quality nursing care of persons with AIDS, in conjunction with advances in medical therapy, is an essential component of ensuring a reasonable quality of life for persons who are living with HIV infection. Owing in part to improvements in treatment, the number of persons alive with AIDS continues to grow. CDC estimates that by 1993 between 151,000 and 225,000 persons will be alive with AIDS, compared with 48,000 in 1988, more than a threefold increase in five years (see Figure 1.1). NIH's stated goal is to convert HIV infection into a chronic, manageable illness, a shift in emphasis that will also require a concomitant shift in research foci. Currently, NIH supports a relatively small amount of research (less than 0.2 percent of AIDS research and training funds) on the chronic aspects of HIV infection: research addressing the care needs of HIV-infected persons amounted to only \$730,150 in fiscal year 1989, and funds for training of professionals in this area totaled \$119,504 (NCNR, 1989).

The purpose of nursing research is to effect both short- and long-term improvements in nursing practice, in addition to restoring patient health and speeding recovery from illness (Larson, 1989). Nursing research addresses a wide range of topics including relief of distressing symptoms resulting from the disease process, development of interventions to alleviate physical symptoms that are secondary to or incompletely relieved by medical intervention, identification of optimal ways to administer medical treatment, achievement of increased compliance with therapeutic regimens, management of therapeutic side effects, prolongation of distress-free intervals, and improvement of quality of life. The neglect and inadequate funding of nursing research have resulted in an underdeveloped knowledge base that must be improved if adequate care is to be provided to the thousands of HIV-infected persons who will be flooding the health care system by the mid-1990s. A report of the NCNR Priority Expert Panel on HIV Infection (1990)

identified significant gaps in knowledge about the care of HIV-infected persons:

Care needs across the spectrum of HIV infection;

Development and testing of nursing interventions to alleviate or control symptoms associated with AIDS or its treatment:

Skin breakdown

Nausea, vomiting, inadequate nutrition, loss of appetite, and diarrhea

Psychological, neurological, physiological, and behavioral effects associated with organic brain changes, treatment, or being chronically ill.

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National Academy of Sciences,
Washington, DC, March 31, 1992.

Hon. Edward M. Kennedy,
Chairman, Subcommittee on Labor and Human Resources, U.S. Senate,
Dirksen Senate Office Building, Washington, DC.

Dear Senator Kennedy: As the Senate considers legislation to reauthorize the National Institutes of Health, the need for surveys of sexual behavior is again being debated. I would like to bring to your attention the work of the Institute of Medicine, National Academy of Sciences, and National Research Council relating to this issue.

At least five recent reports by committees of health care professionals and public administrators as well as academics have underscored the critical role of such studies, in understanding and dealing with urgent health and social problems. In particular the knowledge gleaned in such surveys is essential in improving programs to prevent further spread of the HIV virus and for decreasing the number of unplanned teenage pregnancies. The current knowledge base on sexual behavior dates largely from the Kinsey studies 1938-48. Survey methods are both sophisticated and sensitive and can secure this information while protecting confidentiality. The costs of not knowing are exceedingly high in the face of the AIDS epidemic. The pertinent conclusions of these reports follow:

Institute of Medicine, Confronting AIDS: Update 1988, National Academy Press, 1988.

"Accurate forecasting of the AIDS epidemic depends in large measure on better knowledge of human sexual and IV drug-abusing behavior. Research in the social sciences, particularly in understanding such behavior, has been inadequate in the past... The committee [for the Oversight of AIDS Activities] adds its endorsement to the importance of the social and behavioral studies needed to understand the epidemic. The committee strongly supports continued research efforts to develop better ways to refine predictions about the future course of the AIDS epidemic and to evaluate potential intervention strategies" (pp.

59-60).

Commission on Behavioral and Social Sciences and Education, National Research Council, "AIDS: Sexual Behavior and Intravenous Drug Use," National Academy Press, 1989.

There are substantial gaps in basic knowledge that need to be filled if the country is to contain the spread of the AIDS epidemic. The committee [on AIDS Research and the Behavioral, Social and Statistical Sciences] recommends the Public Health Service support vigorous programs of basic social and behavioral research on human sexual behavior, particularly through such agencies as the National Institutes of Health; the Alcohol, Drug Abuse, and Mental Health Administration; and the Centers for Disease Control ... The committee recommends that data be collected to estimate the prevalence of the sexual risk taking behaviors associated with the acquisition and spread of HIV infection in various populations, including those at higher and lower risk" (p. 165).

Commission on Behavioral and Social Sciences and Education, National Research Council, "AIDS: The Second Decade," National Academy Press, 1990.

"Designing and implementing relevant and effective [prevention] programs requires knowledge about the targeted population and the risk-associated behaviors of concern. The committee recommends that the Public Health Service encourage and support behavioral research programs that study the behaviors that HIV infection ..." (p. 35).

Commission on Behavioral and Social Sciences and Education, National Research Council, "Risking the Future: Adolescent Sexuality, Pregnancy and Childbearing" National Academy Press, 1987.

"Individual data systems vary in their underlying purposes and special emphases as well as their specific characteristics (e.g., definition, sample size, data collection intervals). For these reasons, and because information on sensitive issues requires validation from more than one source, a multidimensional strategy for data collection is needed.

"The panel recommends that data systems that monitor fertility and fertility-related behaviors should be maintained and strengthened. Such data are essential for understanding trends and correlates of adolescent sexual activity, contraceptive use, pregnancy, abortion, and childbearing and as a basis for policy and program development ..." (p. 13, 14).

Institute of Medicine, "Confronting AIDS: Directions for Public Health, Health Care, and Research," National Academy Press, 1986.

"A major research need is for studies that will improve understanding of all aspects of sexual behavior and drug use and the factors that influence them."

We appreciate the opportunity to submit these views for yours and your colleagues' consideration.

Yours sincerely,
Frank Press,
President.

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REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY
VIRUS EPIDEMIC -- JUNE 1988

SECTION V: ADDITIONAL RESEARCH NEEDS

Behavioral and Social Science Research

HIV transmission is linked to specific and potentially changeable patterns of behavior. For individuals currently engaging in those behaviors, prevention of transmission depends on implementing effective behavioral change programs which seek to reduce or eliminate exposure to the virus. Research on sexual and drug-abusing behavior must, therefore, be an integral part of all HIV intervention efforts.

The study of human behavior is a complex endeavor which includes a variety of disciplines with numerous methodologies. The need to change individual behavior and to sustain that change will be paramount indefinitely. Given the central role of behavioral and social processes in the HIV epidemic, it is essential that the social and behavioral sciences be given priority in the funding portfolios of the appropriate Public Health Service agencies (Alcohol, Drug Abuse and Mental Health Administration and the National Institutes of Health).

Evaluative components must be built into any intervention program to determine which elements of the program were successful and which were not. The incorporation of evaluation into such programs is often far from ideal, not only for financial reasons. The forging of a relationship between researchers and members of community projects who may be suspicious of the intentions of researchers is difficult at best. Yet evaluation of programs by trained researchers remains the only way to determine program success.

To date, most of the efforts used to stop the spread of HIV have been informational mass communications, such as pamphlets, [*S4749] public service announcements, advertisements in magazines, and -- to a limited extent -- television commercials. However, some behavioral research indicates that simply providing information may increase awareness about HIV, but does not necessarily lead to change in risk behavior.

Sexual Behavior

Transmission of HIV can occur in any sexual behavior. Research on sexual behavior is particularly relevant for designing and implementing appropriate and effective prevention programs. In addition, research indicates that sexual behavior and attitude vary somewhat as a function of ethnicity and culture. In order to be effective, educational efforts must be sensitive to these differences.

A behavioral model that has been tested in terms of sexual behavior change in response to the HIV epidemic is the Health Belief Model which

states that risk reduction depends on knowledge about HIV, a sense of perceived risk, a sense of personal efficacy (i.e., a feeling of having the mechanical and social skills necessary to make changes), and a perception that community norms support HIV risk reduction.

One area of concern in behavior change, illustrated by the study of human sexuality, is relapse prevention. Maintenance of behavior change is often perceived to be more difficult than the original change itself. Among other areas of concern are: the seeming inability of some individuals to enjoy and maintain exclusive sexual relationships, and those individuals whose behaviors may pose an increased risk of HIV transmission -- including those diagnosed by sex therapists as sexually compulsive, hyper-sexual, or sexually addicted.

Currently, researchers in the field of adult sexual behavior must continue to refer to data collected by Kinsey over 40 years ago. There is an urgent need to update the information base. Data collected in the future should include not only prevalence of behaviors, but also attitudes and beliefs about sex.

Research areas which need attention are not limited to the behavioral area. Some are interpersonal in nature (e.g., developing assertiveness to resist coercion by partners to engage in high-risk sex and developing social skills to such as that found in the NIMH Centers Program grant mechanism.

The NIMH Centers are multidisciplinary and multi-institutional operations. They support basic, clinical and applied research, and prevention and educational research. All Centers contain information dissemination components, and each maintains contacts with community groups for access to high-risk populations. It is imperative that this mechanism for funding research be maintained and funding expanded, particularly for behavioral and social sciences research.

Obstacles to Progress

The Commission has identified the following obstacles to progress in the behavioral and social science research areas:

Social behavioral research has been under funded and undervalued as a tool for developing effective prevention programs.

Better coordination and collaboration are needed among PHS agencies regarding their behavioral research activities.

Significant data are lacking on the sexual behavior patterns of adults and young people of varying ages and cultural backgrounds.

Often, prevention programs are not successful because of insufficient collaboration among service providers and behavioral researchers.

Researchers are not given enough time to evaluate the effectiveness of programs and once a strategy is found effective, the means are lacking for widespread dissemination of that finding.

Parents and educators often disagree on the context and format of

school-based sex education. Some fear that sex education will encourage sexual experimentation in adolescents while others believe sex education is essential to prevention.

HIV prevention programs are not sufficiently comprehensive, lacking research-proven behavior modification components in providing options for individuals attempting change.

RECOMMENDATIONS

In response to these obstacles, the commission recommends the following:

4-101 -- The Department of Health and Human Services, through the Alcohol, Drug Abuse, and Mental Health Administration, the National Institutes of Health, and the Centers for Disease Control should continue and expand the funding of research on adults and adolescents that identify: determinants of risk behavior; models of behavior change interventions (in laboratory, field, and community-based settings); social factors and strategies to affect behavior change; and evaluation and other methodologies.

4-102 -- All HIV-related research funded by the National Institute of Allergy and Infectious Diseases and the National Institute of Mental Health should be reported to a central information gathering source. In the HIV crisis, data sharing should be the rule.

4-103 -- Funds should be made available through the National Institute of Mental Health and the Centers for Disease Control to sponsor training programs for graduate and post-graduate HIV researchers in the field of behavioral research.

4-104 -- Funds should be allocated for training grants for pre- and post-doctoral students in academic settings for research in the disciplines related to HIV research such as psycho immunology, social psychology, human sexuality (including bisexuality), and behavioral sciences.

4-105 -- Social and behavioral research in HIV must be long-term, collaborative efforts such as that found in the National Institute of Mental Health Centers Program grant mechanism. It is imperative that this mechanism for funding research be maintained and increased in behavioral and social sciences research and that the Centers continue to play a significant role in behavioral and social research.

4-106 -- The Department of Health and Human Services, through the National Institutes of Health, the Centers for Disease Control (CDC), and the Alcohol, Drug Abuse and Mental Health Administration should take advantage of work already begun by the National Institute of Child Health and Human Development, in collaboration with CDC, and continue to fund national baseline data collection activities with longitudinal components, that would permit better understanding of sexual practices (including bisexual behavior), attitudes, and risk behaviors of adults AND adolescents of differing ages and cultural backgrounds in order to assess risks and guide intervention activities. Survey research should include proportionate sampling of ethnic, racial, and cultural groups, and regional variations.

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THE PUBLIC AGENDA FOUNDATION

WHO WE ARE

The Public Agenda Foundation is a non-profit, non-partisan research and education organization whose work has focused on understanding and enhancing the public's role in key public policy issues. It was founded in 1975 by former Secretary of State Cyrus Vance and public opinion analyst Daniel Yankelovich to help average citizens better understand critical policy issues and to help the nation's leaders better understand the public's point of view.

Public Agenda plays a role that is distinctively different from other policy research organizations. It is not an advocacy group dedicated to a specific ideology or social goal. Nor is it a "think tank" concerned with the technical analyses of issues for policy makers. Rather, its special purpose is to find more effective ways to present public issues so that citizens may debate the policy alternatives and come to informed judgments about them.

Uniquely combining expertise in public opinion, policy analysis, and citizen education, Public Agenda focuses on issues where there is no consensus for action, either because public understanding is limited or because there is a gap between public and leadership views. In recent years, Public Agenda has worked on such issues as U.S.-Soviet relations, the environment, crime and prison overcrowding and the declining skills of the US work force.

What We Do: Helping Leaders Understand the Public's Views

As a basis for its citizen education work, Public Agenda conducts extensive research into public thinking about critical policy issues, attempting to probe beneath the "top-of-the-head" opinions often captured in polling. Public Agenda explores the reasons why people hold certain views and how they react when given new information or presented with unfamiliar arguments. This kind of in-depth research helps leaders understand more about the public's informed judgment -- what people conclude when they have seriously and realistically considered the choices that critical issues present. Public Agenda's research is disseminated to decision-makers in government, business, labor, foundations, academia, and the media.

What We Do: Helping Citizens Understand Complex Policy Issues

Public Agenda citizen education projects offer people a sense of the country's choices on issues that affect them directly. Video and print materials developed by Public Agenda are based on in-depth research into the public's current level of understanding. Their goal is to help people understand alternative policies with their costs, consequences, and tradeoffs clearly spelled out.

Much of Public Agenda's citizen education work is conducted through The Network for Public Debate, a joint project of the Public Agenda and the National Issues Forums. It represents the combined resources of

television, radio, newspapers, and community organizations across the country dedicated to helping average citizens learn more about critical issues and the choices for addressing them. Among its present projects are:

Help Wanted, a new citizen education campaign conducted in cooperation with the Business-Higher Education Forum and the Business Roundtable. Its purpose is to help citizens understand the relationship between the health of the nation's economy and the skills of the American work force. It focuses on steps that may need to be taken to strengthen the nation's schools and upgrade the training of citizens now on the job. Help Wanted campaigns were conducted in 1991 in Hartford, Indianapolis, Nashville, and Phoenix. In 1992, campaigns will be conducted nationwide in cooperation with the ABC/PLUS Literacy Project.

[*S4750] Public Summit '88, an information campaign developed jointly with the Center for Foreign Policy Development at Brown University that asked citizens in Baltimore, Nashville, San Antonio, and Seattle to consider four alternative futures for our relations with the Soviets.

School Vote, a citizen information campaign on issues facing the public schools, which has been conducted with local media sponsors in the greater Philadelphia area, Milwaukee, and Denver.

Health Vote, a citizen information campaign on rising health care costs conducted by Public Agenda with local media sponsors in six cities across the country from 1982-1985.

Public Agenda also prepares the National Issues Forums Issue Books used each year in citizen discussions sponsored by this nationwide network of libraries, churches, colleges and schools, union locals and service organizations. These Forums, which are nonpartisan, are held in hundreds of communities to encourage public discussion of public policy questions.

Who We Serve

Public Agenda's work serves the needs of different sectors of American life crucial to national debate. They include --

Political leaders who need to know how people understand an issue and what policies are likely to win broad and stable public support.

Foundations and service agencies that want to understand the public's perspective on the substantive areas in which they work.

Corporations that want to understand citizens' priorities on issues of concern both to them and to the public-at-large.

Media who want to go beyond consciousness raising to promote real dialogue and debate on issues of local and national importance. And above all --

The American public, the vast number of citizens who want to participate -- knowledgeably and constructively -- in the difficult policy decisions of our time.

How We Do It

In all of its work, Public Agenda draws a distinction between mass opinion -- the top-of-the-head reactions people have to an issue no matter how volatile or ill-informed those reactions may be -- and public judgment -- the informed views people develop about an issue when they have confronted it realistically and thought seriously about the choices it presents.

Public Agenda uses traditional research techniques, Surveys and Focus Groups, to develop a starting point for its unique methodology, the Citizen Review Panel.

Surveys are most useful in gauging reactions to issues that people are already aware of and knowledgeable about. Using carefully drawn national samples, surveys provide useful generalizations about the population as a whole. But because they must rely on the use of highly structured questionnaires, surveys are often less useful in predicting how people's views change when they confront the choices an issue presents, or when people have an opportunity to consider differing points of view.

Focus Groups, like surveys, are useful in finding out what people's opinions are. Beyond surveys, focus groups, led by trained, impartial moderators, allow the researcher to probe beneath the surface of sentiments, to explore the beliefs, assumptions, or areas of misinformation that are the premises for people's opinions. Focus groups also enable the researcher to elicit more detailed and spontaneous responses from people than surveys, in which responses are necessarily limited by the questionnaire. However, as with any qualitative method, focus groups do not produce results which can be quantified.

Citizen Review Panels are a methodology developed by Public Agenda and distinctive to its work. They are a major innovation in the field of opinion research and can play an important role in helping leaders predict the kind of policy alternatives that are capable of winning broad support among the American public when issues are still emerging before the lines of battle have been drawn by partisan or special interests.

Panels combine the strengths of qualitative research -- the ability to probe beyond people's initial thinking and introduce information and ideas that may be unfamiliar -- with the most important advantages of quantitative surveys -- the ability to obtain meaningful percentages, draw generalizations about the American public as a whole, and look at the special perspectives of particular regions and population subgroups.

I. Introduction and Executive Summary

By the time of the presidential election in the Fall of 1992, nearly 150 thousand Americans will have died of AIDS, Acquired Immune

Deficiency Syndrome. An estimated one and one-half million others are believed to be infected with the deadly HIV virus that destroys the body's immune system, leading to death from a wide range of opportunistic infections. Even if the HIV infection rate in the U.S. has leveled off -- as most forecasters believe -- up to an additional one million Americans will become HIV positive by the end of the decade.

In the 1990s, the U.S. will continue to wage war against the epidemic. But the resources that are committed to that war and the strategies that are employed will, to a considerable extent, depend on public opinion. Public policy can neither be created nor sustained in a political vacuum. To a remarkable extent, what the federal government and other agencies can do to fight the epidemic will be determined or confined within what public opinion analyst Daniel Yankelovich calls "the boundaries of political permission," the parameters within which the governed give their consent.

A Preliminary Analysis of Expert and Public Opinion: In June, 1991, the Public Agenda Foundation, a nonpartisan, not-for-profit research and educational institute headed by Daniel Yankelovich and Cyrus Vance, published a *Public and Expert Opinion About the AIDS Epidemic: A Preliminary Analysis*. That report, supported by a grant from Aetna Life and Casualty, combined an assessment of existing polling data with a review of the thinking of a diverse group of 30 experts to produce an analytic summary of the status of a dozen emerging or pressing issues related to the epidemic.

Hypotheses About the Views of the General Public: Our results suggest that most Americans do not feel that they are in danger of HIV infection. Therefore, most people do not feel the need to support a number of controversial steps to fight the epidemic. For example, since they believe there is only a remote chance that they will be infected by their doctor or dentist, most Americans do not, our results suggest, strongly favor mandatory HIV-testing for health care providers. However, our results also suggest that public opinion about this issue is like a sleeping giant; if the number of doctor-to-patient cases of HIV infection increases even modestly, the public may rise up and call for -- or demand -- mandatory HIV testing for all health care providers, in the process brushing aside arguments about privacy, reliability and cost.

On the other hand, our results suggest that most Americans give a top priority to AIDS education and that as long as parents' wishes are taken into account, huge majorities will support using even explicit and controversial AIDS educational material in the public schools, such as the film "AIDS: Just Say No" which recently sparked controversy within the New York City Board of Education. In addition, our results suggest that Americans favor the idea of conducting a nationwide survey of teenagers' sexual behavior and knowledge about AIDS (much like the studies recently proposed by the National Institute of Health but canceled by the Department of Health and Human Services) as long as such information will be used to help shape AIDS educational messages and strategy.

Our results also suggest that the public is virtually oblivious to the transformation of AIDS from an acute to a chronic illness, and of

the likely social effects of that transformation. But since Americans thoroughly understand that AIDS cannot be transmitted through casual contact, most will rather easily adapt to the idea of working and interacting with people with AIDS or HIV.

II. Views of a Cross Section of Americans About a Number of Emerging Issues Related to the AIDS Epidemic

Introduction to Part II: In the fall of 1991, the Public Agenda Foundation conducted six cross-sectional focus groups with people who were broadly representative of the public as a whole. In total, Public Agenda interviewed a total of 64 members of the general public in six cities:

New York, September 19, 1991;

Philadelphia, September 25, 1991;

San Antonio, October 30, 1991;

Nashville, October 31, 1991;

Denver, November 13, 1991; and

Los Angeles, November 14, 1991.

Respondents were recruited to match the characteristics of the general population according to various demographic criteria; sex, age, education, and race. Health care providers and other medical professionals were screened out. (For more detail, see Methodology, section V.)

In each group, respondents first filled out a brief questionnaire designed to gauge what they knew about AIDS and HIV transmission. After completing the questionnaire, respondents participated in a discussion led by moderators from Public Agenda.

What to Ask a Cross Section of Americans?

In "Public and Expert Opinion About the AIDS Epidemic: A Preliminary Analysis," the precursor to this study, Public Agenda found that public opinion was neither fully understood nor well documented about a number of emerging issues related to the epidemic. Since these issues will almost certainly become increasingly important in the 1990s, we decided that a major part of our focus in Phase One should be on them. These issues are:

The threat of HIV-transmission to patients from doctors, dentists, and other health care providers, including mandatory HIV-testing of health care providers;

The transformation of AIDS from an acute to a chronic illness, including the fact that as treatments improve and people who are HIV-positive live and work longer, others are increasingly likely to work and interact with them;

Intermediate health care for people with AIDS who need help but do not require hospitalization;

The use of hospices for people with AIDS;

The wisdom of using very explicit AIDS-educational materials (such as the controversial film, "AIDS: Just Say No") with high school students; and

[*S4751] Whether the government should conduct a national survey of teenagers' attitudes and sexual practices (such as the study proposed by the National Institute of Health but canceled by the Department of Health and Human Resources in 1991).

Respondents were split on whether such a film should be shown to junior high school students, with some saying such students are too young and others arguing that if kids are sexually active, they should learn how to protect themselves from HIV. A San Antonio man said, "My daughter is 11 years old. Kids now are starting to be sexually active, even at that age. I don't want to scare her, but they need to know about AIDS."

In Sum: If confirmed, our results show there is widespread public support for showing even explicit and controversial AIDS educational material in the public schools. However, they may be split on the wisdom of showing such a film to junior high school students. Our results also suggest that people will insist on two conditions:

That the film not be pornographic or suggestive; and

That parents be notified in advance and have the opportunity to exempt their children from seeing the film if they so choose.

13. The public would favor conducting a national survey of teenage sexual behavior and knowledge about AIDS similar to the one proposed by the National Institute of Health.

Group members were asked about the wisdom of conducting a large scale national survey of the nation's teenagers to determine exactly what they know about AIDS and the spread of HIV, and also to learn about their own sexual behavior. On the one hand, the moderators said, opponents of the study feel that it is inappropriate for the government to ask 13-year-olds about their sexual behavior; they also say that such a survey would promote sexual activity by appearing to condone it and that asking children about things such as anal and oral sex amounted to exposing them to obscene words and concepts. On the other hand, the moderator said, those in favor argue that such a study has never been done and that, in view of the AIDS epidemic, we need to know exactly how much different groups of teenagers understand and exactly what they are doing so that the schools and government can craft educational messages and anti-AIDS policies that are on target.

The argument that knowledge of teen behavior is necessary in order to target education efforts was understood and widely accepted in the groups. As noted, respondents felt educating the nation's teenagers about AIDS was the best and most important way to fight the epidemic. A woman from Denver said, "Given the fact that there is a high rate of

abortion among teens and a high pregnancy rate, we know that teens are being sexually active. So it wouldn't be a waste of the taxpayer's money in order to better educate these teens who are being sexually active."

While some participants expressed concern that such a study might appear to condone sexual activity, most felt that the benefits outweighed the risk. A man from the Denver group said that even if the survey were understood as "condoning sex, it's more important to save lives by finding out how we need to educate teenagers." A man from Nashville said, "We need to know what people are actually thinking at that age, and realize that not everybody is being brought up in the perfect home life."

Most also felt that the use of explicit words would not be a problem. Some parents might find the words offensive," said one man from Los Angeles. "But I don't think it will make the kids want to have sex, because they're probably going to do it anyway." Another man from Los Angeles added, "These words, every teenager knows all those words. And that's any child living in any neighborhood. These words are not a problem."

Among the minority who were opposed to the study, the most popular objection was that there is no need to conduct a study about teenage sexual behavior because we already know they are sexually active and that therefore the money could be better spent. "We know what our children are doing," said a man from San Antonio. "Teenage pregnancy is at an all-time high. This money would be better spent on education." A man from Los Angeles said, "Maybe this money would be better spent on a cure because you can pretty much figure out what teenagers are doing nowadays." Finally, one or two respondents wondered if the government could conduct an accurate survey, given the problems and controversy surrounding the 1990 census.

HEALTHY PEOPLE 2000 -- National Health Promotion and Disease Prevention Objectives

FAMILY PLANNING

Introduction

Families are the bedrock of our society. Formally defined as a group of two or more people related by birth, marriage, or adoption and residing together in a household, it is in families that children and adults are nurtured, provided for, and taught about enduring values by word and by example. It is in families that an individual first learns to make choices that promote his or her own physical and emotional health, as well as that of the broader community.

Decisions about forming a family are of critical importance. Decisions made today may have long-term consequences for a couple's ability to carry out plans for a family in the future. Family planning, the process of establishing the preferred number and spacing of children in one's family and selecting the means by which this objective is achieved, pre-supposes the importance of family and the importance of planning. Family planning requires that fundamental

questions about an individual's relationship to the lives, health, and well-being of others be addressed.

Successful implementation of family planning choices requires mature, thoughtful decisions accompanied by motivation to carry out those decisions. It requires the exercise of personal responsibility. There are many effective means by which family planning choices can be implemented. Childbearing, adoption, abstinence from sexual activity outside of a monogamous relationship, use of contraceptive methods, natural family planning, and treatment of infertility are all means of reaching desired family planning goals.

Safe and healthful childbearing both contributes to, and is a result of, effective family planning. While miscarriage, stillbirth, and infant mortality outcomes cannot be completely prevented by effective family planning, the frequency of occurrence can be reduced. Thus, preconception counseling and good gynecological, maternal, and child health care are required for effective family planning. Reciprocally effective family planning is a valuable aid to good material and child health because sufficient spacing of pregnancies helps to reduce the incidence of maternal morbidity, low birth weight, and infant mortality.

Adoption provides families for children who need permanent homes. It is one of the means by which infertile couples can implement their plans and desires for children. For individuals who are unprepared to raise their children, it is a means of finding families for them. Services and techniques to correct infertility can also help couples to reach their family planning goals.

Out-of-wedlock pregnancy has become an ever greater problem in this nation as the rate of sexual activity among adolescents has increased and the age of initiation of sexual activity has declined. Furthermore, age at first marriage has increased steadily, while fewer couples with out-of-wedlock pregnancies are marrying. Nearly one quarter of American children aged 6 and younger live below the Federal poverty level, many of them living with a single parent in female headed-families. Children from families in which the father is absent are 9 times more likely to have family incomes of less than \$10,000 than those living with both parents. Families with only one parent are more vulnerable to unpredictable or adverse events such as the loss of a job, parental sickness, or difficulty in meeting the needs of severely disabled or troubled children. Further, female-headed families are generally poorer than two-parent families because they lack a second wage earner, because women's wages are often lower than men's, and because women who become parents at a very young age frequently lack education and job skills.

Beyond economic considerations, there is evidence that child health is affected by the marital status of his or her parents. For example, in 1983, for both whites and blacks, unmarried motherhood was associated with higher infant mortality. Among births to married white women, the infant mortality rate was 7.8 per 1,000 live births; among unmarried white women the rate was 13.1 per 1,000 live births. Among births to married black women the infant mortality rate was 14.1 per 1,000 live births, while unmarried black women experienced a rate of 19.6 infant deaths per 1,000 live births. Married women are more likely

than unmarried women to receive prenatal care, even when race and age are taken into account. Other studies point to a relationship between broken families and child health. For example, a recent study of the health histories of 6,000 children found that children of divorced or separated parents have a one-third greater risk of developing health problems, such as pneumonia, tonsillitis, and repeated ear infections, as compared to children from intact families.

In addition to fostering family formation, efforts must also be made to strengthen the family's ability to educate and transmit strong values surrounding sexuality to children in the midst of a media culture that portrays and often condones casual sexual involvement. Postponement of sexual activity until an individual is in a mutually monogamous relationship is the most certain approach to prevention of a host of sexually transmitted diseases and may also help reduce rates of unintended pregnancy.

Various methods are available to prevent pregnancy among sexually active people. These methods include barrier and hormonal methods of contraception, natural family planning methods, and sterilization. These methods vary in effectiveness in preventing pregnancy and protecting against sexually transmitted disease, in health risks, and in compatibility with an individual's or couple's moral or religious beliefs. Choice of family planning methods is important not only in terms of relative effectiveness in preventing or spacing pregnancy, but also in terms of general health. Contraceptive methods may carry adverse health risks. On the other hand, some methods, particularly barrier methods, confer some measure of [*S4752] protection against sexually transmitted diseases. Natural family planning may be preferred by those who find other forms of contraception unacceptable for philosophical, health, or religious reasons.

The objectives presented here focus on reducing pregnancies among teenagers younger than age 18 and unintended pregnancies among all women. In 1988, American women reported that 56 percent of their pregnancies (adjusted for underreporting of abortion) in the last 5 years had been "unintended," that is either occurring too soon or unwanted. Studies suggest that unintended pregnancy may bring special risks. In 1982, among black women whose births were wanted at the time of pregnancy, 10.2 percent of births were of low birth weight; among black women whose pregnancies were unintended, the low birth weight rate was 13.6, a 33 percent difference. The Institute of Medicine, in its report "Reducing Low Birthweight," recommends that improved "family planning services [become] an integral part of overall strategies to reduce the incidence of low birth weight in infants."

If family planning -- serious consideration of family goals, careful selection of a family planning strategy, and conscientious adherence to that strategy -- is put into general practice, the rates of unwanted and mistimed pregnancy should fall appreciably. Unwanted and unintended pregnancy has implications for abortions reported to the Centers for Disease Control in 1987 was approximately 1,353,000. The United States abortion rate among teenagers aged 15 through 19 in 1983 was considerably higher than for many other countries for which data are available.

Research Needs

More information is needed on the characteristics of people who adopt children and who chose adoption as a means of resolving unintended pregnancy. This information would be very useful in improving the design of programs intended to increase adoption.

American women have a comparatively low level of effective contraceptive use and are more likely than their counterparts in other developed countries not to use any method at all. Additional basic research should be conducted to assess nonuse, incorrect use, and effective methods for increasing correct contraceptive use.

The determinants and consequences of early sexual intercourse are poorly understood. Additional research is needed to better understand early initiation, its consequences, and how it might be prevented.

Existing contraceptive methods are often unacceptable to men and women because of difficulty or discomfort in use, expense, or undesirable side-effects. Improved contraceptive methods are needed for men and women. Research should focus on developing methods that are easier to use, that have fewer side effects, and that are less expensive.

Related Objectives From Other Priority Areas

Tobacco

3.4 Cigarette smoking.

3.7 Smoking cessation during pregnancy.

Educational and Community-Based Programs

8.4 Quality school health education.

8.9 Family discussion of health-related issues.

8.10 Community health promotion programs.

Occupational Safety and Health

10.8 Occupational lead exposure.

Environmental Health

11.11 Home testing for lead-based paint.

Maternal and Infant Health

14.1 Infant mortality.

14.2 Fetal deaths.

14.4 Fetal alcohol syndrome.

14.5 Low birth weight.

14.10 Alcohol, tobacco, and drug use during pregnancy.

14.12 Age-appropriate preconception counseling by clinicians.

HIV Infection

18.4 Condom use.

Sexually Transmitted Diseases

19.1Gonorrhea.

19.2Chlamydia.

19.3Syphilis.

19.4 Congenital syphilis.

19.6 Pelvic inflammatory disease.

19.8 Repeat gonorrhea infection.

19.12 Sexually transmitted disease education in schools.

19.13 Correct management of sexually transmitted disease cases.

19.14Counseling to prevent sexually transmitted diseases.

19.15 Partner notification of exposure to sexually transmitted disease.

Clinical Preventive Services

21.2 Receipt of recommended services.

21.6 Provision of recommended services by clinicians.

Surveillance and Data Systems

22.4 Gaps in health data.

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SENSITIVITY, CONFIDENTIALITY, AND INFORMED CONSENT IN SEXUAL BEHAVIOR RESEARCH

SENSITIVITY

Many people are uncomfortable supporting research on sexual behavior because, by its very nature, such research requires discussion of topics that are highly personal. Explicit questions about private behaviors must be asked, and information must be obtained that could embarrass survey participants if their answers were publicly revealed. These concerns are not unique to sexual behavior research; in fact experience tells us that people are usually more comfortable revealing information about sexual behavior than they are information about their incomes (which virtually every federal survey requests). Survey

specialists and scientists follow strict procedures to ensure that confidentiality of responses is maintained. In addition, considerable effort goes into developing questions and data collection techniques to minimize any discomfort the respondents may have in answering questions, and thereby ensure the quality of data collected.

Several survey techniques can be used to ensure data quality and respondent ease in interviews about sensitive topics. First, questions must be designed to be universally understood by the study population as well as be neutral in their tone. Researchers often begin their design of questions by conducting focus groups and open-ended interviews with individuals from their study population. From these, they learn what terms are used in the population to refer to the subject matter of the study, and how well technical terms may be understood. They also learn about the acceptability of different types of language in the study population. This information provides a basis for draft questionnaires which then can be tested with a different sample of the population: in these tests, a respondent who had completed a questionnaire would be debriefed about how well the questionnaire had worked to elicit the needed information. The questions that result from this process reflect the best possible compromise between the need for clarity and the need to minimize sensitivity.

Several interviewing techniques have been found useful in improving data quality by reducing the sensitivity of the interview setting. One of these, widely used in survey research, is the use of a card to depict responses that people may be reluctant to state aloud. The card allows respondents to answer with the letter or number for their response. A second technique is the use of a self-administered questionnaire. With this technique, answers are not known to the interviewer, and many respondents feel freer to respond in this way. New techniques of self-administering questions are now being developed using personal computers, and these are expected to provide even more privacy for respondents answering sensitive questions.

CONFIDENTIALITY

In every step of survey design, measures are taken to protect the confidentiality of responses:

Questionnaires are designed so that any identifying information (for example, names and addresses needed to locate the respondent) is separated from the information given in the interview.

Interviews are required to be conducted in private.

Questionnaires and identifying materials are separated before being mailed to the central processing office. All staff involved in conducting a survey sign a pledge of confidentiality. While computer processing is underway, completed questionnaires are kept in locked cabinets. The resulting data tapes contain no identifying information; where future research steps require a link to identifiers, a number is assigned and the key to these numbers kept under lock and key.

A recently expanded federal program enables investigators to further protect confidentiality by obtaining a "certificate of confidentiality" protecting the data from legal subpoena.

INFORMED CONSENT

No individual participates in a survey without first giving informed consent:

"Informed" means that the respondent must be given information about the purposes and nature of the study, who is conducting it, and information about the questions to be asked.

Often, signed consent is required; in some cases verbal consent is accepted.

When the eligible respondent is under age 18, informed parental consent is required as well as the young person's own informed consent.

Institutional Review Boards at universities and private research organizations carefully review each project to ensure that requirements for informed consent, privacy and confidentiality are met. The creation and performance of these boards is regularly monitored by federal agencies that support research.

In all these ways, it can be seen that procedures are in place to permit the sensitive and responsible treatment of survey data on sexual behavior. Our effectiveness in responding to public health challenges depends on the ability to collect these data, and every effort is made to do so in the most reasonable and meaningful ways.

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[*S4753] The National Advisory

Council on Aging,
Bethesda, MD, October 24, 1991.

Hon. Louis W. Sullivan, M.D., Secretary of Health and Human
Services, Washington, DC.

Dear Mr. Secretary: At our recent meeting of the National Advisory Council on Aging, the non-federal members of the Council expressed concern over the suspension of grant HD26934 which was awarded to the University of North Carolina in May of 1991.

It is our understanding that the scientific merit of the project was judged to be outstanding by the by NIH scientific review panel. We also understand that the research was judged to be of national priority by the NICHD Advisory Council and NIH officials. Consistent with NIH procedures, an award was made based on these time-tested criteria.

We are disturbed about the precedent of suspending a grant after it has been reviewed, judged meritorious, and awarded funds. If there are research areas that are not to be supported by NIH, these decisions should be made prior to the scientific review of applications and the award of research grants.

The NIH review process has served health research well over the years. Therefore, the National Advisory Council on Aging unanimously urges you to reconsider this decision.

Sincerely,
The National Advisory Council on Aging.

Mr. KENNEDY. I had heard that the Senator from New York, Senator Moynihan, was on his way over. I would like to verify that. Then I would be prepared to yield.

Mr. SIMON. Mr. President, I will take 1 minute here.

I will point out that under my amendment, what we have is not only what is in the bill, is if they go ahead, and if the Secretary has to have an ethical review board to go over this, appointed by Secretary Sullivan, under my amendment the Secretary has to believe that it will assist in reducing the incidence of sexually transmitted diseases, the incidence of infection with the human immunodeficiency virus, or the incidence of any other infectious disease, or in improving reproductive health or other conditions of health.

So this is a judgment call to be made by the Secretary of HHS. I am willing to let the Secretary make that judgment call.

Mr. HELMS addressed the Chair.

The PRESIDING OFFICER. The Senator from North Carolina.

Mr. HELMS. Mr. President, I feel obliged to say again what the facts are, not somebody's interpretation of them. Not only does title II require the Secretary to convene such an advisory board before he can withhold funding, but he must fund a project, if a majority of the so-called advisory board approves a project. Since at least one-third to one-half of the board would have to be the same bureaucratic researchers who are pushing the projects, I doubt anybody can conclude that a majority on the board will not approve the projects despite, and over, Secretary Sullivan's objection. In any case, the Secretary has already said, "I do not like them; they are not in the public's interest."

Mr. President, you cannot obscure the truth. I say again, how can it be called just an advisory board when the Secretary is compelled by the combined working of the Simon amendment and the underlying bill to abide by whatever this so-called board decides? I thought we put the Secretary of HHS there to make these decisions. The President charged him with that responsibility.

Cutting through all of the obfuscation -- I am sorry there has been so much of it, Mr. President -- Section 1010 and the Simon amendment both mandate that Secretary Sullivan fund these two sex surveys immediately once this bill is enacted into law.

Mr. President, at this point I would be glad to yield my time back - - provided no other provocative statement is made to which I would like to respond.

Mr. SIMON. Will my colleague yield for a question? I will try not to make a provocative statement.

Mr. HELMS. Sure.

Mr. SIMON. My amendment gives to the Secretary of HHS the judgment call, and he is to approve this only if he believes that this survey -- if you will read my amendment -- will assist in reducing the incidence of sexually transmitted diseases, incidence of infection of human immunodeficiency virus, or the incidence of any other infectious disease, or in improving reproductive health or other conditions of health: that is a judgment call to be made by the Secretary of HHS under this. This is not a mandate. Does the Senator from North Carolina understand that from my amendment?

Mr. HELMS. I beg to differ with my friend. When you couple the Senator's amendment with the underlying provision in the bill, there is nothing but a mandatory requirement that the Secretary of HHS abide by what this so-called advisory board stipulates. We can go up and down and chase that rabbit all we want to, but this is an action taking away the final authority of the Secretary of HHS on this issue. The Justice Department agrees with me, and Secretary Sullivan agrees with me.

Mr. KENNEDY. Mr. President, we are prepared to yield back the remainder of our time.

Mr. HELMS. In that case, I will yield back my time.

Mr. KENNEDY. Mr. President, I ask for the yeas and nays on the Helms amendment.

The PRESIDING OFFICER. Is there a sufficient second?

There is a sufficient second.

The yeas and nays were ordered.

Mr. KENNEDY. Have the yeas and nays been ordered on the Simon amendment?

The PRESIDING OFFICER. They have not been.

Mr. KENNEDY. I ask for the yeas and nays on the Simon amendment.

The PRESIDING OFFICER. Is there a sufficient second?

There is a sufficient second.

The yeas and nays were ordered.

Mr. HELMS. Mr. President, I am going to ask for a quorum call so that Senator Dole can come to the floor. I think he wants to make a few comments.

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Mr. DURENBERGER. Mr. President, I rise to support the amendment offered by the distinguished Senator from Illinois [Mr. Simon] to H.R. 2507, the reauthorization of the National Institutes of Health [NIH], and to oppose the amendment offered by the distinguished Senator from North Carolina [Mr. Helms].

Mr. President, these amendments focus on surveys authorized by NIH that are designed to compile information and statistics on sexual behavior among adolescents and adults. The Senator from North Carolina has argued that these type of surveys are a waste of taxpayers' money. And he has asserted that the specific questions asked in these surveys are immoral and may inappropriately encourage premarital sex.

Mr. President, the tragic fact is that we have an epidemic in our community that is related to sexual activities among our young people and among adults. Sexually transmitted diseases [STD's] are among the most important public health problems in the United States. Approximately 12 million people acquire a sexually transmitted infection each year; two-thirds of those cases occur in people under 25 years of age.

A million people are currently infected with HIV, which we all know is ultimately fatal. Health and Human Services Secretary Louis Sullivan recently announced that AIDS is spreading to small towns and a large share of the heterosexual population. The AIDS epidemic has become the equivalent of the 12th century bubonic plague, striking death in every city and town throughout the Nation.

We cannot afford to ignore this problem and cannot ignore the fundamental fact that most cases of AIDS are contracted through sexual contact. One way of attacking this disease is to understand behaviors that contribute to the risk of pregnancy and sexually transmitted diseases.

The two surveys at issue -- the Survey of Health and AIDS Risk Prevalence [SHARP], a project of the National Institute of Child Health and Human Development [NICHD] is a large scale study designed to assess data on behavior that puts people at risk of AIDS and other STD's. It will provide accurate estimates of the number of people at risk for HIV infection, and will help predict future patterns of the spread of HIV infections. It will provide us with a body of knowledge upon which to base HIV prevention and control strategies and programs.

This proposal was bid competitively, peer reviewed by the NICHD's Advisory Council. The contract was won by the National Opinion Research Center at the University of Chicago. The survey instrument has gone through multiple reviews by the NIH Director's Office, HHS, and the Office of Management and Budget [OMB].

Mr. President, many public health and public policy groups in recent years have called for more information on health risks addressed by this survey. The organizations seeking this information include the American Red Cross, the American Public Health Association, and the American Medical Association.

[*S4758] Mr. President, more attention has been paid to the teenage sex survey. Like the adult survey, this study tries to gather

information about how and why teenagers put themselves at risk for unintended pregnancy and of serious or fatal diseases such as AIDS.

It is important to emphasize that this is not a random leaflet distributed to unsuspecting or innocent children. Parents must give written permission for their teenagers to participate. Interviewers will inform parents fully about the study and give them a chance to see the questions before they ask for permission. In addition, permission from school administrators will be required to administer the screener questionnaire in sample schools. There are rigorous procedures for protecting the privacy of participants.

Mr. President, I describe these surveys in detail to make two important points. The first is that the National Institutes of Health, or world-class research institution, is an entity of which I am very proud. I respect their contributions to science and scientific discovery. The NIH would not have the reputation and respect that it has if it engaged in irresponsible research activities that were harmful to the American public.

My confidence in NIH has been reinforced by a careful review of this controversial issue. Although I am not a social scientist or expert in survey research, I am persuaded that appropriate safeguards are in place to protect against the consequences that Senator Helms fears. These are serious efforts to address pressing public health problems. While the questions, when taken out of context, seem quite graphic, the sad truth is that our young people and many adults are putting themselves at risk. We should not oppose information, no matter how disturbing that information might be.

These studies cannot be a substitute for the important efforts that must be made to prevent risky behavior and promote responsible actions by Americans to protect their own health. In addition to the social tragedy that these diseases represent, they are also very costly. The costs of AIDS treatment and care far outweigh the costs of prevention. Prevention requires knowledge. NIH is responsible for providing the knowledge that I hope will enable us to shape policies that will help educate our citizens on the very real life-threatening dangers they face.

Mr. KOHL. Mr. President, I rise in support of the amendment offered by our colleague from Illinois.

There is one fundamental question at issue here. Do we believe that our scientific research is best determined by scientists or by political leaders? I believe it is best determined by scientists.

We have a very long tradition of independent scientific research - a tradition that has led the Nation to an unparalleled international scientific status in many areas. But in isolated instances in our history there have been incidents in which science has been ruled, not by the national interest, not by the merits of the research itself, but by political judgments. The consequences are almost always chaotic.

There have been attempts to legislate what can be taught in schools, and they have always failed. There have been attempts to legislate what kinds of research can be conducted, and they have failed. Intellectual

freedom is one of the fundamental values upon which our country was founded, and when threatened has always prevailed.

The research freedom provisions in H.R. 2507 preserve that intellectual freedom by preserving the integrity of the scientific review process. The language simply says "no" to politically motivated decisions on human behavior research. It says "no" to the administration's efforts to undermine previously peer-reviewed and approved surveys in order to politically appeal to an outspoken minority.

It says "yes" to sound research, peer-reviewed research, ethical research, and research that has already been deemed to be desperately needed.

Tolerance of political games with research has ominous implications for the Nation's ability to deal with teenage pregnancy, sexually transmitted diseases, and AIDS. The costs of failure are staggering, both in human and financial terms.

We must have the political courage to vote this matter out of the political arena and back into the areas of public health management and scientific research, where it belongs. We can expect, then, that public health administrators and social researchers will be sensitive to the concerns of taxpayers; that they will factor in legitimate public concerns as they design their research.

I thank my colleague from Illinois for his leadership on this matter. I yield the floor.

The PRESIDING OFFICER. The question is on agreeing to the amendment of the Senator from Illinois [Mr. Simon]. The yeas and nays have been ordered, and the clerk will call the roll.

The legislative clerk proceeded to call the roll.

Mr. FORD. I announce that the Senator from Illinois [Mr. Dixon] and the Senator from Rhode Island [Mr. Pell] are necessarily absent.

I further announce that, if present and voting, the Senator from Rhode Island [Mr. Pell] would vote "aye."

Mr. SIMPSON. I announce that the Senator from Indiana [Mr. Lugar] is necessarily absent.

The PRESIDING OFFICER (Mr. Harkin). Are there any other Senators in the Chamber who desire to vote?

The result was announced -- yeas 57, nays 40, as follows:

(See Roll call Vote No. 64 Leg. in the ROLL segment.)

So, the amendment (No. 1756) was agreed to.

Mr. KENNEDY. Mr. President, I move to reconsider the vote by which the amendment was agreed to.

Mr. SIMON. I move to lay that motion on the table.

The motion to lay on the table was agreed to.

VOTE ON AMENDMENT NO. 1757

The PRESIDING OFFICER. Under the previous order, the question is on agreeing to the amendment of the Senator from North Carolina. The yeas and nays have been ordered. The clerk will call the roll.

The legislative clerk called the roll.

Mr. FORD. I announce that the Senator from Illinois [Mr. Dixon] and the Senator from Rhode Island [Mr. Pell] are necessarily absent.

I further announce that, if present and voting, the Senator from Rhode Island [Mr. Pell], would vote "nay."

Mr. SIMPSON. I announce that the Senator from Indiana [Mr. Lugar], is necessarily absent.

The result was announced -- yeas 51, nays 46, as follows:

(See Roll call Vote No. 65 Leg. in the ROLL segment.)

So the amendment (No. 1757) was agreed to.

Mr. HELMS. Mr. President, I move to reconsider the vote.

Mr. MITCHELL. I move to lay that motion on the table.

The motion to lay on the table was agreed to.

The PRESIDING OFFICER. The majority leader is recognized.

[Roll call Vote No. 64 Leg.]

YEAS -- 57

Adams	Akaka	Baucus
Bentsen	Biden	Bingaman
Boren	Bradley	Breaux
Bryan	Bumpers	Burdick
Chafee	Cohen	Conrad
Cranston	Danforth	Daschle
DeConcini	Dodd	Durenberger
Fowler	Glenn	Gore
Graham	Harkin	Hatfield
Heflin	Inouye	Jeffords
Johnston	Kennedy	Kerrey
Kerry	Kohl	Lautenberg
Leahy	Levin	Lieberman
Metzenbaum	Mikulski	Mitchell
Moynihan	Nunn	Pryor

Reid
Rockefeller
Sasser
Wellstone

Riegle
Sanford
Shelby
Wirth

Robb
Sarbanes
Simon
Wofford

NAYS -- 40

Bond
Byrd
Craig
Domenici
Garn
Grassley
Hollings
Lott
McConnell
Packwood
Rudman
Smith
Symms
Warner

Brown
Coats
D'Amato
Exon
Gorton
Hatch
Kassebaum
Mack
Murkowski
Pressler
Seymour
Specter
Thurmond

Burns
Cochran
Dole
Ford
Gramm
Helms
Kasten
McCain
Nickles
Roth
Simpson
Stevens
Wallop

NOT VOTING -- 3

Dixon

Lugar

Pell

[Rollcall Vote No. 65 Leg.]

YEAS -- 51

Bond
Bryan
Byrd
Conrad
Dole
Ford
Gorton
Grassley
Helms
Kasten
McCain
Nickles
Pryor
Rudman
Shelby
Specter
Thurmond

Boren
Bumpers
Coats
Craig
Domenici
Fowler
Graham
Hatch
Hollings
Lott
McConnell
Packwood
Reid
Sasser
Simpson
Stevens
Wallop

Brown
Burns
Cochran
D'Amato
Exon
Garn
Gramm
Heflin
Kassebaum
Mack
Murkowski
Pressler
Roth
Seymour
Smith
Symms
Warner

NAYS -- 46

Adams
Bentsen
Bradley
Chafee
Danforth
Dodd

Akaka
Biden
Breaux
Cohen
Daschle
Durenberger

Baucus
Bingaman
Burdick
Cranston
DeConcini
Glenn

Gore
Inouye
Kennedy
Kohl
Levin
Mikulski
Nunn
Rockefeller
Simon
Wofford

Harkin
Jeffords
Kerrey
Lautenberg
Lieberman
Mitchell
Riegle
Sanford
Wellstone

Hatfield
Johnston
Kerry
Leahy
Metzenbaum
Moynihan
Robb
Sarbanes
Wirth

NOT VOTING -- 3

Dixon

Lugar

Pell