

## The ‘Add Health’ Survey: Origins, Purposes and Design

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### *First of Two Articles*

Efforts are underway in homes, schools and communities to keep young people from engaging in risky behaviors, such as using illicit drugs, smoking, drinking or having early and unprotected sex. What is less clear is why some young people, but not others, engage in these behaviors in the first place. A \$25 million federal study known as the National Longitudinal Study of Adolescent Health, or more commonly as the Add Health survey, seeks to find some answers to this basic question and provide a greater understanding of the factors that might protect against or promote risky behavior.

This is the first of two articles on the Add Health survey. It describes how the survey came about, what it was designed to do and how the data in this massive undertaking are being collected. With this foundation, the second article will take a look at the survey’s initial findings with regard to teen sexual intercourse, one of the risk behaviors considered in the study, and what the results might portend for program, policy and, of course, politics in this highly charged area.

### **Researching Teen Sexuality**

Government-sponsored research on people’s sexual behavior—and especially the sexual behavior of teenagers—remains a controversial political topic even to this day. For some social conservatives, merely documenting the behaviors people engage in—especially in studies funded by the government—is tantamount to an official endorse-

ment and encouragement of those behaviors. And so, when a massive study of this nature involving teens was proposed during the administration of the first President Bush, it was bound to generate heated opposition.

Deeply concerned by the burgeoning AIDS epidemic, leading social scientists in the mid-1980s began making their case that a greater understanding of teenagers’ sexual behavior was urgently needed in order to stem the rate of deadly HIV infections. Among these scientists were Ronald Rindfuss and J. Richard Udry of the University North Carolina (UNC), who in 1988 submitted a proposal to the National Institute of Child Health and Human Development, a division of the National Institutes of Health (NIH), for a large-scale, nationally representative study of adolescent sexual risk-taking. The American Teenage Study (ATS)—which its detractors quickly dubbed the “teen sex survey”—was designed as a five-year national study, with an \$18 million price tag, to provide information about health-related risk behaviors related to teenage pregnancy and sexually transmitted diseases, including, of course, HIV.

Almost immediately after the ATS proposal award was announced in May 1991, ultraconservative members of Congress and activist groups mounted their opposition. Two months later, then-Secretary of Health and Human Services Louis Sullivan took the unusual step of canceling the ATS award, expressing the department’s concern that the study would “inadvertently convey a

message that would be counterproductive to our efforts to discourage casual sex among teenagers.”

A few days after the cancellation, Rep. William Dannemeyer (R-CA) moved to prohibit the federal government from ever again funding surveys on sexual behavior in an amendment to pending legislation reauthorizing NIH. Rep. Henry Waxman (D-CA) countered with a substitute amendment that would allow sexual behavior research provided it met the approval of ethics and peer review boards and addressed public health needs. Other members spoke about the scientific merits and public health imperatives that justify studies on human sexuality. Rep. Jim McDermott (D-WA) asserted: “Children may be embarrassed by such discussion—but they will not die from embarrassment. They can die from AIDS. They can suffer permanent health effects from sexually transmitted diseases. And they can suffer a lifetime from premature parenthood.” When the vote was taken, Waxman’s amendment allowing research on sexual behavior prevailed.

The battle resumed in the Senate, where in September 1991 Sen. Jesse Helms (R-NC) introduced an amendment to the annual appropriations bill covering federal health programs, including research at NIH. Helms proposed that funds slated for sexual behavior research be transferred instead to the Adolescent Family Life Act, which was designed to support abstinence programs for adolescents and related research. Helms cast his amendment as presenting a “clear choice...between support for sexual restraint among our young people or, on the other hand, support for homosexuality and sexual decadence,” convincing the Senate to adopt the provision on a voice vote. While the provision was deleted in conference, House and Senate conferees agreed to withhold funding for the ATS.

## Enter 'Add Health'

In 1993, Congress explicitly banned the ATS in the NIH reauthorization act. At the same time, however, it called for a prospective longitudinal study (that is, a study conducted in multiple phases with the same individuals over time) on the determinants of adolescent health and risk-taking behavior, which gave rise to the Add Health survey. Congress directed that the study provide information about the health and well-being of adolescents in the United States and about the behaviors that promote adolescent health or put that health at risk. The study was to include a focus on how communities influenced the health of adolescents.

As was the case with the ATS, the Add Health survey was designed to achieve a greater understanding of those aspects of a teen's life that are associated with behaviors that threaten his or her health. But whereas the ATS would have looked only at those behaviors contributing to the risk of pregnancy and HIV/AIDS, the Add Health survey considers a range of health-related behaviors—cigarette use, alcohol use, illicit drug use, self-directed and interpersonal violence, and sexual intercourse.

Led by UNC's Udry, the Add Health survey is designed to go beyond demographic descriptions to identify the underlying "social mechanisms" that account for poor health and high-risk behaviors. Typically, reports on adolescent health pay special attention to teens' race, income, family structure and gender to predict how likely they are to engage in risky behaviors. However, according to Robert W. Blum of the Adolescent Health Program at the University of Minnesota and an Add Health investigator, examining adolescent health problems in terms of key demographic factors, while important, says little about what actually influences teen behavior—and even less that

might inform policy and program. "Knowing that white and Hispanic youth are more likely than black youth to report suicidal thoughts and attempts, for example, gives us very little information about what to build our interventions on," says Blum. "There is nothing we can do—or would want to do—to change a person's race. Rather, we must look at neighborhood, family, school, peer, and individual characteristics and how these interact within various groups in order to truly understand specific behaviors and how to develop effective strategies that reduce risk."

According to Blum and other investigators, the Add Health data set has the capacity to focus on individual, biological, behavioral and personality factors and how they interact with social environments, predisposing adolescents to, or protecting them from, health risk behaviors. For example, high self-esteem was found to be protective against smoking for many adolescents. Whether high self-esteem is merely a "marker" indicating that a youth is at decreased risk for smoking, is causal or both is what the Add Health survey seeks to determine.

The survey was conducted in two phases. In the first phase (from September 1994 through April 1995), roughly 90,000 students from grades 7–12 attending 134 schools across the United States answered brief questionnaires about their lives, including their health, friendships, self-esteem and expectations for the future. Before students could participate, parents had to give their permission through procedures approved by each school.

Researchers also gathered information about participating schools by having administrators complete a questionnaire dealing with such topics as school policies, teacher characteristics, student body characteristics and health services. In the spring of 1996, school information was updated in a telephone interview.

In the second phase, with written consent of both the adolescent and their parents, more than 20,000 in-home interviews of students were conducted between April and December 1995. Taking between one and two hours to complete, interviews covered such topics as family life, peer relationships, goals and aspirations, romantic partnerships, sexual partnerships, substance use and criminal activities. This "in-

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home" sample was composed of both a nationally representative "core sample" (of approximately 12,000 students) and a dozen special samples of groups that would otherwise be too small for analysis (for example, twins, Cuban Hispanics and disabled youth). A parent of each adolescent was also asked to complete an interview and many—about 18,000 parents, usually mothers—agreed to participate.

The researchers put into place special procedures to screen respondents for age and experience so that only appropriate questions were asked. Care was also taken to assure teenagers that their answers would remain confidential. On sensitive topics involving sex and drug use, for example, teenagers listened to tape-recorded questions and entered their answers directly into a laptop computer. Now that the data have become available, researchers have gone to great lengths to ensure that no one—not even the study director—can link the name of a participating individual with the information he or she provided.

This first set of in-home interviews, referred to as "Wave I," was followed

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up one year later, between April and August 1996, by a second set of in-home interviews (Wave II), making it possible to measure to what extent experiences at one time influence later behaviors. An additional survey, phase three, is planned for 2001, when the entire original sample group will be interviewed once again. By the time phase three of the survey is conducted, all of the students from phase one will have moved into adulthood.

### Clues for Public Policy

The results of Wave II, in which 15,000 adolescents were surveyed, were reported in December 2000 and will continue to be analyzed over the next decade. Significantly, the data are being made available to researchers other than those who were involved with the study. This key feature of the study is playing out now as a large number of investigators with different perspectives

and new research questions mine the public-use data files for additional analysis.

The Add Health survey promises to go beyond “report cards” on adolescent problems, providing a better understanding of those forces that put young people at risk. Because the study is longitudinal, investigators believe they will be able to identify those factors that are not simply associated with, but actually affect, risk reduction. “Understanding which things are causally related is critically important,” explains Blum. “Add Health results will be suggestive of where we should put our efforts and intervene on behalf of young people. This is, in part, what makes the Add Health survey so extraordinary: It provides us with clues about which programs and services will have the greatest payoff.”

Blum says that the Add Health data,

“if we are willing to hear the findings,” can provide a common ground for the more conservative and more liberal elements of society. As an example, he cites the finding that “connectedness to an adult” is a protective factor across all risk behaviors. “Improving connectedness is not part of any one political agenda,” continues Blum. “It should be a core goal, something that all of us can think through in terms of what it means for programs and services.”

The hope that findings from the Add Health survey will lead to common-ground action, especially in the political arena, is a big hope, indeed. The next article will address emerging Add Health findings with regard to the major risk and protective factors that appear to be linked with one of the key behaviors considered in the study—whether or not a youth has had sexual intercourse. ☪