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The Impact of Legal Controls on Human Subjects Protection:
A Preliminary Case Study[1]

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I. Introduction

Social research needs a strong statement of support. Researchers must become advocates to ensure that a legislative balancing of social values occurs or it is probable that much significant social research will become impossible or impractical to conduct. The right of individual privacy cannot be an absolute. This article presents our observations and conclusions concerning the impact of legal controls on human subjects protection in general, and specifically in the context of a major study, an investigation of the relationship between learning disabilities and juvenile delinquency.

II. The Learning Disabilities/Juvenile Delinquency Study.

During the past several years, much attention has been given to the possibility of a relationship between learning disabilities (LD) and juvenile delinquency.[2] If LD is causally related to juvenile delinquency and can be remediated successfully, special educational programs could play

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a role in preventing delinquency. The study is initially determining the prevalence of LD in delinquent and nondelinquent populations. The second component is a remediation (instructional) program for selected groups of delinquents which will be followed by an evaluation of the effectiveness of the remediation. The study is being conducted primarily in Maricopa County (Phoenix), Arizona; Marion County (Indianapolis), Indiana; and in Baltimore, Maryland.

This study involves the collection and use of information, rather than the physical interventions that are common to biomedical treatment and experimentation. The risk posed to participants is a potential breach of confidentiality of sensitive information. Although it can be argued that taking a battery of tests has the potential for causing psychological harm to a child, such a risk is minimal, if it exists at all in the LD/JD study.

The planning, coordination and management of human subjects protection have been and continue to be massive tasks. Over 25,000 letters have been mailed to about 12,000 individuals and thousands of phone calls have been made in obtaining and maintaining the informed consent for a sample of nearly 2,200 youths. In addition to ethical concerns, legal controls have significantly shaped the course of the

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study. In many instances the study is a precedent for the operational meaning of such provisions.

III. The Legal Controls.[3]

A. Access to Juvenile Justice System Records

Delinquent youth in the sample are those who have been formally adjudicated delinquent or certain other juvenile offender statuses.[4] The minimum participation level of youth who fit the criteria of the study consisted of a review of the youths' education, court, probation and correction system records, and a 20-minute interview to verify and supplement information obtained in the records review and to obtain information about self-reported delinquency. All of these youths judged to be LD were assigned to either the remediation program or a comparison group, and will be re-tested during the evaluation.

Juvenile justice system records come in two general categories: legal files and other files. A "legal file" is a transactional history of a youth's interaction with the legal system for a single alleged offense. The file contains factual allegations, legal proceedings and case disposition. These are generally maintained separately and limitations on access are not as restrictive as for "other files." "Other files" include probation and correction system records which

are normally indexed by the name of the offender rather than by case number and contain pre-hearing investigative reports, diagnostic testing results, social history and other information relevant to determining the most effective rehabilitative treatment.

Statutes which designate juvenile records as public records do not always differentiate between the types of files. Typically, however, courts strictly construe such statutes to encompass only legal files. Information files on juveniles usually have several record custodians: clerks of courts, chief probation officers, and administrators of training schools and other institutions.

Federal Regulations

The Department of Justice's regulations are generally applicable to questions of access to juvenile justice system records.[5] These regulations set minimum standards for juvenile court and corrections system records if the record system has been funded by the Law Enforcement Assistance Administration.[6] The net effect is applicability to all records systems:[7]

[Agencies will] [i]nsure that dissemination of records concerning proceedings relating to the adjudication of a juvenile as delinquent or in need of supervision (or the equivalent) to noncriminal justice agencies is prohibited, unless a statute, court order, rule or court decision specifically authorizes

dissemination of juvenile records, except to the same extent as criminal history records may be disseminated as provided in §20.21(b) (3) and (4).

Restrictions on access may be lessened by a state statute, court order, rule or court decision which specifically permits access to juvenile court records. The exception in §20.21(b)(4) is for research purposes. Access is allowed pursuant to a specific research agreement which protects the rights of individuals. However, the federal regulations establish only minimum safeguards. Most state statutes do not contain a research exception; thus, the federal exception is not applicable.

State Statutes

For the most part, the information contained in "other files" is not covered by statutes but in practice was considered confidential. Rule 19 of the Arizona Rules of Procedure for Juvenile Courts, which allows a court to hold closed hearings, does not specifically address the confidentiality of court (legal) records, but has been applied to such records in practice. Records of youth committed to the Arizona Department of Corrections are confidential.[8] This specifically includes "the reports of the reception-diagnostic centers" to which delinquent youths are first sent. The department may enter into "joint research agreements" to

accomplish relevant research objectives.[9] This is the basis of cooperation with the LD/JD study.

Marion County, Indiana, juvenile court legal records are public records by local court order.[10] The Indiana Commissioner of Corrections is required to protect sensitive and other "privileged" information concerning youth under his overall authority.[11] The state's recent information practices law has been construed by the commission's Youth Authority as requiring informed consent for records access.[12]

Maryland juvenile court records are confidential, and access may not be allowed "except by order of the court upon good cause shown." [13] The Department of Juvenile Services has the responsibility for youths subsequent to adjudication and its research reports are confidential.[14]

The net effect of these statutes is to require informed consent for record access participation. Even when access to legal files could be obtained without the subject's consent, it was impossible to obtain access to the "other files" without consent. In the absence of express research exceptions and on the basis of the scope of information needed, the best strategy was to obtain parental consent. Each court made directory information concerning probationers available, or permitted access to records to obtain this information.

B. Access to Educational Records

For the purpose of this study, nondelinquent youths are considered to be those who have not been officially adjudicated a delinquent or other status by the juvenile justice system. They are involved only in the prevalence study. The scope of their participation includes access to school records for LD screening purposes, a 20-minute interview to verify and supplement information obtained from the records and to obtain information about self-reported delinquency, and, as necessary, intensive diagnostic testing to determine whether they are LD. The educational records of youths in the delinquent sample who are enrolled in public school systems (i.e., probationers and parolees) also were reviewed for LD screening purposes after consent was obtained from parents or guardians.

Family Educational Rights and Privacy Act[15]

This federal law is applicable to all public and private schools which receive federal funds. Funds may be withheld if school districts or educational institutions do not comply. In general, unless a student (or the parent when the student is a minor) gives written consent, an educational institution may not release any personally identifiable information or allow access to records by any third party. The

law distinguishes directory information from personally identifiable information and establishes lesser standards for public disclosure of directory information.[16] A research exception allows record access without individual consent but because the law establishes only minimum standards a more restrictive state law takes precedence.[17]

State Laws, Rules and Regulations

Indiana has no educational records statute; thus, the federal act is directly applicable. Both Arizona and Maryland have laws which supplement the federal act.[18] Neither the Arizona nor Maryland statutes contains a research exception. Thus, access to student records for diagnostic review may occur only with parental consent.

Most of the school systems have promulgated operating rules and procedures for compliance with the federal and state laws.[19] Directory information definitions and the persons authorized to have access to such information vary considerably. Research needs generally are not expressly recognized in such documents, although they may be accommodated in actual practice.

Because of the differences among state laws, the varying local interpretations of state and federal laws, the unlikelihood of persuading Indiana school system officials to

authorize a research exception, and the degree of subject participation; the soundest course of action was to request only directory information of schools and school systems, and to obtain informed consent from parents for all types of subject involvement, including records access.

C. LEAA Controls on Subject Participation and Information Use

42 U.S.C. §3771(a) directs the manner in which information collected in an LEAA-funded study may be used or disseminated.[20] This law and the accompanying regulations were analyzed in the March, 1979 issue of this journal.[21]

D. HEW Regulations

Because of the peer review process imposed as a requirement for research under awards from the Department of Health, Education, and Welfare, researchers also often must comply with the HEW subject protection regulations, regardless of the source of study funds.[22] The LD/JD study consent forms and procedures were required to follow the more detailed HEW regulations, as well as the LEAA regulations.[23]

IV. Implementation of the Legal Controls in a Research Context.

A. Planning for and Management of Human Subjects Protection

The LEAA grant solicitation did not address the issue of human subjects protection, and our proposal did not antici-

pate its logistical and financial implications. Only after the grant was received did the planning begin. Law library resources were utilized to develop an internal working paper which preliminarily identified the relevant law. Visits were made to court, probation system, corrections and school system officials in each city to identify local information access standards and procedures and to gain cooperation. The same persons usually visited the equivalent organizations in each state. As the study proceeded, a single individual was designated to supervise the mechanics of obtaining individual informed consent, and to maintain the cooperation of the organizations involved. (A lawyer need not do these tasks, but one should be available for consultation.)

It is recommended that initial emphasis should be placed on fact finding before plans are finalized and action is taken. This should be done by funding agencies before granting funds, as well as by grantees before attempting to begin a study. Detailed fact-finding and planning efforts will minimize wasted action and unnecessary expense. The research staff should be briefed on the basic elements of human subjects protection and on the relevant fundamentals of the criminal justice system. Adequate time spent identifying potential problems also will reduce the chance that a credibility gap will develop with the participating organizations.

B. Obtaining the Cooperation (Consent) of the Organizations

The ongoing cooperation of schools, courts and corrections systems is necessary for the success of a project such as the LD/JD study. Once initial contacts are established, essential facts, such as the means for obtaining directory information and the potential sizes of samples, can be obtained by telephone. Points-of-contact within the organizations should be either decision-makers, or those who have close ties to them. (An organizational chart may be helpful to understanding the power structure.) Many potentially sensitive problems can be avoided or solved easily because of such relationships. This approach often succeeds where well thought-out legal arguments fail. Researchers should know the legal standards before initiating such contacts. This promotes credibility and productivity and protects against errors by local persons who do not know the relevant legal standards.

In the LD/JD study, attempts were made initially to inform cooperating organizations of the full scope of assistance that would be desired of them and the benefits that they could expect. The elements to be included in making formal requests for cooperation and directory information were identified.

There have been occasional failures of internal communication within cooperating organizations. For example, a decision-maker would authorize an action, but would not always advise the operational-level persons of the authorization. If such persons are in different physical locations, it is wise to obtain and present written authorization to minimize any communication gaps.[24]

C. Record Systems; Structure, Location and Custodians

The early site visits of the LD/JD staff revealed the record systems structures and the custodians for each school, court and corrections system. The general types of files maintained, the restrictions on access to each type, and the specific information maintained in each were determined. Handbooks which described the structure and location of records, and procedures for access were obtained for several juvenile court and school systems.[25] However, the conditions of the records were not always as stated in written and verbal descriptions. Site visits disclosed significant differences in the quality and quantity of information on file and the degree of record systems organization. Copies of forms utilized in the files were obtained for reference purposes.

The effectiveness and efficiency of interaction with record custodians can be improved by knowing what elements of

information are needed before making a request. Changes in requests for data should be minimized, or working relationships may be severely tested. If the researcher is to conduct the actual record search, identify the types of records kept, their contents, and the form (automated or nonautomated) of each file. Determine whether indices exist, their form and location. Be careful in utilizing automated files; they may contain only a subset of all the elements of information required by a study. It may be more cost-effective and politically acceptable to utilize only nonautomated records if the contents of the automated files do not totally satisfy your research needs. Concerning location, determine whether the records are kept in a single room, distributed among different offices within the same building, or located in different buildings. Our diagnostic contractors reported that "the scattered locations within institutions and the extreme variation in format have slowed . . . [the record screening] process down to less than half the planned reviews per day." [26]

Documentary research, such as the review of records in the LD/JD study, may reduce total research costs. On the other hand, it may increase costs if proper planning is not conducted. Nothing should be taken for granted concerning the quality of record system operation.

D. Obtaining Informed Consent[27]

Initially, a decision had to be made whether to utilize a single form to request all possible levels of participation from delinquent youth, or to use separate forms to request consent at several junctures during the study. For example, consent for only the prevalence study could have been requested (as it was for the nondelinquents in the public schools) in one form, and consent for remediation or comparison group participation could have been requested in another form. The greater the degree of participation, the more complex a form becomes, particularly in view of the elements required by law. On the other hand, a greater sense of commitment to a study can be achieved if a single overall consent is obtained. In addition, the use of a single form simplifies the administrative aspects of obtaining consent.

After careful consideration, it was decided to utilize a single general form. Even the use of a single form required a massive logistical effort. It was sent to federal justice department officials, the relevant state juvenile justice and corrections system officials and others for their review and approval. Judicial approval by the participating courts was particularly important. Responses from these officials were often delayed by their busy schedules. Forms were revised as

concerns were identified. Most of the difficulties concerned the understandability of the forms' contents. This was a result of the complexity of the subjects' participation, the number of required elements of disclosure, and the abundance of legal jargon.

After the delivery of many of the final versions of consent forms, the diagnostic contractor's legal counsel expressed the opinion during its internal peer review process that full disclosure had not been made. Herein is the dilemma of "full disclosure" in creating such forms. At one extreme, consent from potential subjects could be sought with no technical description of the research. At the other extreme, full disclosure could be interpreted to mean prior inspection and approval of all questionnaire items. The contractor's legal counsel deemed that disclosure of a self-report delinquency scale was necessary, but not the use of a socio-economic class scale. Since there are no absolutes concerning the meaning of full disclosure, the issue must be confronted anew in each study and with each additional group of research participants.

The effect of modifying the consent forms during the course of the study probably was not significant. Increases in rates of returns to various versions of the forms are

probably attributable to different delivery mechanisms or follow-up efforts, as opposed to the contents. Nevertheless, in retrospect, the communicative nature of the forms should have been tested, using objective readability tests[28] and by administration to persons with education backgrounds similar to the study sample.

A lawyer and a social scientist team should be responsible for designing informed consent forms. The presence of a lawyer assures the legal accuracy of the forms, while the social scientist can "tone down" the legal jargon and make the language more understandable. Isolating the responsibility will maximize consistency.

As of October, 1978 the study had an overall individual informed consent rate of 35%. The positive response rates for public school and juvenile delinquent groups being 42% and 33%, respectively. To answer questions and encourage consent, phone calls were made by ACLD to most parents whose households had telephones and whose telephone numbers were obtained in the directory information. Follow-up letters were mailed to all parents who initially did not provide consent. As of the beginning of the remediation program, there were no reported complaints of failure to disclose fully what participation in the study involved.

E. Obtaining Directory Information

As the consent forms were being designed, directory information (youths', parents' or guardians' names, addresses and phone numbers) was obtained for the nondelinquent sample, and for probationers and parolees in the delinquent sample. Organizations, particularly schools, should be allowed extensive lead time to fulfill the requests. Lead time, though, must be balanced with the need for current information. Because of the mobility of society in general, and of the parents and guardians involved in the LD/JD study in particular, it was difficult to obtain up-to-date information. The informational lags were caused primarily by the changes in subjects' locations, rather than by delays on the part of the record custodians. Subjects generally have no affirmative duty to update addresses and phone numbers, and record custodians usually request updates according to a predetermined schedule.

In requesting directory information, one should determine the form that the request should take (including whether the agency requires submission of certain forms), and to whom it should be directed. Be prepared to make follow-up phone calls to make sure your request is complied with in a timely manner. Request all the directory information you require the first time, rather than changing your request later.

The definition of directory information and the dissemination restrictions vary considerably. On balance, we believe the societal importance of the LD/JD study clearly outweighed the minor intrusion on individual privacy of an agency's providing directory information. Realistically, it is difficult to communicate this rationale to administrators who must comply with complex rules and regulations. Nevertheless, the importance of the research objectives should be advanced as a basis for the release of directory information. In general, researchers should advocate the establishment by organizations of specific procedures for the transfer of directory information.

F. Information Transfer Agreements[29]

Formal agreements encourage additional research on an already acquired research data base, while protecting individual privacy. Covering points in the transfer agreements other than those required by the LEAA regulations improves working relationships. Surprises to both parties are minimized and continuity is promoted because the responsibilities of the parties are specified for the duration of the study. Such agreements should be negotiated as soon as possible after the beginning of a study.

Only educational testing data, rather than information about delinquent behavior, are being transferred under the

LD/JD study agreements. This fully promotes the rehabilitative purpose of the juvenile justice system and minimizes duplicative testing.

Contrary to the recent recommendations of the federal Privacy Protection Commission, LEAA is not required to approve information transfer agreements. However, the written commitment of the agreement does force researchers to examine and justify their conduct with regard to the transfer of data.

No agreements were used with school systems. The consent form used with the nondelinquent sample indicates that consent authorizes the transfer of the educational testing results to the youth's school.[30] The number of schools and school systems involved in the study, and the amount of time involved in negotiating agreements with juvenile justice agencies were the major reasons for choosing this approach.

G. The Privacy Protection Study Commission Guidelines and Recommendations

This commission was a creation of the federal Privacy Act of 1974.[31] Its views are presented because of the implications for future research effects. The commission's guidelines are directed generally to all research and statistical activities, whereas its recommendations are applicable to federally conducted or funded activities and include

proposed legislative action.[32] Such of its recommendations are part of the Carter administration's recent privacy legislative initiative.[33]

The major thrust is that personally identifiable information obtained for research and statistical purposes should be secure from use for other purposes, particularly as a basis for substantive determinations affecting the individual, unless the subject consents. This is a legislative recommendation which would encompass studies funded by federal agencies. The transfer of information from nonresearch and statistical sources, such as confidential juvenile justice system records, to research and statistical activities, should occur only on the basis of demonstrated need, according to the commission.

By stating that information collected for a "research and statistical purpose" may not be used in making a determination about the individual, the commission would seem to prohibit the types of transfers of educational information to schools and the juvenile justice systems as in the LD/JD study. The text of the report, however, recognizes two classes of exceptions: when the subjects receive the benefits of the research findings directly, and when "societal imperatives outweigh the individual's claim to protection." [34]

We believe that the transfers in the LD/JD study benefit youth as a class, as well as providing direct benefits to participating youths, because the transferred information increases the research base upon which a diagnostic evaluation can be made. This should improve the rehabilitative programs of the delinquent youths and the educational programs of the nondelinquent youths. Individual informed consent for these transfers was obtained in most cases, but the information transfer agreements with juvenile justice agencies also apply under this recommendation. The commission's judgment also is that a transfer for other purposes should be allowed when the parties demonstrate that the social importance or value outweighs any potential risk to the individual. Since, under the commission's proposals, the funding agency would be required to approve transfers, a more objective review of both types of justification would be made.

Another guideline generally would allow researchers access to administrative and other nonresearch records of individuals without their consent, such as educational and juvenile justice system records, when the records custodian "determines the research or statistical purpose for which disclosure is to be made is of sufficient social benefit to

warrant the increase in risk to the individual of exposure of the record or information." [35] This right of access, however, is conditioned by the statement "[e]xcept where specifically prohibited by law." In view of the state and federal statutes in force, this promotion of research would not have aided the LD/JD study, nor would it greatly assist in easing the access standards for subsequent research. (What is needed is solid support for a research exception in every recordkeeping practices statute.)

The commission recommends that information transfer agreements negotiated by a researcher under a federal grant or contract must be approved by the funding agency. [36] Another recommendation would require researchers to notify each individual participating in current research, apparently as part of the informed consent process, that the information collected may be disclosed in identifiable form (i.e., through an information transfer agreement) for additional research. [37]

Another statutory recommendation would establish an institutional review process to protect the incompetent individual and the "captive subject" when consent authorizes a disclosure in identifiable form other than for a research or statistical purpose. [38]

The proposed legislative implementation of the recommendations in studies involving federal money should be evaluated both on risks posed to research subjects in the absence of legislation, and on the impracticalities of conducting important social research if such legislation becomes law. A balanced approach is possible only if researchers make sure their position is communicated and understood.

V. Conclusion.

During hearings before the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research[39], the American Sociological Association (ASA) advocated that current guidelines for human subjects protection in research are:

[B]ased on research methodologies which involve the imposition of experimental procedures onto a subject involving the use of specific instrumental approaches to research subjects, thus implying an invasion into the organism itself.

In contrast, explained the spokesperson:[40]

[t]he methodologies of sociology range from the qualitative gathering of data by observation, participation, or informal interviewing to the more structured and quantifiable approaches represented by precoded questionnaires and paper and pencil instruments which are translated into large data assemblies. . . . The model which applies to experimental research should not be indiscriminately applied to sociological studies since it does not effectively assure the protection of human subjects.

In earlier hearings conducted by the Privacy Protection Commission on its draft recommendations,[41] the ASA asserted that "[t]he Commission should take care that its recommendations do not implicitly sound a note of caution against participating in research and statistical activities which is the interpretation that the ASA places on the Commission's statement." [42] We believe the present tone of laws and administrative regulations is generally discouraging to social research[43]. The emphasis on individual privacy without a comparable promotion of research under proper conditions evokes overreactions rather than reasoned decisions concerning study participation. The publicity given the possible (but improbable) abuse of information obtained in a research setting may have created a public attitude which will be difficult to overcome. Even when laws and regulations contain a research exception for records access for important social research, the attitude of decision-makers and record custodians often is prejudiced against total cooperation before any negotiations have begun. Our experience indicates that the degree of cooperation from institutions, such as state and local education and juvenile justice agencies, is diminishing, more often than not without considering the impact on research.[44]

Social research needs a strong statement of support, preferably by legislatures. Criminal justice and other social researchers must communicate with Congress, state legislatures and the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to express their views on the balancing of values.[45] Otherwise, it is highly probable that much significant social research will become impossible or impractical to conduct.

Footnotes

1. This article is a condensation and updated version of a paper presented at the 1977 American Society of Criminology, Atlanta, Georgia. It was partially prepared under Grants 76NI-99-0133 and 76JN-99-0022 to Creighton University from the National Institute for Juvenile Justice and Delinquency Prevention, Office of Juvenile Justice and Delinquency Prevention, Law Enforcement Assistance Administration, U. S. Department of Justice. Points of view or opinions in this document are those of the authors and do not necessarily represent the official position or policies of the U. S. Department of Justice. Contact Mr. Broder for more details on the methodology and other aspects of the study described in this article.
2. For a discussion of the operational definitions of learning disabilities and juvenile delinquency employed in the study see Keilitz, Zaremba & Broder, The Link Between Learning Disabilities and Juvenile Delinquency: Some Issues and Answers 6 (Feb. 1979; article submitted for publication to the Learning Disability Quarterly). For a detailed explanation of how the operational definition of juvenile delinquency was developed see Greguras, Broder & Zimmerman, Establishing an Operational Definition of Juvenile Delinquency (1977: NCJ Report 46419).

3. The best collection of operational and theoretical analyses of the conflicts between law, ethics and society's need for knowledge is in P. Nejelski (ed.), *Social Research In Conflict With Law and Ethics* (1976).
4. See note 2.
5. 28 C.F.R. pt. 20 (1978).
6. Id. §§20.20(a), 20.21(d).
7. Id. §20.21(d).
8. Ariz. Rev. Stat. §31-221 (1976).
9. Id. §31-222.
10. Ind. Code. §31-5-7-15 (Supp. 1976).
11. Id. §11-1-1.1-61 (1973).
12. 1977 Ind. Acts Pub.L. 21.
13. Md. Ann. Code CJ §§3-828(b) (Supp. 1976).
14. Id. Art. 52A, §8.
15. 20 U.S.C.A. §1232g (Supp. 1976). The final regulations promulgated under the Statute appear at 45 C.F.R. pt 99 (1978). For analyses of the Act and its general implications for researchers, see Carter, Harris & Brown, Privacy in Education: Legal Implications for Educational Researchers, 5 J.L. & Educ. 465 (1976); Note, 61 Iowa L. Rev. 74 (1975).
16. 20 U.S.C.A. §§1232g(a)(5)(B) (Supp. 1976). Directory information "relating to a student includes the follow-

- ing: the student's name, address, telephone listing, date and place of birth, Id. §§1232g(a)(5)(A).
17. Id. §§1232g(b)(1)(F).
 18. Ariz. Rev. Stat. §15-152, 153 (1975); Md. Ann. Code Art. 76A, §3(c)(viii)(1975).
 19. For example, the Phoenix Union High School System Students Records Handbook.
 20. The regulations are applicable even if LEAA has only partially funded the study.
 21. Greguras, Information Practices in Criminal Justice Research, Review of Public Data Use, March, 1979, at 6.
 22. Peer review boards are supposed to be comprised of representatives of the entire community, not just the professional academicians. They are intended to give visibility and perspective to the difficult decisions which must be made. The boards are supposed to monitor the implementation of the approved procedures. See, N. Hershey & R. Miller, Human Experimentation and The Law (1976) which analyzes and assesses this process.
 23. 45 C.F.R. §46.103(c)(1976).
 24. It also is advisable to copy the operational-level persons on relevant correspondence whenever appropriate.
 25. For example, the Maricopa County Juvenile Court Center Volunteer Manual contains a section on the structure of the records system and the restrictions on use.

26. ETS Diagnosis Progress Report, 3 (May 16, 1977).
27. Although the textual discussion does not address this issue, we do not believe that a signature on a consent form necessarily is complete assurance that informed consent has been given. On the other hand, we believe everything reasonable has been done to make sure that consent is informed.
28. For possible measures to be utilized see, J. Gilliland, *Readability* 89-109 (1972).
29. For a more detailed analysis of the use of information transfer agreements under the LEAA regulations see Greguras, Information Practices in Criminal Justice Research, *Review of Public Data Use*, March, 1979 at 5.
30. The same authority is also obtained by informed consent for most of the subjects in the delinquent sample.
31. 5 U.S.C.A. §552a (1977).
32. See, generally, Privacy Protection Study Commission, *Personal Privacy In An Information Society*, 567-604 (1977).
33. For a summary of these proposals see *Computerworld*, April 9, 1979, at 1.
34. Id. at 573.
35. Guideline (3). Id. at 602.

36. Id. at 593.
37. Id. at 596.
38. Id. at 596-597.
39. May 3, 1977. A transcript of this testimony and the subsequent testimony referenced is available from the ASA.
40. Id.
41. January 6, 1977.
42. Id.
43. In addition to this being the ASA's position it is also the general position of the authors in Michael & Weinberger, Federal Restrictions on Educational Research: Privacy Protection Study Commission Hearings, Educ. Researchers, April, 1977, at 15.
44. Changes in relevant statutes in Arizona since the study began would have reduced the extent of cooperation which schools and the juvenile justice system could provide, were the study just beginning.
45. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was established by Congress in 1974 to develop ethical guidelines for research involving human subjects. Its mission is to make recommendations to Congress and the Department