



Silenced for Their Own Protection: How the IRB Marginalizes those it Feigns to Protect

Matt Bradley¹

Honor College, University of Utah, Utah USA

Email: mnb1@utah.edu

Abstract

This paper provides a critique of the way IRBs can maintain the marginalization of ‘vulnerable’ populations through an insistence on anonymity that can run counter to a group’s desire to choose how to represent themselves. I explore the relationship between anonymity and risks and benefits in a discussion of my own experience negotiating with an IRB over a proposed participatory action research project that involved youth in the production of a documentary video.

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I made my way to the department main office and anxiously checked my mailbox. I knew that the Campus Committee for the Protection of Human Subjects (also commonly known as an Institutional Review Board or IRB) had met earlier in the week and I was eager to see if they had approved my research proposal to work with a group of young men—most of whom were African-American—to create a video documentary through which they would share their perspectives about home, neighborhood, and community. Sure enough an envelope addressed to me from the IRB was waiting in my box. I quickly opened the envelope, took out the letter, and nervously started to read.

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Over the past year I had met with numerous staff of the IRB office, including the chair of the committee, multiple times, to seek assistance in completing and submitting my application for IRB approval. I had also met with other faculty from the university's Criminal Justice Department and School of Journalism, at the recommendation of the IRB chair, to seek their assistance and advice. I had already submitted my proposal to the IRB and been rejected once. I had made numerous changes and concessions to the IRB, but had also stood my ground on a few points of disagreement and submitted a memo, again at the suggestion of the IRB chair, explaining why I chose not to adapt some of the requirements the IRB imposed on my research.

I skimmed the letter anxious to find out if they had approved my research after this considerable work and negotiation. My heart dropped. 'The Committee continues to feel that you do not appreciate the level of risk to the subjects, their parents, and others who are a part of the video. . . . At this point we do not feel that the value of the benefits you have stated are high enough to outweigh the potential risks to the subjects. Your plan for the subjects to paint a portrait of their community suggest potential problems not addressed. We feel that there is risk that people in the community might be upset about the portrait that has been painted.'

This was the culmination of a laborious, frustrating, and time-consuming experience negotiating the ethics of participatory action research (PAR) with a committee that consisted primarily of lawyers and medical researchers who had very little experience with qualitative research, let alone PAR. Theoretically, IRB requirements and processes should protect people who are the subjects of research from being taken advantage of or abused by researchers, but in some cases IRBs serve to reinforce hierarchical power structures and modes of knowledge production that run counter to the goals of participatory/action research.

My exchange with the IRB committee reveals paternalistic attitudes and perceptions about so-called 'vulnerable' or 'at-risk' groups held by those in institutions who possess the power to direct research agendas, methodologies, and outcomes. The significance of this control is addressed by Wahneema Lubiano's (1996, 74) observation that:

Over the past 250 years, university scholars have created and legitimated the knowledge that has justified the particular oppression [of Black men and women]. University scholars have provided the necessary cultural justifications for the movement of capital and for state imperatives and policies. University scholars have provided fodder for the cultural narratives that tell the stories of Black people. The university generates and disseminates the metaphors and narratives that thoroughly imagine our world. Those metaphors and

those narratives are the very stuff of our educational system, our media representations, our state policy, our individual lives. Black pathology is a thoroughgoing and useful academic production for the state.

By controlling the models of research, who gets to speak and how subjects get to represent themselves, IRBs are in a powerful position as part of the institutional structure. In this position they can, and often do, silence the voices of the marginalized and perpetuate an academic political economy and a traditional top-down research and professional model that quantify and objectify human lives by keeping them nameless, faceless, and voiceless.

The Project: Documentary Film Production as PAR

As part of my work for my Masters degree I sought to create a collaborative documentary with a group of young men with whom I had been working that would explore their ideas about home, community, and neighborhood. We were creating this documentary within the context of a larger community project (which I will refer to as 'Visions') that was exploring the same questions through a lecture series, panel discussions, radio programs, and other similar activities.

The young men with whom I was working were all from working-class families and most of them were black. Many of them identified with a clique of a Chicago-based gang. Through the narratives they shared with me they often identified as outsiders in the predominantly white community in which we lived, and in opposition to police and other authorities. We engaged in the video-documentary project as a way for them to present their voices to the larger community conversation about home, neighborhood, and community. On my first IRB application for the documentary project I explained that the purpose of the documentary would be to allow 'at-risk' youth the opportunity to explore, discuss, and document their perceptions of home, community, and neighborhood and add to the larger community discussion of those ideas. I wrote, 'the principal investigator will facilitate and aid the filming of a 48-minute documentary that will present the perceptions and experiences of the youth in relation to the concepts of home, neighborhood, and community. The youth will have the primary responsibility for deciding what they want to portray, and how they choose to portray it.'

The Challenges

I faced a number of challenges obtaining approval from the IRB on various levels. First and foremost, the IRB at my university had no experience with many of the ethical or methodological issues I was presenting. Likewise, the faculty in

my department, despite that most of them were qualitative researchers, likewise had little experience negotiating the IRB process. They were often as much at a loss at the IRB's responses to my proposals as I was. I submitted my research proposals to the IRB during the 1998-99 academic year, a time when universities that received federal funding were beginning to take the IRB process very seriously, but the different approaches, methods, challenges and ethical issues of qualitative and action research had not yet been fully encountered by the IRB at my university.

As I met with IRB staff to seek assistance preparing my proposal they told me numerous times that they had never encountered research like mine. They often didn't have answers or know how to advise me because they had simply never dealt with research that involved the 'subjects' as co-researchers who were responsible for the design and implementation of the video project rather than just informants. They also did not know how to address the proposal to create a video documentary as a part of the research. They were unsure whether this fell within the realm of journalism—which I was told was not bound by the same IRB requirements because a journalist does not interpret data, she only collects and presents it—or whether it was in fact research. Ultimately they suggested I submit an application for IRB approval just to be safe.

Video projects, especially video projects created within the framework of PAR require 'multiple layers of consent' (Riecken and Strong-Wilson 2006). I had to figure out how to create consent forms for the youth researcher/video producers as well as a separate form for anyone whom they chose to interview. I also had to decide whether these had to be separate from a 'media release' more commonly used by filmmakers. Since there was no model that the IRB office could offer, I spent a good amount of time looking at various release forms and consent forms and creating, then seeking, feedback on forms that would meet the requirements of the IRB process and the layers of consent inherent in a video project. This caused significant confusion for the IRB because they could not quite figure out why I was using more than one consent form and what the role of the youth researchers/filmmakers was.

Second, the risk/benefit equation used by IRBs to determine whether research should be approved or not is largely based in a positivistic model centered in the priorities of traditional, top-down academic research easily bound within perceived research parameters (Brydon-Miller and Greenwood 2006). These priorities run counter to the goals and objectives of PAR in many ways, especially around issues of representation and voice. As Francesca Cancian (1996) asserts, 'participatory researchers focus on power relations and are oriented primarily to community groups, not to policy experts or academicians. The concern with underprivileged communities and power underlies the four major characteristics of

participatory research’: 1) participation in the research by community members; 2) consciousness raising and education of the participants; 3) inclusion of popular knowledge; and 4) political action (Cancian, 1996, 94). IRBs, on the other hand, often maintain the dominant research paradigm that treats people as passive objects to be studied, analyzed, and investigated—and in some cases, based on the academic’s analysis, given prescriptions for modifying behavior—rather than ‘subjects’ in the Freirian sense—people capable of examining and interpreting their world in ways to end oppression and bring about self-determination (Freire, 1970). From a positivist research model, ‘political action’ as a research goal is looked down upon because it ‘taints’ the researcher’s objectivity.

A participatory project presents an opportunity for youth to speak back to structural inequities that put youth at risk. Our project was about creating an opportunity for the youth to confront stereotypes of young black men being ‘at risk’ to themselves or society. It provided an opportunity for young people to gain skills, create a project from start to finish, collaborate with community, learn video production skills, etc. but also a possibility to reframe concerns in their own terms. The IRB’s individualistic model of risk, however, does not understand or acknowledge this, and the fear that the youth will tell what Fine et al. call ‘bad stories’ (2000, 115-117), and even identify themselves as part of their self-representation with these ‘bad stories,’ results in IRB restrictions on what I could collect and insistence on anonymity. I was told by the IRB that I would have to stop an informant if I believed he was about to tell me about an illegal activity he had been involved in.

Risks/benefits

On the first IRB application, I argued that the exact research methodologies were difficult to determine at the time because the youth involved in the project would be largely responsible for choosing how to proceed. I did, however, provide a list of possible procedures including interviewing, participant-observation, cognitive mapping, journaling and drawing. I also indicated that the youth may be given disposable cameras to take pictures of what they consider home, neighborhood, or community, and that video-taping would be a central procedure, but the nature of what would be videotaped could not be determined with certainty because the youth involved in the project would determine what they wished to include in the final video product. The IRB responded by stating, ‘as a general matter, the Committee cannot judge the potential risks to the subjects without knowing your procedures. Thus, as presented, we could not approve your study. You need to give us a list of the range of procedures that might be chosen by the subjects, and, for each one, identify the risks associated with it.’ They also told me

that, ‘simply warning the subjects in the consent form not to make disclosures is not enough to minimize the risk.’

On my second application, in response to their question about the potential risks of participating in the project, I acknowledged that there were potential risks because of illegal activities in which some of the youth may have been involved. I recognized that there was a possibility of some public censure as well as potential legal risks involved if a ‘subject’ revealed illegal activities not already known to the courts. In response to the Committee’s request I specifically stated that there was a possibility that illegal activities could be revealed in journal entries, drawings, interviews, photos or video-taping, and that photos, audio-taped interviews, and video-tapes also presented the possibility of being identified and associated with behavior that is not deemed socially acceptable.

I then explained in detail what I would do to protect the ‘subjects’ from these possible risks. I agreed to store data using first names only, and to assign a pseudonym if the ‘subject’s’ guardian agreed to let her or his child participate but did not give permission for the ‘subject’ to be identified, and that no information that could link the ‘subject’ to the response would be presented in the final video production. In regard to ‘illegal activity’ I explained that ‘no information that could link the ‘subject’ to any information presented in the final video production will be presented.’ I also clarified that in the final documentary any photographs, audio-taped interviews, or videotapes that revealed illegal activities not known to the legal system, would be edited in a way to conceal the identity of the ‘subject.’ Likewise, ‘any journal entries or drawings that disclose illegal activities not known by the legal system will be presented anonymously without any identifiers or other information that could link the journal entry or drawing to the ‘subject.’” In the case that identifiable data were used in the video, I explained that it would not be used unless it had a verifiable signed release form, and that the participants would ‘be given the opportunity to review all data collected from them and either approve it for inclusion in the final video production, or request that it be withdrawn and destroyed.’

In my second application I also amended the consent form by adding in **BOLD TYPEFACE** an explicit warning about the possible implications and consequences of participating in the research project including legal ramifications; the possibility that data could be subpoenaed; the potential to reinforce negative stereotypes or perceptions; embarrassment; damage to a person’s reputation; or difficulties obtaining employment, enrolling in school, or participation in social activities.

I also included the following in the IRB application:

While there are potential risks involved when publicly presenting personal experiences or attitudes that may not be pro-social, the benefits of being able to have open and honest dialogue about such experiences and attitudes within the context of the community and community development are great, especially when it is driven by youth who are willing to share their experiences. Such an occasion may give the youth an opportunity to become involved in community activities and discussions, and reflect on and share their past experiences in a way that can be productive and helpful both for them and for the larger community. This would provide an opportunity that many of these kids have never had.

The IRB again rejected my proposed research because they did not feel the ‘benefits’ I had stated were ‘high enough to outweigh the potential risks to the subjects.’ The letter also made it clear that the IRB didn’t believe the steps I was taking to protect confidentiality were adequate.

The committee’s comments beg the question as to what are the ‘benefits’ of research? I struggled for quite some time to understand my university’s IRB-defined ‘benefits.’ No one ever explained to me what constitutes a benefit or how they are measured against risks. After this and other experiences, however, it is clear to me that the IRB committee defined ‘benefits’ in very different ways than do participatory researchers. The IRB did not appear interested in the benefits that may accrue to the community or people involved in the research process. Rather, they defined ‘benefits’ in terms of the accrual of academic knowledge. The IRB application asks researchers to list any benefits that are ‘to be gained by the subject.’ Following this question the application provides numerous examples of ‘benefits’ that should be disclosed, including monetary gain, reimbursement of expenses, class credit, merchandise, or services. All benefits are framed in terms of material goods rather than any kind of political empowerment or amelioration of social inequalities.

The next question on the application asks, ‘what information may accrue to science or society in general as a result of this work?’ I answered this question by explaining that the project would provide insight into perceptions about those who are labeled ‘at-risk’ or ‘delinquent’ and would create public awareness about the experiences and situations of these youth. I also wrote that it would foster dialogue about their place in the community and add their voice to the discussion about the community’s future. The IRB responded that ‘the Committee would like a better idea of the benefit of the research to the body of knowledge in general.’

From my perspective the IRB had little interest in how the knowledge would benefit the communities or people who are involved in its production, but

were interested rather in how it would contribute to the ‘general body of knowledge’ that is manifest in publications, conference presentations, and other means by which knowledge is commodified by the academic economy. What constitutes ‘benefits’ and who gets to make that decision are significant questions that point to one of the ways by which IRB committees can maintain the hierarchical control over research processes in ways that continue to alienate and silence voices that seek more than just another line on a CV.

Anonymity, Voice and Paternalism

The concerns that the IRB has with protecting those they feel are at risk from potential risks are reasonable and justifiable, especially considering some of the gross abuses of human subjects in past research practices. What concerns me, however, is that the limitations on research and the insistence on confidentiality that were imposed by the IRB at my university as they attempted to protect the ‘human subjects,’ and - let’s not kid ourselves - the university’s ass as well (Bradburd 2006; Brydon-Miller and Greenwood 2006; Fine et al. 2000; Riecken and Strong-Wilson 2006), have the ability to make research benign and meaningless and sustain the marginalization of people by relegating them to the status of anonymous objects of study. This is especially problematic for the participatory researcher who is interested in working with vulnerable and marginalized populations in a way that acknowledges their knowledge and experiences and seeks to amplify their voice and self-determination.

This tension between maintaining anonymity and facilitating marginalized voices marks a significant ethical issue approached very differently by traditional researchers and action researchers. As Manzo and Brightbill point out, ‘participant anonymity cannot be guaranteed in community group work focused on local change’ (Manzo and Brightbill, 2007, 33) and the desire to preserve anonymity is often ‘in tension [...] with their desire to facilitate marginal peoples’ voices in their own community and in broader political processes’ (ibid, 36). They argue that an insistence on anonymity can ‘muffle the voices of participants while authorizing that of the researcher’ (ibid). In relation to the role of IRBs, Brydon-Miller and Greenwood ask ‘When does protection become paternalism, and concern become control?’ (Brydon-Miller and Greenwood, 2006, 122).

The IRB’s insistence on anonymity in my case smacked of the paternalism and control suggested by Manzo and Brightbill and Brydon-Miller and Greenwood. Evident in the communications I received from the committee is the notion that the people whom I was involving in my research are not smart enough to make decisions for themselves or to understand the implications and possible repercussions of their decisions. Even more problematic, however, is the notion

that the committee is smart enough to make these decisions for the ‘subjects’ and will make choices both about what I can or cannot collect from them and how they can represent themselves.

This was disturbingly evident in the second rejection letter I shared at the beginning of this article. Although I went to great lengths to explain our collaborative process, the IRB did not value or take the time to understand it, nor did they understand that the process of planning, filming, editing, and presenting the documentary would not be mine alone, but would be directly influenced by the ‘subjects’ with whom I worked. Because the youth didn’t have credentials (i.e. degrees, formal training in filmmaking, etc.) they were not considered by the IRB as co-researchers, but only as ‘subjects’—the objects of my study, not partners in my research. The IRB did not recognize or understand their part in the project or their choice. It denied them the opportunity to choose how they would present themselves and their world, and it denied them the opportunity to experience the consequences of their decisions. In essence the Committee made it very clear that they did not deem the youth I was working with mature or able enough to understand the implications of our work and to choose wisely how to carry it out. The comment ‘there is a risk that people in the community might be upset about the portrait that has been painted’ is especially troubling in its implications for research. Should we silence the voices of a group of ‘at-risk’ youth or a group of young black men living in a predominantly white town because the portrait they paint might upset people?

It is my experience that the goals and objectives of participatory research and the mission and objectives of the IRB as interpreted at the university where I did my work directly contradict each other in many respects. Budd Hall (1993) argues that ‘participatory research fundamentally is about the right to speak’ and more specifically is ‘a process which supports the voices from the margins in speaking, analyzing, building alliances, and taking action’ (xvii). Ironically, in their attempts to ‘protect’ the ‘subjects’ of research, the IRB perpetuates the marginalization and oppression of the disenfranchised and disadvantaged they claim to protect, all the while ensuring the survival of the commodification of knowledge for an academic political economy dominated by a cultural elite. The IRB has power to determine who will have the right to speak in relations to research agendas tied to the university, and unfortunately that power is often wielded in a manner that continues to marginalize and disenfranchise.

I would be amiss, however, to not mention many of the changes that have happened in the way IRBs approach research since the experience on which I have reported here. As I mentioned, I undertook this project almost ten years ago, and the frustrations and different needs of qualitative and action researchers have been heard on many campuses. The university at which I now work has separate forms

for health sciences/biomedical research and social behavioral science research. Qualitative researchers are now sitting on IRB committees and bringing their insight to the review process. Brydon-Miller and Greenwood report on the successes they had at their respective campuses when action researchers have sat down in dialog with IRB members. They write that since these discussions at Cornell, 'IRB reviews of Action Research projects have been [...] thorough, fairminded, and thoughtful' (Brydon-Miller and Greenwood, 2006, 120). IRB panels are also revisiting the ways they approach qualitative and participatory action research as a result of the efforts of professional organizations such as the American Anthropological Association. These collective efforts are slowly changing the paradigms for research and creating better understandings of participatory research at the IRB level.

From my own experience, one of the mistakes I made was not involving the young men with whom I worked in the process of creating and reviewing the IRB application and consent forms. I tackled the IRB committee by myself, which further replicated the model I was trying to challenge by asserting the traditional model of researcher and subjects. As Brydon-Miller and Greenwood (2006, 126) argue:

We should develop strategies for incorporating the development of IRB proposals and consent forms into the action research process itself. We should see this as a form of community education and as a means of increasing ownership of the research process, rather than as an impediment to our work.

They suggest that this would include a discussion of the pros and cons of maintaining confidentiality versus giving credit to participants. Though I had this and other similar conversations with the young men with whom I worked, it was never explicitly in relation to the process of getting IRB approval for the project. I wonder how a more direct involvement in the process may have changed the outcome or even the IRB's view of the young men whom they regarded so paternalistically.

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