

## **Toward a Natural History of Ethical Censorship**

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**A**cting under a mandate to protect human subjects of research, institutional review boards (IRBs) have become nationwide instruments for implementing censorship. As censors, IRBs constitute an historical novelty in the United States. In the past censorship has been administered as the overt policy of centralized agencies. Examples include the use of government criminal prosecution offices to ban books as obscene and the Hays Commission, Hollywood's all-encompassing, "self-policing" funnel for pre-screening and forcing the editing of movies. Previous forms of censorship were not always shy to declare their purpose. While stimulating many subtle processes of repression in work organizations, Cold War politicians histrionically demanded repression of subversive professors, journalists, and entertainment writers, providing clear political targets for opposition. By contrast, the IRB censorship role has operated behind multiple masks: the institution's inspiring ethical mandate, which itself emerged as a way retrospectively to oppose infamous examples of brutish, overbearing state power; the confidentiality that surrounds IRB administrative proceedings, which exists without explicit rationale but may be justified as a beneficent precaution to protect researchers from the humiliation of public rejection when proposals are found wanting; and the operationalization of repressive power in a form especially difficult to map, namely through the highly differentiated, vast social geography of higher education.

Advocates and critics of IRB power often debate the interest of avoiding harm to research subjects against the value of protecting freedom for critical inquiry and expression. But if IRB censorship operates in relatively hidden ways, a research program will be required to ground any compelling conclusions. How to structure that research is not obvious. Malcolm Feeley wisely counsels that

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we make use of the convergence of research traditions that led to legality studies.

Before directing his work toward illuminating legality as a morality for the exercise of power, Selznick had developed a series of organization studies, kicked off by Michels' finding of the systematic emergence of hierarchical domination emerging in the administration of socialist parties (Selznick 1949). When social research began to focus specifically on issues of legality, the investigative domain was, most consistently, social relations at work: in labor relations (Selznick et al. 1980); in the exercise of police discretion (Skolnick 1966; Bittner 1967); in the everyday routines of court administration (Feeley 1979). Investigators studied people at work in order to see through the vagaries and isolate the systematic ironies that frustrate the achievement of legality in the practicalities of governance.

At about the same time, legal academics were discovering a series of injunctions implicit in the morality of law (Hart 1961; Fuller 1969; Davis 1969). Three will be indispensable for understanding how IRBs have institutionalized the power to censor.

1. No law (or regulation) can be morally defended if it demands the impossible.
2. Laws should be floated for public discussion by those likely to be affected.
3. As they review and adjudicate individual cases, administrators should make themselves reviewable. Minimally, officials should make records of what they have considered and decided so that they can take distance from themselves in reviews conducted at a later date. Maximally, they should articulate reasons that can be reviewed publicly.

Research following in the footsteps of legality studies would describe three courses of organizational history. How have IRB rules and procedures changed in what is now a 30-year history? How has the evolution of IRBs been shaped by the changing environment of higher education as a social institution? How has the history of social research been shaped by the impact of IRB power? With a broad appreciation of these ongoing transformations, we will be better prepared to define key value questions about the exercise of IRB powers.

## **The Evolution of IRBs**

Junior scholars are framing contemporary ethnographies of IRBs within an historical perspective on the movement to protect

research subjects (Stark 2006). Debates over original intention are central to current arguments about extensions of IRB jurisdiction, for example, whether to cover oral history within the meaning of “research” (Institutional Review Blog 2007). But however one reads foundational documents, such as the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979), or the underlying federal regulations (45 CFR 46), the historical record is clear that the IRB interpretation of regulatory requirements has changed in practice.

The thrust has been overwhelmingly expansive. Across the nation’s campuses, IRB regulation has progressively come to govern the softer social sciences, legal academic studies, journalism, history, and large stretches of the humanities, including, on some campuses, creative writing and the visual arts. Countervailing instances of jurisdictional contraction are rare.

Likewise, procedural changes that geometrically increased IRBs’ effective powers have been institutionalized. For years, the exemption clauses (45 CFR 46.101 (b)) were treated on all campuses as presumptively excluding a wide swath of unfunded social science and virtually all research in the humanities from any contact with IRBs. Procedural immunity from IRB oversight was progressively effaced and then decisively abolished around 2000, as campuses came to reflect a view communicated by federal human subjects administrators that “self-exemption” was contaminated by conflicts of interest (Plattner 2003). Whatever the original intention (for exceptionally clear evidence that “self-exemption” was anticipated, see McCarthy 1984), it was only after many years of practice that IRBs began to require certification for “exempt” research on a case-by-case basis.

In the late 1990s, disasters in biomedical research provoked federal human subjects protection officials, who had become increasingly dubious that campuses were rigorously implementing oversight in biomedical research. A national panic ensued among research administrations; university leadership feared that a cutoff of all research funding might be on the horizon. Although the procedural problems were lodged on the hard science side of campuses, and even though no new harms had emerged in social science research to galvanize regulators’ concerns, the campus research community as a whole was mobilized to dramatize moral sensibility. The straightforward language of the exemption clauses, which leaves research outside of IRB review if information is recorded anonymously or if there is no reasonable expectation that the study will place subjects at risk, was erased in the flurry of administrative efforts to manifest care for the putative interests of research subjects in general.

## **IRBs in the Evolution of Higher Education**

IRBs have radically reconfigured structures of privacy and transparency in colleges and universities. On the one hand, they have created new areas of closely held, intimate knowledge within IRBs about faculty and students. On the other hand, IRBs have operated through processes closed from outside oversight. On many campuses, even at a public university such as UCLA, the membership of the IRB is kept confidential; administrators have resisted requests that they put the names of committee members on the university's Web site. Research proposals are handled discreetly; communications between the IRB and the researcher are shielded from public view, and not because researchers insist on confidentiality or claim that property interests in research designs require that outsiders not see what they are up to before they publish.

Faculty on IRBs typically serve for a short time, commonly two or three years. They enter committee roles with no preparation or any career interest in having their performance publicly criticized. Confidentiality facilitates the recruitment of faculty to volunteer for membership on IRBs by insulating them, as well as the research administrators they serve, from review, much more clearly than confidentiality serves to protect researchers, much less subjects, who, at the proposal stage, usually are not yet identified.

Commentators have remarked on the tendency of IRBs to correct formal imperfections in applications and statements of protocol. This pattern indicates the widespread experience among IRB members of professional as opposed to ethical discomfort with the proposals they review. In his presidential address, Malcolm Feeley recalls a conversation with

the faculty chair of the IRB at a well-known university [who] informed me that if a research project is, by her lights, poorly designed, any amount of risk—even the harm associated with wasting a subject's time—is too great. Her campus's IRB had rejected, and would continue to reject, applications because of unsound methodology (Feeley 2007:175–82).

Because ways of perceiving quality are understood to vary greatly by professional specialization, opportunities to evaluate work across departments and disciplines have become severely restricted. On Ph.D. committees, and in promotion cases, faculty review faculty in methodologically and substantively distant departments, but then the file consists of mentor-protected and relatively polished products. IRBs override internal school boundaries as they subject faculty and students to compulsory and fateful pre-publication review, often at a relatively raw, formative stage. The upshot is a steady generation of professional dismay among

reviewers, which has created a significant source of motivation for expanding IRB oversight independent of issues concerning likely effects on research subjects.

Considering that a research university is unique in its commitment to evolve ways of interacting with the world that will advance knowledge, the burden that has been placed on IRBs is unparalleled. After decades in which the university, in part in recognition of the differentiation of methodological competencies, has become progressively differentiated internally in professional recruitment and review procedures, IRBs have created a reverse thrust. A relatively miniscule set of faculty, not selected to provide general intellectual leadership to the campus as a whole, exercises oversight over what are literally the most varied ways of conducting research imaginable. Operating behind closed doors, IRBs are profoundly shaping the nature of the university, repressing some lines of inquiry and encouraging others on grounds that reach far beyond perceived, much less demonstrated, consequences for research subjects.

## **IRB Censorship and the History of Critical Social Research**

Malcolm Feeley describes a series of research projects that are potentially controversial for their substantive findings and appear to be incompatible with IRB rules. Indications of IRB censorship have been available for at least 20 years. Psychologists documented censorship by submitting proposals to IRBs that were identical in all but the political significance of the propositions they tested (Ceci et al. 1985). Following up a session at a national conference of ethnographers at UCLA in May 2002, I have been gathering cases that show that IRB censorship has moved beyond the hypothetical.

At first glance, a portrait of IRB censorship displays a colorful national quilt of parochialism, diverse and frequently petty in the interests served, almost charming in the honoring of America's rich intolerances, regionally varying partisan biases, and wild fears.

- In Utah, Brigham Young University's IRB blocked an inquiry into the attitudes of homosexual Mormons on their church. When the same anonymous questionnaire study design was transferred to another researcher, the IRB at Idaho State University found the study unproblematic (Ballard 2003).
- Three Ohio State University professors, alleging IRB violations, pressed their administration to block a student's dissertation degree, in an effort to discredit his advocacy, in public testimony before the Kansas Board of Education, of "creation science" (Hall 2005).

- At one university, an IRB opposed a proposal by a female black researcher to limit her study to female black prison inmates, finding the racial limit unjustifiable, although not objecting to the gender limitation (Hamilton 2003). At another university, an IRB limited a white researcher to interviewing white subjects, finding that the topic—career aspirations—could be too upsetting to black subjects (Sieber et al. 2002).

Any “hot button” issue may tempt opponents of a study’s substantive arguments to reach for the IRB as a tool of repression. The targets of critical studies, as distinct from the subjects contacted in gathering data, have increasingly appreciated the leverage value of IRB regulatory authority. When he was chair of the psychology department at Northwestern University, Michael Bailey was attacked by transsexual professors at other universities who were outraged at his argument, in a popular-readership-oriented book, that some candidates for male-to-female sex change operations are aroused sexually by the idea of being a woman (Dreger, forthcoming).

While substantive research objectives alone may motivate opponents to invoke IRBs to order to intimidate would-be researchers and discredit finished research, certain mainstay methodologies of the American tradition of critical social research are especially vulnerable to third-party efforts at repression. Muckraking and advocacy research, whether done with the formal elegance of a quasi-experimental design, in the classic tradition of a white paper mapping general patterns of abuse, or as a case-focused exposé geared to generate news that will lead to remedial action, is under fire on a national scale.

“Auditing” studies have been a powerful methodology for linking academic research and the civil rights movement. (For an example from the early days of the law and society movement, see Schwartz & Skolnick 1962.) Pager’s celebrated quasi-experimental research program demonstrating criminal record/racial discrimination in employment (Pager 2003) was targeted by a political appointee in a temporary position, who, in line with a Republican administration policy opposing proactive investigation by the Equal Employment Opportunity Commission (EEOC), overturned her previously approved National Institute of Justice (NIJ) grant on the explicit rationale that the government should not pay for deception in research. Later, after the temporary appointee had left NIJ, the overturning was overturned. But the forces of repression remain strong, and they are not monopolized by partisan political operatives. Pager, a Princeton professor, learned that a study similar to hers was blocked by an IRB at another East Coast university.

IRB leaders often state that, whatever happens at less-autonomous institutions, they will resist political pressures. At UCLA, an IRB chair mentioned to me that a proposed study of university admissions practices had been blocked by an IRB at a Cal State campus. The study had the potential to reveal illegal behavior, namely affirmative action, which was prohibited when Proposition 209 became California law. It could not happen here, the chair assured. After I gave a talk at the UC-Berkeley law school, the IRB chair responded to the example of the Brigham Young case reassuringly: such repression could not happen in the context of the Bay Area's notoriously progressive attitudes toward traditionally stigmatized sexual identities.

IRBs sometimes produce censorship along the pattern practiced by local newspapers, which favor one party in this region of the country, another elsewhere; likewise, in value statements that nod to local community values, university research administrations sometimes recall obscenity doctrine. But there is an inherent conflict between the protective ethos in IRB culture and the thrust of many auditing and muckraking studies, which is to damage subjects, if not as named individuals or companies, then as representatives of a type of abhorrent social practice. IRBs duck direct acknowledgment of the adversarial nature of such research when they insist that researchers inform subjects of the nature of their research objectives, a requirement that often kills the feasibility of the study. In fact, the repression of auditing and muckraking studies is not limited to inconsistencies with the values of the local community.

At UCLA, a labor institute developed a white paper lamenting the health benefits that Indian casinos offered their (largely Mexican and Filipino) workers. Despite the university's support for the labor institute when anti-union legislators at the state capitol have sought to eliminate its funding, publication was banned by the IRB after a complaint by an advocate for Indian tribes that the study had not gone through IRB review (Britton 2003; Sahagun 2003). Across the bay from UC-Berkeley, critical social research projects aimed at protecting gay men and poverty minority youth have been successfully repressed. William Woods had conducted a series of studies into HIV prevention (Binson et al. 2001), but the UC-San Francisco IRB recently blocked a well-funded study that would have examined, among other things, compliance by bathhouses with public health regulations. Although the critical aspect of the protocol Woods proposed was a noninteractive inspection, essentially entering and observing what type of HIV prevention was done at the bathhouses, the IRB severely compromised the study by insisting that he describe the study's objectives and seek verbal consent from bathhouse managers. Also at UC-San Francisco, Ruth

Malone was blocked when, as part of a community participatory study, she and community co-investigators proposed a study of retailers to determine the prevalence of illegal single-stick cigarette sales in a low-income, predominantly minority neighborhood. Although Malone had secured written commitments from prosecutors not to prosecute law violators, the IRB, after consulting with university “risk management” and legal counsel, blocked the study on the stated grounds that it would be unethical for the researchers to provide the occasion in which store clerks might break the law (Malone et al. 2006).

These cases reveal the multiple conflicts of interest that push IRBs into a censorship role. Independent of the interests of subjects, the IRB serves various third-party interests in suppressing troublesome research results. The vulnerabilities IRBs protect against often do not pertain to the adjudicated delinquents studied but to those responsible for their supervision. IRBs protect bathhouse managers and retail cigarette sellers, not as individuals but as members of business groups whose profits might be hurt by an advocacy study. An auditing study would bring no harm to the anonymous employers who might be found discriminating by race, but the EEOC would be shown deficient in its responsibilities.

Determining the extent to which IRBs are effectively censoring research, particularly critical social research, will never be worked out precisely. The difficulties are not only in developing a national picture from isolated cases on dispersed campuses but estimating the iceberg of suppressed research plans from the tips, which themselves surface only through occasional public access to the routinely obscured workings of IRB power. Even more hidden in the repressive shadows of IRB power are the plans for original field research that are dropped in favor of proposals to study data sets already gathered and approved. Buried in the deepest regions of the university’s social life is the lost imagination that accumulates geometrically as intimidated researchers fail to become models inspiring subsequent generations of students. It is now a commonplace that graduate students confess amazement when reading sociological ethnographies that they presume could not now be undertaken because of IRB obstacles.

Higher education has grown over the last 50 years into a massive national institution, drawing in and socializing the population most likely to develop and articulate critical perspectives on public and private power. Over the last 30 years, IRBs have evolved to compromise the research freedoms taken for granted by the first academic social researchers in the Progressive Era. Participant-observation studies that ranged over hobohemia and through taxi dance halls, that mapped out the social geography of vice operations and the spontaneous formation of gang-like youth cultures



in 1920s Chicago neighborhoods, are now routinely in violation of ethical rules because, no matter the good faith efforts to comply on the part of investigators, they cannot meet IRB prior review requirements in a meaningful way. Auditing studies, a research tool for revealing invidious discrimination that was unhindered by administrative restraint when the law-and-society movement began, is at risk of repression. Even public government sites and records, the access to which is guaranteed by statutes designed to enlist the general population in overseeing civic operations, may no longer be presumed to be accessible to researchers due to the novel constraints that IRBs read into human subjects protection regulations. The impact of IRBs on critical social research must be appreciated not only as hindering some academic careers but as a significant turning point in American political history toward the repression of progressive inquiry and expression.

### **The Legality Remedy**

Understood pragmatically, legality changes the interaction environment of decisionmaking by creating a series of processes in which the reviewed become capable of examining and publicly criticizing the review to which they are subjected, both on a retail, case-by-case basis, and on a wholesale, policymaking level. As a baseline commitment, legality in the operation of IRBs would prohibit policies with which researchers cannot practically comply. When ethnographic field research and open-ended interview projects are subject to IRB review, researchers can promise as a matter of formality to adhere to the research roles suggested by their preconceptions of the field, but IRB-certified research designs will predictably become inadequate. As researchers in the field learn about their subjects' vulnerabilities, as a practical matter exigencies in the field will commonly preclude return to the IRB for another stage of review. For example, researchers planning to interview presumed terrorists may on paper guarantee anonymity, but even when the researcher and the IRB attempt to anticipate risks to researcher and subject, they cannot reasonably anticipate how fieldwork interaction will develop, which third parties may be overseeing and communicating locally about the research, and what contingencies will set off recriminatory attacks (Jacobs 2007). IRBs can effectively guard against such risks only by becoming ongoing, in-the-field research partners, in which case their interests would become conflicted and their approvals would become prohibited "self-exemptions." If IRBs wish to prohibit such research because of inherently unpredictable risks to subjects and researchers, legality would require that they do so openly, rather

than in the half-approving, half-restricting manner of current operations. By prohibiting commands of the impossible, legality would require IRBs openly to embrace or abandon their censorship power.

Legality would require that IRBs publicly disseminate proposed rules before they take the force of law. Currently campus researchers are unaware of the choices that IRBs make in policy interpretation, much less of any reasoning that may be behind the choices. For example, campus researchers have not been invited to consider whether their school should opt in or out of the obligation to use the IRB to supervise unfunded research (Shweder 2006). It is likely that much of what passes for reflection behind important IRB policymaking could not withstand informed public review. Consider the profundity and care that currently is shaping official thinking about whether oral history should properly be included within the federal regulations' conception of "research." An IRB consultant revealed the crude application of a biomedical analogy when he reported that

Dr. [Michael] Carome finally clarified OHRP's [Office for Human Research Protections] position on oral history. As many of you know, in 2003 Dr. Carome wrote a letter stating that OHRP concurred with the position that oral history activities in general do not involve research as defined by the HHS regulations. Many oral historians took that to say that oral history was excluded from IRB review, including the Oral History Association. In his presentation at PRIM&R [Public Responsibility in Medicine and Research] Dr. Carome clarified that this was meant in the same sense that drawing blood "in general" was not research (Cohen 2006).

Legality would also require that applications and IRB decisions be made matters of public record, at least when the researchers do not seek confidentiality and there is no reasonable basis for concern about harming subjects by revealing research proposals. Currently, some campuses do and some do not provide models and decision-trees to guide applicants. But opening the files to show the applications and IRB responses would inaugurate far-reaching changes in the interaction environment of IRB power. One result would be to create a stream of models useful to subsequent applicants. Over time, publication of what IRBs are doing would generate pressure to eliminate or justify apparent inconsistency, which sometimes is the result of current IRB membership's ignorance of prior members' considerations. Opening administrative decisionmaking to public review would enable a highly motivated regulated community to improve and institutionalize the decision maker's memory.

The upshot of making the reviewers reviewable would be an ongoing communal discussion of the critical policy issues that for

more than 20 years now have been finessed in the miasma of discretion surrounding IRB decisionmaking. Colleges and universities claim that they need to retain discretion in IRB processes in order to evolve an ethical culture to fit the unique character of the school. Opening IRB files would make that facile promise an everyday working reality.

At least three critical issues would no longer be neglected. First, there is virtually no probing reflection in IRB culture on alternatives to prior restraint as a means of controlling the ethical qualities of research. (For an exception, which holds that exploratory “research must be submitted to the IRB for retroactive review if/when the investigator anticipates or decides to disclose the data and/or results, or to submit them for publication—unless IRB review is still not required on other grounds,” see University of Pennsylvania 2002:8.) U.S. courts have been especially wary of prior restraints, or “licensing,” as a danger to First Amendment freedoms. Laws setting up penalties for fraud, defamation, and violations of intellectual and reputation property rights are post hoc alternatives that have long served to protect the subjects of journalism, entertainment media coverage, academic research, and general audience prose. There is no historical evidence that the social science and humanistic research now pre-reviewed by IRBs ever harmed subjects significantly, much less in ways that could not be redressed through post hoc remedies. The optional decision to push all ethical review of social science and humanistic research through a prior review sieve is not only massively inefficient, it is also counterproductive where risks are most serious. Because researchers who interact intimately with their subjects in the field cannot anticipate risks accurately, the only effective ethical review must come after the research act. The current optional decision to subject all “research” with human subjects to prior review creates a series of transparent pretenses and deprives the academic community of the opportunity to confront ethical challenges in detail, functionally weakening the culture of ethics in higher education.

Second, legality would narrow, if not eliminate, the current IRB practice of issuing discretionary interpretations of critical substantive provisions without the benefit of commentary from the researchers who know what different policy options will mean in practice. A pressing current need is to develop a well-reasoned definition of “research,” which is defined in the federal regulations as “a systematic investigation designed to develop or contribute to generalizable knowledge.” Is “design” best understood as a matter of researcher intent or as a formal matter represented by sampling or experimental design, formal questionnaire, and a specified protocol for presenting provocations to subjects? Perhaps universities

should clarify a warrant for regulatory jurisdiction that incorporates but reaches beyond “research,” however defined. Given that schools can opt out of applying the regulatory framework to non-funded research, it is not clear why ethical considerations would limit locally devised review mechanisms to research aiming for generalizable knowledge. From the standpoint of the subjects who might be harmed, a literary essay, a poem, or a photography display in the university art museum can breach confidentiality and cause economic and emotional harm as readily as can research that would claim the mantle of science. Again, the maintenance of discretionary privilege by IRBs undermines the potential to evolve the ethical culture influencing campus research.

Finally, legality would promote recognition of the inherent conflict between critical social research and protection for research subjects. Outside of biomedicine, the meaning and measurement of “harm” to subjects invites political manipulation. Perhaps particularly in ethnographies, but more generally in social research, subjects may object that they were deceived and their interests harmed even when they remain unidentifiable individually but are implicated in the class of people addressed in a study’s findings (Emerson & Pollner 1991; Bosk 2001). For more than a century, social research has made a place in the American cultural landscape by targeting people seen by researchers as abusing power and privilege. There is an unavoidable tension between the current culture of research ethics and the political wisdom of the First Amendment, whether understood as a matter of constitutional law (Hamburger 2005) or as an historical tradition establishing a role for advocacy research in American civil society.

Administrative discretion in the workings of IRBs has enabled censorship to emerge under the cover of a culture of research ethics. Discontent and criticism of IRB power appears to be increasing in blogs, academic journals (e.g., a recent issue of the *American Ethnologist*, a forthcoming issue of *Northwestern University Law Review*), and white papers by academic task forces (e.g., Gunsalus et al. 2003; Citro et al. 2003; AAUP 2006). However compelling the criticism, there appears to be no current mechanism by which the reflections of the research community can gain traction on the evolution of IRBs. The sociological genius of legality is in altering the interaction field around decisionmaking. Were IRBs to recognize formally that they cannot properly demand the impossible, were they to invite public discussion of policy alternatives, and were they to open their files to public oversight, they would fundamentally alter the trajectory of institutional development by forcing confrontation with the central value choices currently ignored in the evolution of ethical research culture.

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