

CLASHING DISCIPLINES: ORAL HISTORY AND THE INSTITUTIONAL REVIEW BOARD

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ABSTRACT: Archivists are finding that, often for the first time, our institutions are taking a closer look at the way we conduct research and questioning the very methods that we have used for many years. The primary body that does that inquiry is often the institutional review board (IRB). A review concept originally designed by and for the sciences, the IRB and the archivist often find themselves at odds when they first meet. This paper offers an example of how you can work with your IRB to come to an acceptable solution, satisfying the theory and practices of archival administration while remaining within the confines of the review board regulations.

In an age of increasing regulation, it has become difficult to keep up on all the current standards, whether it's the latest tax code or new practices for immigration and naturalization. This is also true in the vast field of institutional research. Archivists are finding that, often for the first time, our institutions are taking a closer look at the way we conduct research and questioning the very methods that we have used for many years. The primary body that does that inquiry is often the institutional review board (IRB). A review concept originally designed by and for the sciences, the IRB and the archivist often find themselves at odds when they first meet. It is my intent to share the experiences I had at my institution as well as those of several others, not so much as a cautionary tale, but as an example of how you can work with your IRB to come to a satisfactory solution, satisfying the theory and practices of archival administration while remaining within the confines of the review board regulations.

IRBs have been a requirement of institutions receiving federal funding for research since 1966, with a major revision implemented in 1991. The 1991 regulations, *Title 45, Part 46 of the Code of Federal Regulations, Protection of Human Subjects*, are known as the "Common Rule" or 45 CFR 46. Developed by the Department of Health and Human Services, the Common Rule is also followed by 16 other federal departments.¹ The main reason for the development of IRBs was to make sure that test subjects had given informed consent for studies or experiments and are treated ethically. This concern goes back to the Nuremberg Code of 1948, which created standards for judging the physicians and scientists who did experiments on concentration camp prisoners.² In addition to requiring a review board, the Common Rule also sets up conditions for exempt research and research that is eligible for an expedited review by one IRB member.

In her remarks before the National Bioethics Advisory Commission on April 6, 2000, Linda Shopes, former president of the Oral History Association and a member of the American Historical Association Council, stated that "the biomedical and behaviorist frameworks within which 45 CFR 46 was developed have resulted in IRBs' evaluating oral history projects according to standards and protocols not appropriate for historical research, thereby calling into question the underlying assumption of peer review."³

The first time I heard about an IRB was in early June 1999. The secretary of the Luther College faculty, who formerly served as archivist, apprised me of a resolution that had passed at the last faculty meeting of the year. Two members of the psychology department had proposed that my institution put into place a board they would call the "Human Subjects Review Board." This IRB would have jurisdiction over all research being done at the college, including the oral histories that are regularly conducted by students in our history department.

Not long after this, I heard again about the regulatory board from the history professor who supervised the oral history program. She had grave concerns about what this oversight might mean for her students' research. The proposal gave the board far-reaching authority to approve, change, or not approve any and all research involving human subjects at the college. The policy was based on several principles, including the concept of informed consent and the potential for a subject to remove him- or herself from the experiment at any time. These elements were cause for concern for both of us because they went beyond the boundaries of regulating research into the area of setting archival policy.

As I began researching these boards, I found that there were other institutions that were having difficulty explaining how their oral history program might be affected by the stringent requirements of the review board. The requirements for informed consent and for research participants to be able to remove themselves from the experiment at any time added layers of bureaucracy to the process of documenting events through the use of oral history.

Last year, a stuttering study conducted by researchers at the University of Iowa found itself on the front page of national newspapers. The study, conducted in the 1930s, used children living in a state-run orphanage to prove that negative reinforcement could cause children to stutter. While the researchers' initial theory—that children could be taught to stutter—was proven, there was never any effort after the study was concluded to correct their speech. The study was supervised by noted speech pathologist Wendell Johnson, but was never published because even then his colleagues suspected what a barbaric study it was and how it might be viewed negatively in the wake of the Nazi human studies in the concentration camps.

After the study became widely known, the University of Iowa issued an apology for the experiments and noted that the university now has strict procedures that would prevent this type of research on humans in the future. In the age of the IRB, a study like Johnson's would never have been allowed to take place.

Review boards were also in the news in June 2001 when a woman died while participating in an asthma study at Johns Hopkins University. According to university records, the study had not received full approval from the university's review board. The United States Office for Human Research Protections halted any further experiments at the

university until an outside panel could examine what had happened.⁴ The external review board faulted the university for not providing adequate oversight of the experiments. Although the researcher was at fault for using contaminated samples, the harshest criticism was for the review process that they described as “dangerously overburdened and decentralized.”⁵

Incidents like these and others in the late 1990s have led IRBs to become more vigilant in their review of research projects. Unfortunately, that vigilance has had a negative effect on a great deal of social science research, including oral histories.

The oral history community first began to confront the IRB situation in 1998. Concerned by a potential negative effect on their community, the American Historical Association, the Oral History Association, and the Organization of American Historians corresponded with approximately seven hundred IRBs. They provided the review boards with their standards of practice and asked that the standards be considered when the boards reviewed oral history projects. In addition, they persuaded the government to include oral history among those research activities that are eligible for expedited review.

Many of the concerns of the oral history community were well-founded. Review boards were often attempting to make substantive changes in research projects. They were asking researchers to submit detailed questionnaires prior to conducting any interviews. Sometimes they would ask the historian to maintain narrator anonymity on both the tape and the published work. Finally, some review boards asked that the oral history tapes either be destroyed or retained in the researcher’s private possession after the project was completed.⁶ Any of these conditions would severely hamper the continued collection of oral histories by an archival institution.

In May 2001, the American Association of University Professors (AAUP) published a report titled “Protecting Human Beings: Institutional Review Boards and Social Science Research.” The report was prepared in conjunction with the American Anthropological Association, the American Historical Association, the American Political Science Association, the American Sociological Association, the Oral History Association, and the Organization of American Historians. The report was written both for researchers and for IRBs responsible for implementing government regulations over social science research.⁷

Among the concerns of social science researchers was that their work was being judged against a model designed for science and medical research. The IRBs were originally designed to protect vulnerable human beings such as those in the Wendell Johnson study. Most research done by social scientists does not pose a threat of physical or emotional harm to those involved. Although the experiment might cause the subject some unease, embarrassment, or discomfort, these are all acceptable under the Common Rule as emotions that are “ordinarily encountered in daily life.”

Following its study, the AAUP made a number of recommendations. Their work on this issue has helped the government better understand how social scientists conduct research and how that research is different from many scientific and medical studies. The broadening of research that can be approved under the expedited review process is a successful example of this change.

The AAUP has also fought for better representation of social scientists on IRBs. This helps not only in the initial review, but also in cases that might be appealed. The AAUP also calls for better education of researchers. The associations asked that there be campus-based seminars, symposia, and opportunities for new researchers to talk with veterans of the IRB process. The report also calls for social scientists to be vigilant about their rights, to call into question when they think a review board is infringing on their rights. Finally, the AAUP recommended that IRBs consider having academic departments give preliminary approval for a project. This would help departments be more aware of the process and help them guide their researchers through the IRB process.⁸

The situation at Luther College could have been easily resolved, but several factors worked to complicate the matter. Our first problem was that the review board was not familiar with the archives program and our policies. The board was made up of faculty from the three divisions of science, social science, and humanities, a representative from the dean's office, and a member of the board of regents who was a medical doctor. None of the representatives on the board had any substantive experience with oral history. This required us to educate the board before we could request their approval for our program.

An integral element of the review board's policy is that a research subject should be able to remove him- or herself from the study at any point. While my opinion as archivist was that the oral history interviewee could stop the interview or choose not to place either the tape or transcript in the archives, our board wanted subjects to be able to remove their interviews from our collection at any point in the future.

That option was unacceptable to me. It was essentially requiring that we put all oral histories on deposit in perpetuity. Without clear-cut rights to the interviews, I stated that we would not accept them and it would ultimately end what had been a successful research tool for the archives. If we said that oral histories could be removed, despite having a deed of gift, then what would stop anyone from retrieving material they had given to the archives at any point in the future?

I went to the hearing with the history faculty member who had been instrumental in our oral history program. Among the questions we faced was that of a student who might participate in an interview, only to ultimately have a career in politics. The board wanted to know why we would not remove an interview that could be potentially embarrassing. I informed the board that we could place restrictions on an interview before it was placed in the collection, but it was not standard archival practice to have a policy of adding restrictions later or allowing for materials to be removed from the collection after a deed of gift had been signed.

In preparation for our hearing, I did some research into what other institutions had done about working with their IRB. Queries to the archives and oral history Listservs garnered assistance from Professor Charles Lee, the executive director of the Oral History Program at the University of Wisconsin-La Crosse. Professor Lee provided us with a copy of his informed consent document. During the course of the hearing, we offered to draft our own consent document for use in addition to our customary release forms.

This document seemed to answer the questions of the board and there was no further discussion about removal of archival property from the collection. Further, the board

stated that for similar classroom projects a brief notification to the board was all that would be necessary for their continuing approval. If a student were going to do a full-scale project such as for a senior paper, then the student would be required to submit a presentation for approval before the board.

I felt that the determination of the board was very fair. It did not encroach on the ownership issue in the archival collection and also did not put up an unnecessary impediment to continued oral history research. I think it was important for a student doing significant research (i.e., the senior paper required for each of our students) to go through the full process. If our students go on to do graduate-level research, they will benefit from having already experienced the process.

One shortcoming of the review boards' increased vigilance is their lack of visibility. Not only was I not apprised of our board before it was instituted, but I learned of other administrative offices that were not aware that they now fell under the jurisdiction of the board. The review board needed to do a better job of educating the college on the extent and goal of their role in college-related research.

An article in the *Chronicle of Higher Education*, "The Wrong Rules for Social Science?" focused again on the IRBs' call to keep the names of their interview subjects anonymous or to destroy the tapes after they have been transcribed. In addition to the request to screen questions beforehand, some IRBs have encouraged researchers to not ask questions that might embarrass the subject.⁹

The federal regulations do not call for these measures. Instead, these measures are developed by the boards themselves. Under the expedited procedure, a researcher can have a project approved by just one member of the board, but often that member will insert untenable restrictions on the project. This extends the amount of time that it takes to begin what are often already lengthy projects.

According to the *Chronicle of Higher Education* article, many social scientists are not submitting their projects to the boards. This is sometimes a deliberate action by researchers who believe the regulation is a violation of academic freedom and First Amendment rights, but it is also sometimes the result of ignorance of the regulations.

At Indiana University, Dr. Carole Nowicke consulted the IRB for permission to conduct a Tuba-Euphonium Oral History Project. The IRB would not accept the oral history consent form that had been used by the university's Center for the Study of History and Memory. After rewriting the form five times, the consent form is now four pages long and requires participants to sign or initial the material in nine places. In a meeting with the IRB, the question of whether or not participants could remain anonymous came up.¹⁰ Anonymity is common in scientific research, but nearly impossible in oral history where much of the meaning of the interview is incumbent upon knowing the identity of the person and his or her context in history.

At Western Kentucky University, Dr. Erika Brady took a proactive role. The IRB became interested in the work she was doing in folklore and requested a review of her research. She reacted by having herself appointed to the board. Having someone familiar with humanities research was essential to the board's understanding of how humanities research differs from the sciences. She also surveyed other programs and found out how they had worked with their IRB. Finally, she reviewed the release form her program used and revised it to conform more closely to the requirements of the IRB.¹¹ By

being proactive, one can demonstrate one's willingness to work with the IRB to come to a mutually agreeable solution.

At Luther College, the one regulation our board added to our proposal concerned the informed consent document. This was a cause of concern for the member of the history department. Our procedures already call for us to talk with the person being interviewed about signing over the interview rights to the archives. Now, in addition, we have a page-long document that makes sure subjects are giving their informed consent. It is similar to a document an individual might read and sign before participating in a psychology experiment. The document reads as follows:

I give my informed consent to be interviewed about my life experience.
I consent to publication of this interview, and other legal uses, as limited
by the policies of the Luther College Archives.

1. I have been informed that the general purpose of this interview is to document my personal history.
2. I have been informed that there are no known expected discomforts or risks involved in my participation in this interview.
3. I have been informed that there are no "disguised" procedures in this interview. All procedures can be taken at face value.
4. I have been informed that the interviewer will gladly answer any questions regarding the procedures of this interview.
5. I have been informed that I am free to withdraw from the interview at any time without penalty of any kind.

Archivists' concern with such documents is not uncommon. Mary Larson, assistant director of the Oral History Program at the University of Nevada at Reno, said that "the formal tone of documents can put off some people, especially those lacking education or language skills."¹² At Luther College, we tend to work with older people in town, and the consent form could potentially be confusing and unnecessarily frightening to them.

In its report to President Bush, the National Bioethics Advisory Commission addressed the issue of informed consent. In its final report issued in August 2001, the commission stated that it was important that the informed consent process match the research being proposed. The informed consent process should be neither a conversation between the researcher and the subject nor simply a form to be filled out. The National Bioethics Advisory Commission also recognized that a signed consent form could be problematic for some types of research, including social science research. They agreed that the basic process of informed consent needed to take place, but that it was possible for an IRB to agree to a documentation format other than signed consent forms.

Ultimately, the IRB process has had some positive and negative effects on our oral history program. According to the head of Luther College's IRB, the decision to approve the oral history program in its expedited form was largely based on reading the policies and procedures of the Oral History Association and recognizing that they were similar to the policies of the IRB.

The Luther College IRB document calls for the principal investigator to explain to the subjects, prior to their participation, the objectives of the research, the procedures

to be followed, and the potential risks and benefits. The Oral History Association requires that interviewees be informed of the purposes and procedures of oral history in general and of the aims and anticipated uses of the particular projects to which they are making their contributions. The IRB regulations state that the investigator should respect the privacy of subjects. They should protect confidential information provided, advising subjects in advance of any limits upon their ability to ensure that the information would remain confidential. In regard to confidentiality, the Oral History Association states that interviewees should be informed that they would be asked to sign a legal release. The interviews would remain confidential until interviewees had given their permission for their use. The interviewer also has the responsibility of apprising interviewees of their rights to edit the interview, restrict access, retain copyright, and to know of the expected disposition and dissemination of all forms of the interview, including electronic distribution.

Additionally, the policies and procedures of the Oral History Association call for interviewers to be sensitive to their interviewee to guard against exploitation. They should apprise interviewees of their right to not answer any questions that make them uncomfortable and, if they wish, to remain anonymous after the interview. All of these policies dovetail with the regulations of the IRB.

These examples of difficult negotiations with IRBs are not rare. More stories have begun to appear in publications, such as the article "Don't Talk to the Humans: The Crackdown on Social Science Research," which appeared in the September 2000 issue of *Lingua Franca*. Christopher Shea's article included numerous examples of researchers who had struggled to adjust their research style to the requirements of the IRB. On Listservs, this topic continues to be discussed every few months as colleagues share their "war stories."

But the solution does not lie in railing against the IRBs, but rather in learning to work with them. The work of the Oral History Association provides a strong foundation for archivists and historical researchers to make their claim that their methods are in line with the basic requirements of 45 CFR 46. Follow the example of Dr. Erika Brady at Western Kentucky University: join the IRB, if possible. If you cannot do that, work with the members to understand the elements of your research. Go prepared when you meet with the board and show them forms that other IRBs have accepted as examples. Provide them with the Oral History Association's guidelines. This kind of preparatory work can assist in a more positive interaction with the IRB.

Of course, it is still possible that the IRB will put undue requirements on your project, as the board did at Indiana University. In that case, it is important to work to maintain your project and hope that, in the future, the situation can be renegotiated with the IRB.

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NOTES

1. The National Endowment for the Humanities is not one of the 17 participating agencies.
2. American Association of University Professors, "Protecting Human Beings: Institutional Review Boards and Social Science Research," *Academe* (May-June 2001): 56.
3. Linda Shopes, "Institutional Review Boards Have a Chilling Effect on Oral History," *Perspectives Online*, September 2000, <<http://www.theaha.org/perspectives/issues/2000/0009/0009vie1.cfm>> (September 9, 2002).
4. Susan Levine and Rick Weiss, "Hopkins Told to Halt Trials Funded by U.S.," *Washington Post*, July 20, 2001, sec. A, p. 1.
5. Amy Argetsinger, "Panel Blames Hopkins in Research Death," *Washington Post*, August 30, 2001, sec. B, p. 3.
6. American Association of University Professors, 57.
7. American Association of University Professors, 55.
8. American Association of University Professors, 67.
9. Jeffrey Brainard, "The Wrong Rules for Social Science?" *Chronicle of Higher Education*, March 9, 2001, p. A21.
10. Carole Nowicke, "Institutional Review Boards," October 1, 2002. E-mail to the author.
11. Kelly Feltault, "Institutional Review Boards," June 29, 1999, h-oralhist discussion list on-line posting, <<http://h-net.msu.edu/cgi-bin/logbrowse.pl?trx=vs&list=h-oralhist&month=9906&week=e&msg=S4BvbgGt%2bIprs0qWsU1zyw&user=&pw=>>> (September 19, 2002).
12. Brainard, A21.