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The IRB as Gatekeeper: Effects on Research with Children and Youth

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Abstract

Gatekeepers play an important role in research conducted with children and youth. Although qualitative researchers frequently discuss institutional and individual gatekeepers, such as schools and parents, little attention has been paid to the role that Institutional Review Boards (IRBs) play in determining who is allowed to research particular populations and the ramifications of these decisions for findings involving children and youth. In order to examine this role, we compare negotiations of two researchers working on separate projects with similar populations with the IRB of a large Midwestern university. In both cases, it is likely that board members used their own personal experience and expertise in making assumptions about the race, social class, and gender of the researchers and their participants. The fact that these experiences are supported by findings across a wide range of IRBs highlights the extent to which qualitative research with children is changed (or even prevented) by those with little knowledge of typical qualitative methodologies and the cultural contexts in which research takes place. While those such as principals, teachers, and parents who are traditionally recognized as gatekeepers control access to specific locations, their denial of access only requires researchers to seek other research sites. IRBs, in contrast, control whether researchers are able to conduct research at *any* site. Although they wield considerably more control over research studies than typical gatekeepers, the fact that they are housed in the institutions at which academic researchers work also means that we can play a role in their improvement.

Keywords
institutional review boards, gatekeepers, qualitative research, children and youth, race, culture

Disciplines
Educational Sociology | Quantitative, Qualitative, Comparative, and Historical Methodologies | Race and Ethnicity | Sociology | Sociology of Culture | Theory, Knowledge and Science

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Introduction

Researchers hoping to study a setting or population commonly have to deal with gatekeepers who control access to research sites. Negotiations with gatekeepers are particularly important for qualitative researchers, who depend on access in order to develop an understanding of the individuals and groups they desire to study. In the case of research with children, the issue of access becomes even more difficult because children are often studied in institutions controlled by others, and children alone cannot legally consent to participate in research (Leonard, 2007). In order to study children in schools, for example, researchers must often gain permission from school superintendents, principals, teachers, parents and, finally, the children themselves.

While the practice of dealing with gatekeepers has been documented in many handbooks for qualitative research (e.g., Best, 2007) as well as in many qualitative studies (e.g., Lareau, 2011), one influential gatekeeper is often not identified as such – the Institutional Review Board (IRB). We argue that despite their distance from the research setting, IRBs serve as important gatekeepers in research, especially in qualitative work with children and youth. While typical gatekeepers have a recognized association with research sites, the distance between IRBs and research settings adds to the difficulties set before researchers. Unlike those in a research setting, IRB members evaluate proposed studies based not on specific knowledge of a particular context, but on their perception of facts, in addition to personal and professional experiences (Stark, 2012). As a result, they often request changes that are unrelated to research ethics, not grounded in knowledge of a researcher's field, and may even prevent research entirely (Schneider, 2015; Stark, 2012). This is particularly problematic for research involving children because the voices of children have historically been absent from social science research (Prout & James, 1990).

Research on IRBs is relatively rare, but a few studies have explored the practices of IRBs in detail (e.g., Stark, 2012; van den Hoonaard, 2011). Compared to other professions, academic research faces a much higher level of scrutiny for work that often involves considerably less risk. As Schneider (2015) notes, "Doctors cause over 50,000 unnecessary deaths annually – incalculably more than research misconduct in all its history. Yet doctors are regulated by licenses and tort liability, not a Treatment Review Board" (p. xxvi). The "rhetoric of scandal" surrounding research (Schneider, 2015, p. xxvii), however, contributes to IRB practices that make it more difficult for researchers to pursue knowledge related to children and youth and "sensitive" topics like sexuality (Irvine, 2012). Van den Hoonaard (2011) refers to the effects of this difficulty as an "ethics chill" (p. 298) that silences the voices of researchers and participants and runs counter to the notion of academic freedom (Schneider, 2015). Furthermore, the effectiveness of these practices for protecting research participants is unknown (Abbott & Grady, 2011). Sociologists have echoed these frustrations, decrying IRB overreach and the resulting limitations on research (Adler & Adler, 2016; Irvine, 2012; Levine, 2001).

In this paper we examine the gatekeeping role that IRBs play by detailing our experiences negotiating IRB approval and the effects these negotiations had on our subsequent research. In comparing our experiences, the intention is not to vilify a particular IRB or university, since similar problems have been found across the U.S. and Canada (Stark, 2012; van den Hoonaard, 2011). Rather, this comparison is intended to highlight the ways that IRBs act as key gatekeepers in the research process with important implications for those seeking to conduct qualitative work with children and youth.

Institutional Review Boards

Development

The Institutional Review Board system was developed in order to conduct assessments of risk-benefit criteria in human subjects research. Operating on the 1979 Belmont[1] principles of autonomy, the early goal was to protect participants from physical harm in medical research, such as that which occurred in the Tuskegee syphilis experiment (Heimer & Petty, 2010).[2] In 1991, the Federal Policy for the Protection of Human Subjects, or the "Common Rule," was established and additional protections for "vulnerable populations" were added for pregnant women, human fetuses, neonates, and children (Office for Human Research Protections, 2016). The Common Rule regulations were designed to lessen the differences in power and interests between researchers and participants. In universities, IRBs began as self-regulating, cooperative bodies of researchers reflecting collectively about ethical dilemmas in research (Klitzman, 2011). Unfortunately, due to their original focus on biomedical research, social scientists have rarely been involved in the creation of the IRB guidelines to which they are legally obligated to conform (Schrag, 2010). As a result, IRBs often fail to distinguish "important differences between experimental field – like psychology and education – and more open ended, qualitative work – such as ethnography and oral history" (Schrag, 2010, p. 189).

IRBs in Practice

While IRBs are intended to ensure that researchers observe participants' rights and that the benefits of a given study outweigh its risks, in practice they also evaluate methodology and the character of researchers (Stark, 2012) and increasingly monitor research as it is conducted (Schneider, 2015). Summarizing the practice of IRBs, Schrag (2010) argues that many "make ill-informed, arbitrary decisions while congratulating themselves on their ethical rigor" (p. 9). These decisions are also made with a focus on worst-case scenarios and avoiding litigation (Heimer & Petty, 2010, Stark, 2012; van den Hoonaard, 2011). As Schneider (2015) notes, "if IRBs say no

to research they are safe; if they say yes, they risk institutional disgrace, lawsuits, and federal

sanctions that have included (briefly but unforgettably) closing down research at major

universities" (p. xxviii). Thus, rare but "provocative" studies like those of Humphreys,

Zimbardo, and Milgram loom large in the decision-making process of IRB members (van den

Hoonaard, 2011, p. 12).[3] Fear of repeating these infamous mistakes, along with "the belief that

people are vulnerable, the questioning of science and scholarship, and the societal drive for

accountability," lead to the continuation of a system in which every study is examined in

advance (van den Hoonaard, 2011, p. 286) and consent forms are increasingly long and

decreasingly comprehensible for those they are intended to protect (Schneider, 2015).

This shared backdrop leads to common practices at IRBs across the country but not

common results. Stark (2012) studied IRB meetings and interviewed board members and IRB

chairs from across the country. She found that different IRBs used the same techniques but

reached different conclusions for very similar studies. These techniques included close

examination of application documents for signs of the researcher's character, arguments based

on facts as well as private and professional experience, the use of local precedents to guide

decisions, and reliance on the anonymity of board members in meeting minutes (Stark, 2012).

These findings are supported by van den Hoonaard (2011), who observed five research ethics

committees in Canada.

The use of these common techniques is rooted in decisions made during the formation

of the ethical guidelines that led to IRBs. Aside from the exclusion of social scientists (Schrag,

2010), these discussions in the U.S. focused on review procedures rather than ethics principles

(Stark, 2012). The Belmont Report, for example, does not specify how to decide concrete cases

(Schneider, 2015). As a result, Stark (2012) argues that IRBs are declarative bodies (turning

hypothetical situations about what *may* be acceptable into shared reality about what *is*

acceptable) composed of knowledge experts rather than rule experts. These experts "invoke

regulatory language to show that they are aware of what they are doing, especially when they use

their discretion to interpret the rules creatively" (Stark, 2012, p. 13).

      In their decision-making processes, IRBs spend much of their time determining the

characteristics of the participants and researchers who are *not* in the room (Stark, 2012).

Imagining the perspective of participants is a way to reduce the likelihood of lawsuits, and board

members often "imagined the people who featured in their own lives as stand-ins for research

participants," reinforcing the race, class, and gender biases of board members in the process

(Stark, 2012, p. 14). Schneider (2015) argues that IRBs are paternalistic, telling people whether

and how they can participate in research and treating participants as "manipulable victims" (p.

xxix). This "victim view" is particularly problematic for research involving children, since adults

view children as inherently vulnerable, incapable of making their own decisions, and needing

protections from adults (Qvortrup, 1993).

      Supported by the Common Rule, IRBs can therefore overestimate children's need for

protection (Wagener et al., 2004) and underestimate children's agency and abilities (Mammel &

Kaplan, 1995). This particular treatment of children and youth can result in what Swauger (2009)

identifies as procedures that "inadvertently block the voices of youth" (p. 63). Youth who are

minorities, immigrants, or disabled are seen as needing even greater protection, making it even

more difficult for researchers to include their voices, as the suggested changes in Brent's

research sites show below. Furthermore, the exclusion of researchers from discussions as to

which groups constitute vulnerable populations and what precautions should be taken actually

slows the review process (Stark, 2012).

As declarative bodies, IRBs have the legal authority to request (or demand) changes based on their decisions and researchers have little recourse to appeal (Schneider, 2015; Stark, 2012). As Stark (2012) found, "IRBs might suggest changes to researchers' site selection, sample size, recruiting methods, or interview questions" (p. 73). If researchers disagree with these suggestions, there is typically no higher body to which they can appeal, because IRBs are "procedurally insulated from challenge" (Schneider, 2015, p. xxi). Studies that are qualitative and/or critically theoretical in orientation often undergo multiple revisions (Katz, 2007), as IRB staff lack training in alternative epistemologies and what constitutes sound research and spend valuable time asking researchers to make their studies "appear more conventional" (Lincoln & Tierney, 2004, p. 219). Of course, just because participants sign consent forms does not mean that they, or the researcher, are "fully informed" about all that may occur in the field, as is highlighted in Melissa's experience below. Although IRBs have power as declarative bodies, their individual members do not, leading to a lack of individual accountability among IRB members (Stark, 2012). This is demonstrated in meeting minutes, where names are excluded from the details of conversations (Stark, 2012) and, in many cases, where the entire membership of the IRB is kept confidential (Katz, 2007). These characteristics of IRBs affect the way decisions are reached, since the types of arguments (including personal knowledge) used in closed meetings would be ineffective in open settings (Stark, 2012).

As many have argued, the system by which IRBs oversee the ethical conduct of research is flawed. Flaws in oversight are partially attributed to individual board members making recommendations outside of their particular areas of specialization (Stark, 2012), using their own perceptions and experiences of race, class, and gender to "fill in the gaps" of knowledge about particular subjects. De Vries and Forsberg (2002) note that at the turn of the century, one quarter

of IRBs at U.S. institutions were exclusively white and 70% were majority male. As Stark (2012)

argues, IRB members frequently imagine relatives or neighbors as stand-ins for research

participants and "the membership of the IRB informs who is called to mind" in these

circumstances (p. 15).

Flaws in this process also hinge upon the incongruence of "collective memory," in which

individual board members (some of whom rotate rapidly, depending on university policy) do not

retain knowledge for how or why particular studies were discussed or approved in the past (Olick

& Robbins, 1998). What occurs instead is a reliance on collective memories that maintain the

identities of the institution, which, because of historical precedents discussed above, do not

routinely include ideas of working with children or other vulnerable communities. What results

is a system that is "inconsistent," "idiosyncratic," and reliant on a "local instance of

interpretation" (Martin & Inwood, 2012, p. 14).

A key outcome of these flaws is the uneven restriction of research, since one institution's

IRB may allow a study based on local precedent, while precedents for a different IRB may lead it

to deny the same study (Schneider, 2015; Stark, 2012). These realities increase the difficulty of

conducting research on understudied topics and groups, decrease collaborative research across

universities, and cause some researchers to avoid ethics review or conducting empirical research

altogether (Hamilton, 2016; van den Hoonaard, 2011; van den Scott, 2016). Problems are

magnified by the fact that researchers, who presumably have the most expertise regarding the

methods and ethical procedures appropriate for their work, are not allowed to determine these

things for themselves or to take part in the conversation at IRB meetings. As Schrag (2010)

argues, "That Venkatesh could not anticipate the consequences of his actions is no reason to

think that a committee of experimental psychologists, education researchers, and laypeople could have done better" (p. 188).[4]

The flaws in this system are particularly problematic for those whose work falls outside of the typical methods employed by biomedical researchers. As we argue below, researchers proposing qualitative work with children and youth face a particularly difficult situation because those deciding whether or not their studies are "ethical" may not have much knowledge of qualitative research *or* research with young people. In qualitative research, decision making about research in the field rarely works as regulators imagine (Heimer & Petty, 2010), especially when doing research with children. While IRBs tend to be concerned with researchers' power over subjects (especially children), IRB panels fail to recognize that subjects typically wield more power in social science research than anticipated; participants can even reshape research questions by responding in unexpected ways (Heimer & Petty, 2010; Katz, 2007). As a result, IRBs may base their recommendations on forms of personal knowledge and expertise that are not supported by existing facts or research. In addition to highlighting the gatekeeping roles that IRBs take on in qualitative studies of children and youth, this chapter adds to the often neglected sociological study of IRBs (Dixon-Woods, Angell, Ashcroft, & Bryman, 2007) and the lack of study on IRBs in general (van den Hoonaard, 2011).

Negotiating Access with IRB Gatekeepers

Both authors attended the same graduate program[5] and shared a dissertation advisor. We submitted proposals for our separate qualitative dissertation projects involving children and youth to the university IRB within a few years of each other. The schools in Melissa's proposal and Brent's initial proposal are also located in the same district. The following accounts detail our experiences negotiating the process of IRB approval and the effects these negotiations had on

our subsequent research. This comparison highlights the ways that IRBs act as critical

gatekeepers in the research process, with important implications for those seeking to conduct

qualitative work with children and youth. While principals, teachers, and parents are traditionally

recognized as the gatekeepers controlling access to specific locations, their denial of access only

requires researchers to seek access elsewhere. IRBs, in contrast, control whether researchers are

able to conduct research in *any* setting.

Melissa's Experiences

Research Topic and Initial Proposal

Melissa's broad research topic focused on understanding the interactional and

communicative underpinnings of school engagement for Latina/o students in the Midwest. At the

time of the study, this particular school district in the Midwest had seen a sharp increase in the

number of Latina/o U.S. born and immigrant students. Melissa was interested in students'

experiences at a historically white, high achieving high school in the district. While the school

was well-equipped academically, there were few resources for students with English as a second

language (ESL). Melissa was interested in possible gaps in educational services for these

Latina/o students and their academic engagement in such an environment. She also proposed to

understand the general experiences of this new youth population at the school.

Melissa began making preliminary contacts at the high school to gauge receptiveness to

her project and to provide a comprehensive proposal to the IRB at the university she attended.

She provided a two-page research plan to the school's principal outlining an ethnographic project

in which she would conduct participant observations with students throughout the 2005-2006

academic year. In the spring of the same year, after developing rapport with students and

understanding overall educational patterns, she proposed to conduct at least three focus groups

with students to get feedback on observed patterns and overall sentiments regarding school

experiences. The school principal was receptive to having someone come in and interact with the

Latina/o "newcomer" students. Earlier in the summer, he had been approached by a researcher

(and tenured professor) from Melissa's university. This senior researcher was conducting an

overall assessment of how residents from the town viewed Latina/o "newcomers," so the idea of

having someone conduct research with the new Latina/o students was somewhat established.

The principal's initial hope was that Melissa would fill the role of a volunteer who could

help the overloaded ESL teacher (who was the school's former Spanish teacher) and her assistant

(who did not speak Spanish) with issues such as tutoring and translation. Melissa explained the

process of participant observation and suggested that gathering data on existing patterns would

provide information on much-needed services at the school, which could then be used to propose

policy changes to the school board and also support requests for additional funding. After a few

emails back and forth and one in-person meeting, Melissa and the principal agreed that her role

was to be a participant observer with the students and also to serve as an "unseen" resource to the

ESL teacher, helping her to contact volunteers, find scholarship resources for students, and

provide general feedback on academic needs of students as data collection occurred. The

principal agreed that once Melissa obtained IRB approval, he would send a memo including

Melissa's research plan to all teachers, notifying them of her presence and purpose in the school.

Melissa was also provided a roster of all "Hispanic" students in the school, which included

names and grade levels but no other identifying information.

IRB Concerns and Adjustments Made

During late August 2005, concurrent with discussions with the school principal, Melissa

applied to her university's IRB. Because the academic year at the university was already in

progress, getting feedback from the IRB was delayed, as many others were proposing projects and the IRB had just reconvened. Melissa initially applied for an expedited review because she would not be invasive of students' privacy, nor was she conducting research on particularly vulnerable experiences (such as trauma). Consent forms were constructed and filed for students over the age of 18, as well as for students under age 18, who required both student and parent signatures to participate.

When feedback was received two weeks into September 2005, initial concerns were those frequently heard when conducting research with children: since children were considered "vulnerable populations," did their age allow them to consent and what was the plan to get their parents' consent? The proposal was upgraded to full review status because of the ages of participants. One additional concern mentioned by the IRB was gaining consent of immigrant parents if and when youth were underage. Melissa proposed writing letters to parents explaining the study and also visiting the homes of students to speak with their parents if they still had questions or concerns. In order to obtain informed consent, Melissa was asked to send letters to parents, but the parents' addresses were not provided by the school, requiring Melissa to ask students for their addresses, which she could not do without parents' consent, placing her in a proverbial catch-22.

During these negotiations with the IRB, the senior professor at Melissa's university, who was conducting research on town residents' responses to the "newcomers," was informed by a colleague that Melissa was interested in working with students in the same town. In February 2005, he had amended his own study to include "the voices and perspectives from the Latino community members themselves" by conducting classroom observations of Latina/o students and interviewing them and their parents. The goal was to "round out" his data, but he stated his

team "never undertook this work to a significant degree" (email communication Sept 19th, 2005).

He proposed an amendment to include Melissa as a member of the research team in exchange for

assisting with some analysis of his data, reasoning that this might receive approval more quickly

than a new full review study on underage youth. Melissa agreed and was added to the team

toward the first of October and, after approval, began working in the school in mid-October.

Effects in the Field

Melissa's negotiations with the principal and efforts to obtain IRB approval to enter the

field were only the beginning of her negotiations with gatekeepers. In order to understand the

lives of young people, young people themselves are more important gatekeepers than adults

(Mayall, 1999). Melissa sent out consent forms to 40 (out of 60) of the school's ESL students

(not all served by the program were Latina/o; some were Chinese, Russian, or from other

countries). Melissa received consent from 25 Latina/o students, 10 of whom were over the age of

18 and did not need parental approval. Because of the delay in IRB approval, Melissa was in the

field from mid-October through the end of May. In their two prior months of school attendance,

students had established friendships, connections (or lack thereof) with teachers, and routines.

This did, however, allow Melissa to observe established groups and practices of academic

engagement and/or coping mechanisms that had already been developed by the students.

Melissa's interactions with her participants varied by both by gender and race. She easily

established rapport with Latinas, both immigrant and U.S.-born, and two became her closest

informants.[6] With Latinos, however, her experience was not uniform. Initially, immigrant males

were reluctant to speak with Melissa, citing "respect" as a reason for not engaging closely with

an older Latina. U.S.-born Latinos, however, we very open in their views of the school and their

own academic trajectories. One Texas-born Latino also became a close informant. He began to

serve as a "representative" for immigrant males and was the one who conveyed the reason for their aforementioned reluctance to interact.

Melissa eventually developed a friend/ally status with the students – the ally status was achieved toward the end of the school year when students had developed trust regarding her role in the setting. At the end of Melissa's study, she provided school administrators a brief summary of her findings and recommendations for assisting Latina/o students with academic engagement, which they utilized as evidence in a grant application. The school was awarded the grant toward the end of the next school year but, unfortunately, many of the students who participated in the study did not benefit from it because they had dropped out or left the school. Had approval for Melissa's study been granted earlier, this ally role could have developed sooner, potentially leading to earlier implementation of policy recommendations and receipt of the grant.

While the IRB delay turned out to be beneficial in terms of observing already-existing school patterns, the discussion above highlights its negative impacts. Further, had Melissa not been added to an existing study, the delay in field entry and data collection would have been much longer, which would have affected the patterns she was able to observe. During her time in the school, Melissa witnessed disengagement with the academic process among students whose language gap was seemingly too large to overcome and with older students who had almost completed school by the time they arrived in the U.S. Because Melissa was present with them throughout the academic year, however, they stayed engaged in their relationship with her and were some of the most willing to participate in, and contribute to, focus groups at the end of the spring. The focus groups were best attended by the immigrant males, possibly because this "official" avenue of interaction with Melissa was a safe space where they could practice "respect" for her as a Latina, while simultaneously conveying their views on the school and their

educational experiences. Had the delay for Melissa's entry into the field been any longer, the window of opportunity to develop a relationship with these students could have been missed and the nuances of their academic experiences would not have been understood.

Brent's Experiences

Research Topic and Initial Proposal

In August 2007, Brent submitted a proposal to the university IRB with the stated intention of better understanding "how late elementary students deal with negative peer interactions such as bullying, teasing, and insults" and using the knowledge gained from this study "to suggest ways that schools and school corporations can better prepare students for these types of interactions and more successfully deal with them when they arise." In many ways, this research was proposed in direct response to the literature on bullying, which was then dominated by psychological, typically quantitative, approaches (Faris & Felmlee, 2011; Yoneyama & Naito, 2003). In contrast, Brent hoped to examine the school cultures in which these behaviors took place.

The methods in his initial proposal involved ethnographic observations in classrooms, at recess, and at lunch, followed by two-person focus groups with students and interviews with principals, fifth grade teachers, and staff members. The rationale for interviewing students in pairs was that doing so would diminish the power differential between an adult researcher and the 10 to 11-year-old students, while also allowing for meaningful discussions between students. He proposed using passive parental consent for school observations (in which information sheets about the study would be sent to all parents and returned only if they did not want their children to participate) and obtaining informed consent from both students and parents for interviews. The

proposed sites of his research were fifth grade classrooms in two elementary schools in the same

school district that Melissa had studied.

IRB Concerns and Adjustments Made

Brent's proposal was reviewed at the September meeting of the IRB, after which the IRB

chair contacted him via e-mail with "substantial concerns" about the study and its design. A

primary concern was with the proposed research sites, which had major consequences for the

study. As the chair's message stated, "We have committee members who are familiar with the

school system you want to use and they wondered why you picked those schools." This

familiarity included statements that "they are two of the three bottom tier schools in the system"

and that one of the schools was a location to which "every Latino student in that school system is

bused…for ESL teaching." Akin to a "screening process," IRB members questioned whether the

race and social class composition of these schools would affect his results, whether he spoke

Spanish, and whether the concept of bullying translates to the countries from which the Latina/o

students originated. As a result of these questions, Brent spoke to his dissertation advisor and the

two of them agreed that it would be best to propose working in a different school district entirely,

in schools where nearly 100% of students were white.

Another IRB concern was with the ability to maintain confidentiality when interviewing

students in pairs. The IRB was not convinced that group interviews would decrease power

differentials, arguing that "the kids are used to sitting in a classroom with 30 other kids and the

teacher is still the power figure." With no perceived benefit, the IRB chair stated, "We suggest

that the kids be interviewed alone, or you have more kids and don't ask about personal

experiences with bullying, just deal with hypothetical scenarios." Discussing personal

experiences was also a more general concern, since the committee wanted to know about Brent's

"plan for handling situations when a child reports or experiences significant distress." In response to these concerns, Brent adjusted his proposal to exclude interviews with pairs of students and to only ask about hypothetical situations rather than the concrete previous experiences of students as victims. For example, in the interview protocol the question "When people have been mean to you, what did you do about it?" became "What do you think you would do if somebody was mean to you?"

Concerns with smaller effects on Brent's proposal included the specifics of his planned observations, clarification of concepts such as "bullying" and "teasing," and the distribution of consent forms. The committee wondered about Brent's role in the field and whether or not he would intervene in bullying episodes, prompting him to clarify his adoption of a "quiet friend" role in line with those used by Corsaro (1985), Thorne (1993), and Eder (1995). In his later discussions with school principals, Brent was told that, for liability purposes, he was not allowed to intervene in student behaviors but could inform another adult of those situations, which satisfied the IRB's concern in this area. Related to his observations, the IRB requested that Brent provide his "behavioral/observational coding/recording instrument" to help them understand what he meant by his "key constructs" of bullying and teasing. In response to this, he provided a detailed list of possible signs that one may be a victim or bully, as noted by Olweus (1993). Regarding the use of passive consent, the IRB's only concern was that Brent consider mailing letters in case forms distributed to students at school were not given to parents, which he noted he would do.

Near the end of September 2007, Brent submitted a letter of response to the IRB's concerns along with 20 copies of his revised proposal. After the committee's October meeting, he received an e-mail with "a few remaining concerns" that also noted appreciation for his earlier

"thoughtful and detailed response." These included more questions regarding his intervention in student interactions, a question about the delivery of consent forms for the two parts (observations and interviews) of his study, and minor clerical issues regarding consent forms, such as the location of dates and correction of typos. As noted above, the issue of interventions was settled by the school district and the other questions and requests were relatively simple to address. These responses were accepted via e-mail in November and the official IRB approval was granted at the end of November 2007, three months after his initial proposal submission.

It is worth noting that the approval process may have been slower if Brent had not been able to respond to the IRB's requests in time for consideration at the next monthly meeting or, perhaps more importantly, if he had pushed back against the IRB's requests or suggestions. Although his approved proposal was similar to his initial submission, Brent made substantial changes to the format of his interviews and the location of his study, even when the IRB did not explicitly state that they recommended changes. As a graduate student scheduled to defend his dissertation proposal and begin his research in December, Brent felt compelled to make changes to alleviate any committee concerns rather than taking a stand on issues like group interviews, which may have led to different types of data but prolonged the approval process (see van den Scott, 2016, for a discussion of the relationship between graduate students and IRBs).

Effects in the Field

Brent began his fieldwork in December 2007. Five parents returned the information forms stating that they did not want their children to be observed, but he was able to observe the remaining 77 fifth grade students, eventually receiving permission to interview 53 of them (including two of the students he had not been allowed to observe, highlighting the benefit of waiting to obtain permission for interviews until the students had grown accustomed to his

presence in their schools). One negative impact was due to Brent's voluntary suggestion to refrain from asking about specific personal experiences in relation to victimization, since there were several students with whom the ability to ask questions about interactions he had witnessed would have provided a deeper understanding of bullying in school. On the other hand, it is likely that the IRB's line of questioning about his initial choice of schools positively influenced the strong rapport that he, a white male, was able to develop with the students. Although he was unable to interview students in pairs, his regular presence at lunch provided him with a setting in which to closely observe students' conversations, including several regarding bullying.

Discussion: Comparing Experiences

Both of us faced challenges from the IRB but were ultimately able to complete our research projects. As is likely the case for many researchers, especially graduate students, timing played an important role in the difficulties we faced. Reasonably expecting an expedited review process, Melissa's proposal was filed close to the time that she hoped to begin her research, but with the tentative approval of school gatekeepers already in hand. The addition of Melissa to a senior researcher's project was a secondary adjustment to the difficulties she faced (van den Hoonaard, 2011). Notably, the senior researcher did not face any IRB difficulty in adding her to the established project, even though this change resulted in much more fieldwork being completed in the school. Expecting a full review due to experiences such as Melissa's, Brent submitted his proposal four months before he planned to start his research and intended to use the IRB's authorization to help gain approval from institutional gatekeepers. Due to the scheduling of IRB committee meetings, he received approval just in time to begin his fieldwork.

In Brent's case, the IRB's suggestions appeared to do relatively little harm to his data collection and, regarding his research setting and rapport with students, likely improved it.

Nevertheless, some of his interactions with the IRB had troubling implications for research with children, qualitative studies, and researchers more broadly. As Stark (2012) notes, IRB members often rely on personal experience when evaluating proposals. As previously noted, the IRB's response to Brent's original proposal stated, "We have committee members who are familiar with the school system you want to use." While the questions based on this familiarity were potentially beneficial, they were unrelated to issues of ethics and were also, in part, incorrect. Although the IRB claimed that these were "two of the three bottom tier schools in the system," one of the two was actually the *best* elementary school in the system, at least according to problematic measures such as state standardized test scores. The IRB's concern with Latina/o students, while perhaps justified, may have also been overstated, given that only 16% of the students in the other elementary school (roughly 13 out of 80 fifth grade students) were in this category. That IRB members would state personal knowledge as fact is problematic, even if the intention was to produce better research.

Melissa's experiences in relation to obtaining parental permission highlight the difficult positions researchers face as a result of IRBs' singular focus on informed consent (Stark, 2012). In order to obtain informed consent from parents, Melissa was asked to send letters to parents but the parents' addresses were not provided by the school, requiring Melissa to ask students for their addresses, which she could not do without the parents' consent. The IRB's concern regarding how she would get information on students' addresses in order to contact their parents for informed consent may have been a tactic intended to protect a vulnerable population. However, it was also one that seemed to disregard the ability of youth to make decisions about whether or not they wanted to be involved in the research.

Viewing youth as incapable of making decisions is a traditional, adult-centered model that disregards youth as "reflexive social agents" (Best, 2007, pg. 11). While the concern of protecting participants' privacy is legitimate, the issue may not have been raised at all if the participants had been adults. The IRB also asked Brent to send letters to parents but did not discuss whether he should be allowed informational access to their home addresses. It is possible that the presumed immigrant status of parents played a role in the IRB's caution regarding Melissa's proposal, though it is unclear whether this might have been due to a view of immigrants as a group that should be carefully protected or the type of race and gender biases that Stark (2012) notes can influence members of IRB boards when imagining research participants.

Cultural assumptions may have also been a factor in the IRB's concern about Brent's knowledge of Spanish, a question they did not ask Melissa. Given her focus on students with "newcomer" status, this would seem to have been particularly relevant for her research. It is unknown whether the IRB simply assumed that she spoke Spanish due to her last name and if the possible perceived status of being Latina (they did not ask her) legitimized her as an "insider researcher" who would have no problems accessing populations of Latina/o immigrant students (Hodkinson, 2005). In neglecting to ask about this fact, the IRB overlooked factors that impacted Melissa's experience in the field. "Insider" researchers are not without barriers to accessing their own or similar communities. Some researchers, such as Guevarra, (2006) and Milroy, Wei, and Moffatt (1991), highlight identity qualities and differences that can affect the scope and richness of data gathered. That being said, while insider reflections may critically analyze methods and status, they usually do not mention the "qualification screenings" to which their IRBs may have subjected them, as Brent described in response to his initial proposal.

Our experiences suggest that racial and cultural preconceptions are an important part of interactions between IRBs and researchers. While this reveals a problem with IRB members relying on personal experience and assumed expertise when suggesting changes to others' research projects, it also reveals how a lack of knowledge about the culture and experiences of racial and ethnic minority communities can affect recommendations and serve as barriers to accessing these populations. Although power is a frequent concern of both IRBs and those who have studied their impact on research (Heimer & Petty, 2010; Katz, 2007; Lederman, 2016), researchers examining IRBs have rarely discussed the intersection of power, race, and socioeconomic status among board members. As most boards have 80% or greater white membership (De Vries & Forsberg, 2002), the racial and cultural preconceptions of IRBs derives from a particular viewpoint that may or may not include informed practices of working with minority or vulnerable communities.

The IRB's insistence on accessing Brent's "behavioral/observational coding/recording instrument" is also problematic. The use of inductive approaches, such as grounded theory (through which researchers develop theory based on qualitative data collection), directly counters the development of a predetermined "check-list for what you will be coding." Indeed, one of the primary findings of Brent's study is that students (as well as teachers and school staff members) in these schools often did not define bullying in the same ways as academic researchers (Harger, 2016). A general lack of familiarity with qualitative research methods was also evident in questions from the IRB about how he would "know which kids you are allowed to observe and which you are not," in the case of students whose parents declined permission for observation. His response stated that he would "become familiar with the names of the students in the grade level" that he was observing through his time with the students in their classrooms, at lunch, and

at recess, which ultimately satisfied the IRB. This question suggests, however, that the members

of the IRB were not familiar with ethnographic protocols that include continuous personal

interaction with research participants.

Conclusion

In this chapter, we examine the gatekeeping role that IRBs play by detailing our

experiences negotiating IRB approval and the effects these negotiations had on our subsequent

research. In Brent's case, the IRB required changing the sites of his observations, as well as the

methodologies used to interview students. Melissa's approval was brokered by a senior

researcher who was, fortunately, able to add her to his existing project. In both cases, it is likely

that board members used their own personal experience and expertise in making assumptions

about the researchers and their participants. Rather than revealing problems with a single IRB or

university, the fact that these experiences are supported by findings across a wide range of IRBs

highlights the extent to which qualitative research with children is changed (or even prevented)

by those with little knowledge of common qualitative methodologies (Stark, 2012; van den

Hoonaard, 2011).

Many IRBs, as highlighted in our accounts, are ill-informed about non-biomedical

paradigms and, as a result, do not operate uniformly when making recommendations for

protecting participants (Lincoln & Tierney, 2004). IRBs likely have an even stronger negative

effect on those who seek to conduct less traditional forms of research with children, such as

participatory action research. In effect, while IRBs were intended to be ethical gatekeepers, they

presently function similar to any other bureaucracy (Zywicki, 2007) and, like other

bureaucracies, sometimes lose sight of optimal functioning (Heimer & Petty, 2010). Despite their

considerable control over the research process, the fact that they are housed in the institutions at which academic researchers work also means that we can play a role in their improvement.

Researchers offer a wide range of suggestions for such improvements. Schrag (2010) calls for an end to regulation entirely, but because it is unlikely that the federal government will move away from requiring ethical guidelines, we recommend that university IRBs adopt more open processes and allow researchers a seat at the table during the review of proposals. As Schneider (2015) notes, "the problem is not regulation, but bad regulation" (p. xxx). Open processes would encourage IRBs to move away from the sorts of personal evidence and local precedents on which they frequently rely, and giving researchers a role in the conversation would bring experts to the table with knowledge of the particular methods and populations to be studied (Stark, 2012). In this way, IRBs could avoid insisting that researchers adopt the "fragmented or incomplete" knowledge of board members (van den Hoonaard, 2011, p. 291).

Change in IRBs is possible, given that the IRB at the center of our experiences stopped requiring full reviews of research with children in the years following our own studies. In the absence of major changes, however, researchers can work to counteract the negative practices of IRBs. Adler and Adler (2016) offer some practical suggestions for researchers navigating IRBs, such as submitting research topics instead of lists of fixed questions, overestimating sample sizes, and speaking directly with IRB administrators about potential research designs. Stark (2012) notes that IRBs spend a significant amount of time discussing proposals without local precedents, so researchers may be able to help this process by providing examples of studies in which methods similar to those they are proposing were used. This may also reduce the common problem of widely different standards being used by different IRBs. Perhaps most importantly, larger numbers of social science researchers, and particularly those who use qualitative methods

and/or study protected groups, must serve on their IRBs. IRB members who are attuned to the intricacies and flexibility inherent in fieldwork are important in developing local precedents that are more favorable for those conducting research with children and adolescents.

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Notes

[1] See Childress, Meslin, & Shapiro (2005) for more information on the Belmont Report.
[2] From 1932-1972, the U.S. Public Health Service and the Tuskegee Institute conducted a study with 600 black men to understand the progression and treatment of syphilis. The men did not give informed consent, receive proper treatment for the illness, or receive an opportunity to quit the study. The project was only projected to last 6 months, but went on for 40 years.
[3] Stanley Milgram (1974) stirred controversy when he used deception to test the limits of obedience to authority figures in a series of studies designed to convince participants that they were administering electric shocks to another person. Laud Humphreys' (1975) field studies on men having anonymous, gay sex in public bathrooms raised issues of voluntary, informed consent, as the men he studied were not aware they were being studied and were identified using license plate numbers and interviewed several months later at their homes. Finally, in the Stanford Prison Experiment, Phillip Zimbardo (1971) studied how readily people would conform to the roles of guard and prisoner in a role-playing exercise that simulated prison life. In the exercise, participants were not fully informed they would be arrested at home and several experienced severe distress over the roles that they and their fellow participants adopted.
[4] Sudhir Venkatesh was a graduate student who studied the inner workings of a gang. In his account of these experiences, titled *Gang Leader for a Day* (Venkatesh, 2008), he claims to have been unaware of qualitative research practices when entering the field and reports providing confidential information about his research participants to gang members that could be used against them.
[5] We have chosen not to name this institution here because our goal is to bring attention to the gatekeeping role that IRBs at a wide range of institutions play for researchers seeking to conduct

qualitative research with children and youth. Indeed, the fact that similar problems have been found across the U.S. and Canada (Stark, 2012; van den Hoonaard, 2011) supports our decision not to single out a particular university.

[6] There were a few reasons for the quick rapport Melissa built with Latina participants. First, Melissa was the only person of Latina ethnicity in the school besides the students. There was a Latino coach, but the Latinas in the school did not have much interaction with that person. Students were drawn to Melissa through a sense of common identity. Second, Melissa spoke Spanish with many students upon first meeting, which increased initial levels of comfort and also established Melissa as a "credible," trustworthy person. Finally, although there was a large age gap between Melissa and the participants, Melissa was able to discuss popular topics of student interest relating to being teens and new immigrants. Her experiences in general society were a source of great interest to the Latinas, as they frequently quizzed her about her experiences growing up as an educated woman in the United States.