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Privacy and Behavioral Research

Preliminary Summary of the Report of the Panel on Privacy and Behavioral Research

In recent years there have been growing threats to the privacy of individuals. Wiretapping, electronic eavesdropping, the use of personality tests in employment, the use of the lie detector in security or criminal investigations, and the detailed scrutiny of the private lives of people receiving public welfare funds all involve invasions of privacy. Although the social purpose is usually clear, the impact on the persons involved may be damaging. Our society has become more and more sensitive to the need to avoid such damage.

This concern has led to extensive discussion about the propriety of certain procedures in behavioral research, by the Congress, by officials in the various agencies of the government, by university officials, by the scientific community generally, and by leaders in professional societies in the behavioral sciences. The Office of Science and Technology appointed a panel[*], in January 1966, to examine these issues and to propose guidelines for those who are engaged in behavioral research or associated with its support and management.

The panel has restricted its attention to issues of privacy arising in connection with programs of data collection and study which are intimately associated with behavioral research. For example, it has not reviewed a number of the programs for data collection which are sponsored by the federal government, such as the various censuses, health and welfare statistics, and financial information secured from business and industry. These programs may also encroach upon the privacy of individuals, either through the burden of disclosure which they impose on respondents or through their availability for unintended purposes.

It is our opinion that the principles described in this report for protection of privacy in behavioral research should apply equally to such inquiries. When response is mandatory, as in the case of information that must be furnished to the government, there is an even greater burden on the sponsoring agency to protect the individual against disclosure unless disclosure is specifically sanctioned by statute.

The panel has not reviewed in detail the wide variety of mechanical or electronic devices which make it possible to intrude into private lives. We have become acquainted with a few of the problems in that field, however, and are dismayed to observe the disregard for human values indicated by the advocacy or actual practice of eavesdropping, the use of lie detection without clear justification, and the frequent willingness to institute surveillance procedures to handle the problems of a small proportion of our population at the risk of eroding the

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[*] The Panel on Privacy and Behavioral Research was appointed by the President's Office of Science and Technology. The members of the panel are as follows: Kenneth E. Clark (chairman), dean, College of Arts and Sciences, University of Rochester, Rochester, New York; Bernard Berelson, vice president, Population Council, Inc., New York, N.Y.; Edward J. Bloustein, president, Bennington College, Bennington, Vermont; George E. Pake, provost, Washington University, St. Louis, Missouri; Colin S. Pittendrigh, dean, Graduate School, Princeton University, Princeton, New Jersey; Oscar M. Ruebhausen, Debevoise, Plimpton, Lyons & Gates, New York, N.Y.; Walter S. Salant, Economics Studies Division, Brookings Institution, Washington, D.C.; Robert Sears, dean, School of Humanities and Sciences, Stanford University, Palo Alto, California; Benson R. Snyder, psychiatrist-in-chief, Medical Department, Massachusetts Institute of Technology, Cambridge; Frederick P. Thieme, vice president, University of Washington, Seattle; Lawrence N. Bloomberg, assistant chief, Office of Statistical Standards, Bureau of the Budget, Washington, D.C.; and Colin M. MacLeod, deputy director, Office of Science and Technology (now vice president for medical affairs, The Commonwealth Fund, New York, N.Y.). Consultant to the panel is Richard M. Michaels, technical assistant, Office of Science and Technology, Washington, D.C. The full text of the report will be available about 1 March 1967 from the Superintendent of Documents, Government Printing Office, Washington, D.C. 20402.

rights and the quality of life for the majority.

Likewise, the panel has not reviewed in detail the propriety of procedures involved in employment or social welfare activities. Enough examples have been brought to our attention, however, to make us feel that examination of procedures in these spheres is needed also.

The attitudes of various segments of our society about proper procedures for the protection of privacy and the right to self-determination have been explored by the panel. It has reviewed relevant research in the behavioral sciences and the administrative practices of universities and government agencies. It has also consulted with the scientific community through its professional organizations.

Threats to Privacy

The right to privacy is the right of the individual to decide for himself how much he will share with others his thoughts, his feelings, and the facts of his personal life. It is a right that is essential to insure dignity and freedom of self-determination. In recent years there has been a severe erosion of this right by the widespread and often callous use of various devices for eavesdropping, lie detection, and secret observation in politics, in business, and in law enforcement. Indeed, modern electronic instruments for wiretapping and bugging have opened any human activity to the threat of illicit invasion of privacy. This unwholesome state of affairs has led to wide public concern over the methods of inquiry used by agencies of public employment, social welfare, and law enforcement.

Behavioral research, devoted as it is to the discovery of facts and principles underlying human activity of all types, comes naturally under scrutiny in any examination of possible threats to privacy. All of the social sciences, including economics, political science, anthropology, sociology, and psychology, take as a major object of study the behavior of individuals, communities, or other groups. In one context or another, investigators in all of these disciplines frequently need to seek information that is private to the men, women, and children who are the subjects of their study. In most instances this information is freely given by those who consent to cooperate in the scientific process. But the very nature of behavioral research is such that there is a risk of invasion of privacy if unusual care is not taken to secure the consent of research subjects, or if the data obtained are not given full confidentiality.

While the privacy problem in scientific research is small in comparison to that which exists in employment interviewing, social welfare screening, and law enforcement investigations, the opportunity for improper invasion is not negligible. About 35,000 behavioral scientists are engaged in research in the United States, 2100 new Ph.D.'s are graduated each year, and the total number of students enrolled for advanced degrees in the behavioral sciences exceeds 40,000 at the present time.

It is probable that relatively few of the studies undertaken by these scientists raise serious questions of propriety in relation to privacy and human dignity. From a survey of articles published in professional journals and of research grant applications submitted to government agencies, we have concluded that most scientists who conduct research in privacy-sensitive areas are aware of the ethical implications of their experimental designs and arrange to secure the consent of subjects and to protect the confidentiality of the data obtained from them.

It cannot be denied, however, that, in a limited number of instances, behavioral scientists have not followed appropriate procedures to protect the rights of their subjects, and that in other cases recognition of the importance of privacy-invading considerations has not been as sophisticated, or the considerations as affirmatively implemented, as good practice demands. Because of this failure there has been pressure from some quarters, both within the government and outside of it, to place arbitrary limits on the research methods which may be used. Behavioral scientists as a group do not question the importance of the right to privacy and are understandably concerned when suggestions are made that the detailed processes of science should be subjected to control by legislation or arbitrary administrative ruling. All scientists are opposed to restrictions which may curtail important research. At the same time they have an obligation to insure that all possible steps are taken to assure respect for the privacy and dignity of their subjects.

Conflicting Rights

It is clear that there exists an important conflict between two values, both of which are strongly held in American society.

The individual has an inalienable right to dignity, self-respect, and freedom to determine his own thoughts and actions within the broad limits set by the requirements of society. The essential element in privacy and self-determination is the privilege of making one's own decision as to the extent to which one will reveal thoughts, feelings, and actions. When a person consents freely and fully to share himself with others—with a scientist, an employer, or a credit investigator—there is no invasion of privacy, regardless of the quality or nature of the information revealed.

Behavioral science is representative of another value vigorously championed by most American citizens, the right to know anything that may be known or discovered about any part of the universe. Man is part of this universe, and the extent of the federal government's financial support of human behavioral research (on the order of $300 million in 1966) testifies to the importance placed on the study of human behavior by the American people. In the past there have been conflicts between theological beliefs and the theoretical analyses of the physical sciences. These conflicts have largely subsided, but the behavioral sciences seem to have inherited the basic conflict that arises when strongly held beliefs or moral attitudes—whether theologically, economically, or politically based—are subjected to the free-ranging process of scientific inquiry. If society is to exercise its right to know, it must free its behavioral scientists as much as possible from unnecessary restraints. Behavioral scientists in turn must accept the constructive restraints that society imposes in order to establish that level of dignity, freedom, and personal fulfillment that men treasure virtually above all else in life.

The root of the conflict between the individual's right to privacy and society's right of discovery is the research process. Behavioral science seeks to assess and to measure many qualities of men's minds, feelings, and actions. In the absence of informed consent on the part of the subject, these measurements represent invasion of privacy. The scientist must therefore obtain the consent of his subject.

To obtain truly informed consent is often difficult. In the first place, the nature of the inquiry sometimes cannot be explained adequately because it involves complex variables that the nonscientist does not understand. Examples are the personality variables measured by questionnaires, and the qualities of cognitive processes measured by creativity tests. Secondly, the validity of an experiment is sometimes destroyed if the subject knows all the details of its conduct. Examples include drug-testing, in which the effect of suggestion (placebo effect) must be avoided, and studies of persuasability, in which the subjects remain ignorant of the influences that are being presented experimentally. Clearly, then, if behavioral research is to be effective, some modification of the traditional concept of informed consent is needed.

Such a change in no sense voids the more general proposition that the performance of human behavioral research is the product of a partnership between the scientist and his subject. Consent to participate in a study must be the norm before any subject embarks on the enterprise. Since consent must sometimes be given despite an admittedly inadequate understanding of the scientific purposes of the research procedures, the right to discontinue participation at any point must be stipulated in clear terms. In the meantime, when full information is not available to the subject and when no alternative procedures to minimize the privacy problem are available, the relationship between the subject and the scientist (and between the subject and the institution sponsoring the scientist) must be based upon trust. This places the scientist and the sponsoring institution under a fiduciary obligation to protect the privacy and dignity of the subject who entrusts himself to them. The scientist must agree to treat the subject fairly and with dignity, to cause him no inconvenience or discomfort unless the extent of the inconvenience and discomfort has been accepted by the subject in advance, to inform the subject as fully as possible of the purposes of the inquiry or experiment, and to put into effect all procedures which will assure the confidentiality of whatever information is obtained.

Occasionally, even this degree of consent cannot be obtained. Naturalistic observations of group behavior must sometimes be made unbeknownst to the subjects. In such cases, as well as in all others, the scientist has the obligation to insure full confidentiality of the research records. Only by doing so, and by making certain that published reports contain no identifying reference to a given subject, can the invasion of privacy be minimized.

Basically, then, the protection of privacy in research is assured first by securing the informed consent of the subject. When the subject cannot be completely informed, the consent must be based on trust in the scientist and in the institution sponsoring him. In any case the scientist and his sponsoring institution must insure privacy by the maintenance of confidentiality.

In the end, the fact must be accepted that human behavioral research will at times produce discomfort to some subjects, and will entail a partial invasion of their privacy. Neither the principle of privacy nor the need to discover new knowledge can supervene universally. As with other conflicting values in our society, there must be constant adjustment and compromise, with the decision as to which value is to govern in a given instance to be determined by a weighing of the costs and the gains—the cost in privacy, the gain in knowledge. The decision cannot be made by the investigator alone, because he has a vested interest in his own research program, but must be a positive concern of his scientific peers and the institution which sponsors his work. Our society has grown strong on the principle of minimizing costs and maximizing gains, and, when warmly held values are in conflict, there must be a thoughtful evaluation of the specific case. In particular we do not believe that detailed governmental controls of research methods or instruments can substitute for the more effective procedures which are available and carry less risk of damage to the scientific enterprise.

Ethical Aspects of Human Research

Greater attention must be given to the ethical aspects of human research. The increase in scientists and in volume of research provides more chance for carelessness or recklessness and, in the hurried search for useful findings, can lead to abuses. Furthermore, if standards are not carefully maintained, there could develop an atmosphere of disregard for privacy that would be altogether alien to the spirit of American society. The increased potentials for damage and for fruitful outcomes from new knowledge are in no small part results of increased federal support of behavioral science. While no one would suggest that ethical standards should be different for scientists supported by public funds and for those supported by private funds, the government has an especially strong obligation to support research only under conditions that give fullest protection to individual human dignity. Government must avow and maintain the highest standards for the guidance of all.

To summarize, three parties—the investigator, his institution, and the sponsoring agency—have the responsibility for maintaining proper ethical standards with respect to government-sponsored research. The investigator designs the research and is in the best position to evaluate the propriety of his procedures. He has, therefore, the ultimate responsibility for insuring that his research is both effective and ethical.

The formalization of our ethics concerning privacy in connection with research is too recent, and perhaps too incomplete, to permit the assumption that all investigators have a full understanding of the proper methods for protecting the rights of subjects. Furthermore, the investigator is first and foremost a scientist in search of new knowledge, and it would not be in accord with our understanding of human motivation to expect him always to be as vigilant for his subject's welfare as he is for the productiveness of his own research.

We conclude, therefore, that responsibility must also be borne by the institution which employs the investigator. The employing institution is often a university or a government laboratory in which there are other scientists capable of reviewing the research plan. Such persons, drawn in part from disciplines other than the behavioral sciences, can present views that are colored neither by self-interest nor by the blind spots that may characterize the specific discipline of the investigator.

Finally, the sponsoring agency is obligated to make certain that both the investigator and his institution are fully aware of the importance of the ethical aspects of the research and that they have taken the necessary steps to discharge their responsibility to the human subjects involved. We believe that, in the majority of instances, it is neither necessary nor desirable for an agency to exceed this level of responsibility.

Conclusions

From our examination of the relation of behavioral science research to the right to privacy, we have been led to the following conclusions.

1) While most current practices in the field pose no significant threat to the privacy of research subjects, a sufficient number of exceptions have been noted to warrant a sharp increase in attention to procedures that will assure protection of this right. The increasing scale of behavioral research is itself an additional reason for focusing attention in this area.

2) Participation by subjects must be voluntary and based on informed consent to the extent that this is consistent with the objectives of the research. It is fully consistent with the protection of privacy that, in the absence of full information, consent be based on trust in the qualified investigator and the integrity of his institution.

3) The scientist has an obligation to insure that no permanent physical or psychological harm will ensue from the research procedures, and that temporary discomfort or loss of privacy will be remedied in an appropriate way during the course of the research or at its completion. To merit trust, the scientist must design his research with a view to protecting, to the fullest extent possible, the privacy of the subjects. If intrusion on privacy proves essential to the research, he should not proceed with his proposed experiment until he and his colleagues have considered all of the relevant facts and he has determined, with support from them, that the benefits outweigh the costs.

4) The scientist has the same responsibility to protect the privacy of the individual in published reports and in research records that he has in the conduct of the research itself.

5) The primary responsibility for the use of ethical procedures must rest with the individual investigator, but government agencies that support behavioral research should satisfy themselves that the institution which employs the investigator has effectively accepted its responsibility to require that he meet proper ethical standards.

6) Legislation to assure appropriate recognition of the rights of human subjects is neither necessary nor desirable if the scientists and sponsoring institutions fully discharge their responsibilities in accommodating to the claim of privacy. Because of its relative inflexibility, legislation cannot meet the challenge of the subtle and sensitive conflict of values under consideration, nor can it aid in the wise decision making by individuals which is required to assure optimum protection of subjects, together with the fullest effectiveness of research.

Recommendations

These conclusions lead us to make the following recommendations.

1) That government agencies supporting research in their own laboratories or in outside institutions require those institutions to agree to accept responsibility for the ethical propriety of human research performed with the aid of government funds.

2) That the methods used for institutional review be determined by the institutions themselves. The greatest possible flexibility of methods should be encouraged in order to build effective support for the principle of institutional responsibility within universities or other organizations. Institutions differ in their internal structures and operating procedures, and no single rigid formula will work for all.

3) That investigators and institutions be notified of the importance of consent and confidentiality as ethical requirements in research design, and that when either condition cannot be met, an explanation of the reasons be made in the application for funds.

4) That when research is undertaken directly by, or purchased on specification by, a government agency, responsibility for protection of privacy lies with the agency. When independent research is funded by the government, however, responsibility lies primarily with the scientist and his institution, and research instruments or design should not be subject to detailed review by government agencies with respect to protection of privacy.

5) That universities and professional associations be encouraged to emphasize the ethical aspects of behavioral research. When a training grant is made, a university should be requested to indicate its understanding that support of education on the ethics of research is one of the purposes of the grant.