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## Ethics as Obligation: Reconciling Diverging Research Practices with Marginalized Communities

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# Ethics as Obligation: Reconciling Diverging Research Practices With Marginalized Communities

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## Abstract

This article argues that research design is impacted by ideological frameworks, and when conducting community-based participatory research (CBPR), can create challenges and conflicts throughout the Institutional Review Board (IRB) and other institution's approval processes. I explore the ideological frameworks that underpin conventional and CBPR methodologies to show how collaboration can influence the questions asked and answered, the roles of researchers in the project, and how research findings can better impact the community at the center of the research. I offer a snapshot of our CBPR project with women who were currently and formerly incarcerated and document the challenges we encountered given our CBPR methodology and the unique population at the center of our study. I explore the ethical challenges, complications, and delays that emerged from these conflicting ideologies and methodologies. I propose that *how* we engage in research and our research practices impact the questions we ask and answer, how people are represented, and ultimately the material conditions of people's lives. I conclude with recommendations for researchers and IRBs, and even more importantly, community partners to make CBPR projects more inclusive and ethically sound and to hold researchers and IRBs accountable to more inclusive research practices that can create more effective research outcomes and greater community impact.

## Keywords

research ethics, institutional review board, IRB, community-engaged research, community-based participatory research, marginalized communities, incarceration

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## Community-Based Participatory Research and the Red Tent Women's Initiative

I began my work with women in and outside of the PCJ [Pinellas County Jail] through my encounter with RT [the Red Tent Women's Initiative]. I began volunteering with them in 2015 to better understand the program, the women within it, and incarceration in general. Although I had facilitated research with women engaged in street-based sex work, I had not worked with women who were incarcerated outside of that context. Volunteering with RT gave me opportunities to learn more about the jail environment and better understand the issues women faced while also gaining jail administrators' and RT women's trust. Because this research project was not initiated by an organization or group of women prisoners, I started from scratch, so to speak, and wanted to make the process as community-based and participatory as possible. (McCracken, 2019, pp. 8–9)

I draw on this excerpt from my book because it clearly situates me and my relationship to this community-based participatory research (CBPR) project as an outsider to Red Tent (RT) and to incarceration. Red Tent works with women inside and outside the county jail to “implement positive coping skills to address issues such as unresolved trauma, addiction and socioeconomic disadvantage” (“Red Tent in the Pinellas County Jail”). I first met Barbara Rhode, the founder of Red Tent, in February 2015. I volunteered with the group for about a year before I first submitted my proposal to the IRB for approval of this research project.

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Because I wanted to work with women (cis and trans) who were currently and formerly incarcerated, I designed two “sister” studies which took place inside and outside the jail. I did not discuss the project with the women prior to obtaining IRB approval because I wanted to document our research process. And although I realize this choice is contrary to CBPR practices, I could not document the process without IRB approval. I therefore chose to submit an application that outlined how I would work with currently and formerly incarcerated women in the RT program to determine the core issues and focus of our research and to document our CBPR process. As a researcher, I had ideas about what we would discuss and how we would conduct the research, and yet once I actually began the research with the groups, everything changed. My initial IRB application outlined how we would work together, and we were able to document *how* we created the study design. When we determined what we wanted the project to look like, we then had to navigate the IRB (through amendments) and the jail’s bureaucracy.

I submitted the IRB application to work with women who were formerly incarcerated in January 2016 and obtained approval in March 2016. This group worked to determine what questions were most important to ask and how we wanted to gather this information. I received approval of my second IRB application to work with women who were currently incarcerated in March 2017. We continued these discussions as separate groups inside and outside the jail and determined we wanted to create a survey that could be delivered to women who were currently and formerly incarcerated. We completed the Women Researching Incarceration Standing Together (WRIST) Survey in January 2018.

In this article I offer a snapshot of our project and document the challenges we encountered given our CBPR methodology and the unique population at the center of our study. I begin this article by examining the ideologies that underpin research projects in general and use this analysis to provide a framework through which I critically examine and explore the impact of my institution’s IRB and the jail bureaucracies on our research methodologies and research ethics throughout. Our navigation of this project provides opportunities to reflect on our ethical obligations within CBPR and the relationships we create to determine better research practices that protect research participants and serve participants and society as a whole—most especially when researchers are working with marginalized and/or vulnerable communities. I conclude with recommendations for researchers and IRBs, and even more importantly, community partners to hold researchers and IRBs accountable to more inclusive research practices to create more effective research outcomes and greater community impact.

### *Research Ethics and the Need for Institutional Review Boards*

Between 1946 and 1972, the American public learned about public health research that harmed participants physically and psychologically. Researchers at the Fernald and Willowbrook

State Schools exposed mentally-impaired children to radioactive minerals (1946–1953) and hepatitis (1957), doctors at the Jewish Chronic Disease Hospital in New York injected live cancer cells into terminally-ill patients (1964), and most infamously, scientists with the US Public Health Service chose not to inform hundreds of low-income African Americans of their syphilis status or the possibility of a cure during the Tuskegee Syphilis Study (1972) (Freimuth et al., 2001; Malone et al., 2006; Moon, 2009; Reverby, 2010; Thomas & Quinn, 1991). After Tuskegee, the US Congress convened the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to develop guidelines for research involving human subjects (Department of Health, Education, and Wellness, 1979). Institutional Review Boards (IRBs) emerged as a way to prevent researchers from engaging in unethical and harmful research practices. They are federally mandated to safeguard people from potential physical, mental, emotional, and cultural harms (Health and Human Services, 2010 and 2016; Klitzman, 2011a).

Central to these regulations was the creation of the Belmont Report (1979) which establishes three ethical principles—respect for persons, justice, and beneficence—in which all research involving humans should be grounded. This report emphasizes that beneficence is “often understood to cover acts of kindness or charity that go beyond strict obligation. In this document beneficence is understood in a stronger sense, as an obligation” (Office for Human Research Protection, 2010). The report extends the Hippocratic Oath “do no harm” to the realm of research and states researchers have a primary “obligation” to their participants; or in other words, it is *obligatory* for researchers to respect people’s rights, rather than to simply present a show of “good faith.” In this article I consider what this obligation looks like when we engage in community-based participatory research, most especially when working with marginalized and vulnerable communities.

The Belmont Report defines “vulnerable subjects” as “Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized” (“Selection of Subjects”). In this project, I identify our participants as vulnerable, marginalized, and stigmatized; vulnerable because the majority of them were incarcerated while working on this project, and marginalized because many engage in (or are perceived to engage in) highly-stigmatized activities (such as sex work or drug use, etc.). Individuals who are or have been incarcerated are also stigmatized and often viewed as outside the “mainstream” (at least by those who have never been incarcerated). All research raises ethical concerns, and these concerns can be heightened when researchers work with vulnerable, marginalized, or stigmatized communities, which can then significantly impact participants and the research findings and outcomes (Bowen & O’Doherty, 2014; Fine & Torre, 2006; Lutnick, 2014).

I explore the ideological frameworks that underpin conventional and CBPR methodologies to show how collaboration can influence the questions asked and answered, the roles of researchers in the project, and how research findings can better

impact the community at the center of the research. I propose that *how* we engage in research and our research practices impact the questions we ask and answer, how people are represented, and ultimately the material conditions of people's lives.

Ethical research protects participants and creates a study that serves the needs of the participants and society as a whole. While investigators are responsible for maintaining research integrity, in an academic setting the IRB is the final arbiter of what qualifies as harm and the board, in turn, determines required safeguards (Klitzman, 2011b, 2012). In spite of these protections, members of vulnerable populations and community-based organizations have criticized how IRBs define risks and harms associated with research participation, noting that IRBs often approve protocols without community input (Allman et al., 2014; Das & Horton, 2015; Ditmore & Allman, 2011; Gilbert, 2006; Glass & Kaufert, 2007; Kelley et al., 2013; Saunders & Kirby, 2010). Sharp and Foster argue that even though regulations and regulatory boards exist, it can be difficult for established researchers and IRBs to "identify risks involving the disruption of social relationships within communities of which they have little knowledge or familiarity (2002). Similarly, risks that researchers or review boards view as minor may be viewed by study participants (or other members of the group placed at risk) as substantial" (Sharp & Foster, 2002, p. 146). Bromley et al. (2015, p. 900) theorize in their investigation of community-engaged studies: "the shift in ethical focus from subject to participant will pose new ethical dilemmas for community-engaged investigators and for other constituents interested in increased community involvement in health research." I echo these concerns and place them at the center of my work with women who were currently and formerly incarcerated. To do so, I interrogate research methodologies and their underlying ideologies and values to determine how researchers, IRBs, and communities might better work together to center communities in the research.

### *Research Ideologies and Their Impact on IRBs*

Here I document the ethical challenges encountered when community-based participatory research encounters positivistic frameworks upon which Institutional Review Boards typically rely. Positivistic research studies, or those based on the philosophy that "every rationally justifiable assertion can be scientifically verified" (Lexico, n.d.), were the standard for which the IRB was created. The language included in the Belmont Report: "IRBs are designed to safeguard human subjects," reveals the positionality of researchers and participants, placing the researchers' power at the center. In this framework, research is enacted upon a "subject," as in "one that is placed under authority or control," or "one that is acted on" (Merriam-Webster, n.d.). The researcher elicits information from the "subject," and then engages in "doing" research on their minds and/or bodies. The ideologies that underlie this research model impacts how IRBs identify a study as

"research" and determine how it should be facilitated in order to be approved.

The previously-mentioned historic and infamous studies relied on a framework where researchers held the majority of the power and knowledge—they designed the study, determined the research questions, and had the contextual knowledge from which the study emerged. IRBs were created *because* these knowledge and power differentials were the norm and an oversight board was mandated to intervene if and when researchers abused their power. Because research methodologies emerge and change, we have opportunities, as well as the obligation, to investigate IRBs' approval processes and to ask: Who are existing IRB frameworks designed to protect?

CBPR is a multidisciplinary approach that cleaves from positivist and empiricist research and is ideologically different from more conventional research. Within CBPR, co-researchers are primary to the creation of the research questions and methods due to their knowledge of the research area. Researchers participate in the lives of the community they research (Blumenthal & DiClemente, 2013; Sanders & Ballangee-Morris, 2008; Swantz, 2008; Wallerstein & Duran, 2017), and the research goals can ultimately "create social change that can be applied to and potentially transform the community" (McCracken, 2019, p. 10). CBPR derives from Kurt Lewin, Paulo Freire, and Marja-Liisa Swantz's work (Hacker, 2013; Swantz, 2008; Wallerstein & Duran, 2017). Lewin (1946) partnered with community members to develop the research process in the 1940's, and in 1970, Paulo Freire investigated the role of power in research and presents an environment of reciprocal learning with community participants (Freire, 1970; Hacker, 2013, Wallerstein & Duran, 2017). These core concepts, then, are the primary goals of the research: to create partnerships, investigate the role of power in existing relationships, build capacity, and create new knowledge that positively impacts the community at the center of the study.

The ideological frameworks that inform research directly impacts the communities at the center of the research—most especially when populations are marginalized. Because IRBs were created to intervene if power imbalances result in unethical practices, they are designed to "read" research proposals in a particular way. For example, if we consider the Tuskegee Syphilis Study (1972), the academic researcher was not a member of the community being researched (low-income African-American men with syphilis), had more knowledge of the research subject (syphilis) than the "subjects" and was responsible for analyzing and disseminating the research findings. Therefore, the IRB was created to intervene in these unequal power relationships where the academic researcher typically determines the research questions, design, methodology, and protocols, and often studies a group of individuals for a particular purpose (What are the long-term effects of contracting syphilis?). Although other information may be recorded about the research group, that primary question drives the research and determines what knowledge can be obtained. When a study

design does not follow this format, it can challenge how IRBs typically “read” and understand research.

Existing IRB requirements in CBPR projects can potentially harm participants and co-researchers—most especially when they solidify the power differential that exists between “researcher” and “subject.” For example, requiring informed consent prior to data collection with co-researchers in collaborative spaces can deter participation. Although drafted to include accessible language, consent documents can be intimidating and cause a participant to feel ignorant or not capable of participating because legal documents are often a cause for fear, particularly in communities who have had previous negative interactions with law enforcement or other legal professionals. This suspicion may stem from a participant’s fear that the legal document or consent form may lead to recourse from parties who may not have been aware of their inclusion in a marginalized community (for example, as sex workers or individuals who use illegal substances). Aligning the necessity of confidentiality and mandated informed consent can make CBPR particularly challenging.

In addition to feeling intimidated, many marginalized individuals and communities are tired of being “researched,” spoken for, and left behind by external researchers. Often, marginalized communities are viewed by academic researchers as not having the ability or knowledge to speak for themselves, design research, or carry it out to directly benefit their community. Rather, researchers with more institutional power and resources come into communities (often not understanding the issues), to give participants the “opportunity” to participate (often without providing compensation)<sup>1</sup> for the *privilege* of being part of a project that *may* contribute to society but does not necessarily contribute to their lived experience or community. Likewise, these populations often have fewer resources and time to participate in the research itself. And once the data is gathered, the academic researcher often leaves the community, builds their career from the knowledge they gained, and shares it with an elite group who have access to expensive academic journals that require membership or institutional access. Often the findings are not shared with the community and members are left wondering what became of their contribution (aside from bolstering an “outsider’s” career).

As a qualitative ethnographer, I choose to move in close and inhabit, to the fullest extent possible, the community and world of the individuals with whom I create research. I have always been an “outsider” when working with marginalized communities, yet I take additional and thoughtful steps to become more of an “insider.” For example, in our design and development of our research in the county jail, I:

worked to minimize the differences between the women and myself—notably, that I have never been incarcerated. [...] I identified as a professor, researcher, sex worker rights’ activist, mother, and friend who is interested in the women’s lives. I did not lead any of the classes, nor did I advise the women on their actions or plans for the future. I listened as a friend, laughed with them, and joked

about things (as I would in my everyday life) that RT coordinators might not. (McCracken, 2019, p. 33)

The CBPR methodology directly impacts the research design, which in turn can complicate the IRB approval process. For example, because I wanted to capture our research process while we created our CBPR project, I had to educate my IRB and help them understand research “subjects” were also co-researchers—that they helped develop the research, analyze data, and returned to the drawing board when we struggled. These ideas seemed foreign to my IRB, and this challenge led to power imbalances between myself and co-researchers because I was required to outline the procedures prior to co-creating our process together, present them to co-researchers, and then go back to the IRB with amendments in order to integrate the co-researchers ideas, questions, and strategies.<sup>2</sup>

An excellent depiction of how research ideologies differ between more conventional research with CBPR is outlined in Love’s (2011, p. 52) explanation:

An interesting comparison of CBPR and traditional research suggests that traditional research is like an old-fashioned marriage in which the husband (or researchers) has more power and control over resources and decisions than the wife (or community). CBPR, in contrast, resembles the more modern, egalitarian marriage in which both partners (researchers and community) respect and build on one another’s strengths and share resources and responsibilities. Traditional research is typically unidirectional and exclusive, whereas CBPR is collaborative and inclusive.

Many researchers have documented how the positivistic framework built into the IRB review process creates difficulties for CBPR research projects (Banks et al., 2013; Durham Community Research Team, 2011; Guta et al., 2012; Sanders & Ballangee-Morris, 2008). Many researchers have also explored the numerous challenges they face when proposing CBPR to IRBs (Glass & Kaufert, 2007; Flicker et al., 2007; Love, 2011).

IRBs often interpret research as studies where researchers have more power than—or over—participants. This hierarchy may not directly benefit those who are at the center of the research, but rather general scientific knowledge. When participants are co-researchers, the hierarchical relationships are *flattened*, so to speak, and the researcher is no longer the all-knowing individual who makes the decisions. This project has led me to consider how many of the IRB “protections” can further stratify research, create power imbalances, and impact the ethical framework of the research and ultimately what and how knowledge is created.

### *What Is the IRB’s Role: Adversary, Protector, and Partner?*

IRBs protect human subjects, and they also serve to protect academic institutions from potential lawsuits that could emerge as a result of research. Hessler et al. (2011, p. 149) note that when they interviewed five of the 14 IRB members in their

study, they “learned that all of them believed that protecting the university from lawsuits was more important than blowing the whistle on research subjects who might be breaking the law.” IRBs can place protecting the university from legal action as a priority above all else. As Malone et al. (2006, p. 11) argue: “The current ethics culture of academia may sometimes serve to protect institutional power at the expense of community empowerment.” I do not believe this sort of protection was the case for my project, and yet it does happen, and it is important for researchers to understand the many perspectives the IRB must consider and represent in their considerations.

It is vital that we shift the IRB’s role from an adversary, protector, and/or gatekeeper alone to a partner that helps researchers conduct more ethical and inclusive research. One way this relationship can change is through increased education for both IRBs and researchers. As Levine and Skedsvold (2008, p. 504) argue “by increasing opportunities for researchers and IRB members to discuss issues surrounding human research protections, the overall system becomes more transparent, and the groundwork is laid for building trust in the process.” IRBs need to work with increased efficacy and efficiency in order to make CBPR sustainable and create more inclusive and ethical research practices.

### *Participants as Co-Researchers and Co-Creators of the Research*

Effective CBPR demands that participants are co-researchers and co-authors and that their knowledge, experience, and expertise are central to the research questions, design, and facilitation. Even more importantly, their involvement at this level creates a partnership with shared control and directs what findings and outcomes emerge. As Winterbauer et al. note, “whoever makes decisions during the research process controls the direction and consequently, outcomes of the research itself” (2016, p. 5). Most importantly, the research questions must be developed in tandem with the community engaged in the research, which directly impacts what findings can emerge from the study.

I have worked with multiple IRBs to approve research protocols—always with vulnerable populations—and consistently find obtaining approval to engage in a CBPR project incredibly difficult because IRBs do not consider research participants as partners or accept flexible research practices. Due to this schism, the approval process can stretch out over months or even years. The time it takes to approve such research can leave researchers reluctant to continue pushing for approval, and as Fiske (2009, p. 30) states “what IRBs usually fail to consider is that the university’s research can cease if the researchers become so frustrated with the local logistics that they all leave or give up.”

When participants are co-creators of the research, the ethical issues that arise in the study shift necessarily: no longer does the researcher have power *over* co-researchers and participants. Rather, researchers try to work as *equals* and draw upon different knowledge bases to create the research design and new

knowledge together. The crux of this type of ethical engagement is power, and to maintain equal involvement as much as possible, the co-researchers are valued and empowered as researchers on par with the principal investigator.

Researchers and community co-researchers can also share the data analysis and document the findings from a variety of perspectives. Notably, the “findings” can then be disseminated directly to the community in the most effective format that is most useful *for* the community. This process can be outlined during the research design phase and revised as warranted (Glass & Kaufert, 2007).

### *Research Practices That Challenge Positivist Ideologies*

I present examples from our CBPR project and include how institutional frameworks (IRBs, universities, and jails in this case) understood and responded to co-researchers and their potential contributions to the research so that we can learn from these challenges, create institutional education, and creatively work to conduct research, preferably with institutional support, with those most impacted at the center of the project. Learning opportunities emerge when CBPR tenets intersect with traditional IRB requirements.

Although not directly related to IRB requirements, I also include the challenges we encountered because we chose to work with women who were currently incarcerated. I include it to inform researchers and encourage community partners to consider how these potential delays, decisions, and variables might impact the study, the participants, and ultimately the research findings and outcomes for the community. The inside jail study required a letter of approval from the jail, and their approval process was lengthy and created a one-year delay. I drafted the jail’s letter of support in January 2016 and did not receive their letter of commitment (after multiple reminders and requests) until March 2017. During that time, jail administrators and I discussed how we could conduct the study inside the jail. For example, the research group had agreed we wanted to give participants two gift cards for their initial participation in the project, but compensating people while currently incarcerated, even after their incarceration, was strictly denied. We tried to work around this inequity by inviting participants, upon their release, to join us in the outside jail study where they could be compensated for their participation.

We also wanted to have women who were currently incarcerated facilitate the groups with other women (rather than me, as an outside researcher). We called these individuals Red Tent Facilitators, or RTFs, and we hoped it would allow for greater ease and communication because everyone in the group would have experienced incarceration. The jail administrators did not want the “inmates” to appear to have power over other “inmates” and therefore, would not allow RT participants to facilitate groups inside the jail. We also wanted to serve food at our research gatherings, and they denied this request as well. We incorporated all of these practices in our outside jail study, and we had hoped to create the same conditions on the inside.<sup>3</sup>

*Research is not always straightforward, linear, or designed by outsiders.* It bears repeating that IRBs were *designed* to recognize research as a linear arrangement whereby approval is sought at the beginning of the process. This lack of a straightforward path within CBPR can lead to one of the most uniquely challenging aspects of this research. Within CBPR, the research process is usually not linear; it starts from one point and spreads out in a variety of directions—some of which stick and become foundations of the work and some that shape the work but are left behind. For example, in my study, I began the research process with questions in the specific areas I wanted to address: incarceration, violence, and trauma; but as the group progressed, the women determined which questions were most important and potentially impactful.

Because the process is not linear, it is difficult to lay out the research steps as IRBs require—primarily because there are many unknowns at the beginning of a research project and much of the methodologies develop within the research process itself. This natural progression is essential when we value co-researchers as equals—we can inclusively engage everyone in a way that is most comfortable for them, potentially creating a stronger research design which can result in better findings, outcomes, and impact. When our co-researchers became central to the project, our entire focus changed. Rather than focus on the relationships between trauma and incarceration, we decided there were three key areas we wanted to explore: trauma, mental health and illness, and substance use and abuse. We soon found these three areas were inextricably entwined, and we came to this understanding in our discussions in both inside and outside jail groups. This shift not only changed what we asked, but how we wanted to gather the data and present our findings.

*Integrating collaborator values and goals.* There are activists, scholars, and community groups who are actively working to help researchers be *better* researchers and, more importantly, *better* collaborative research partners (Boilevin et al., 2019; Ferris & Lebovitch, 2013; Lebovitch & Ferris, 2018). Flicker and Guta (2008, p. 3) argue: “Institutional review boards and researchers should be encouraged to adopt localized context-dependent strategies that attend to the unique vulnerabilities of their particular study populations.” The CBPR framework is designed to address challenges participants may encounter in the research process because members of the community engaged in the research are directly and uniquely familiar with the distress that may occur as a result of the research process itself. In our project, a co-researcher suggested we ask participants to draw a map or timeline of significant events that had occurred in their past and discuss how these events may have been related to their incarceration and, if applicable, recidivism. Another co-researcher objected to this strategy because she thought this recollection would be painful for participants and potentially distract them from the group’s conversation. After much discussion, we decided each facilitator would talk with their group and determine if they wanted to incorporate that activity into their group, leaving the decision up to the women

it would impact. Underpinning CBPR research is the ideological framework of responsiveness to the needs of co-researchers to create research that aligns with the aims, needs, and values of the community at the center of the research.

*Amending the research processes—leadership, investment, and timing.* Our process continued to emerge and shift as the research unfolded, and we had to submit amendments to the IRB for each change. For example, I initially designed the study to hold focus groups with women who were currently incarcerated because in my talks with RT employees and participants, we determined that holding one focus group with the women inside the jail would be the best way to gather many individuals’ opinions about incarceration and recidivism. However, once we held these focus groups, we found that the women wanted to continue to meet and form an ongoing research group—which necessitated an amendment and time spent waiting for approval.

When amendments are required by the IRB, delays occur, which then affects the research itself. Delays create a lack of flow between what the group wants and what it can achieve. In our case, none of the people who were engaged in the initial focus group were still involved in the process when the next phase of the project was approved. This situation occurred multiple times in our 4-year project.

*Institutional challenges and power imbalances: Hiring from within “Vulnerable” Communities.* Researchers must compensate people for their time and expertise. Researchers are being paid by their institutions or external funders to engage in research, and it is inequitable to expect participants to engage without compensation. When I began this project, I planned to hire research assistants (RAs) who were RT participants who had been incarcerated. RT works with women inside and outside the jail, and I wanted to hire people who had direct experience with incarceration and compensate them for their time and expertise. When I discussed this option with RT staff and volunteers, we decided to advertise for RAs on RT’s Facebook page. Fortunately, I was awarded a University of South Florida St. Petersburg Internal Research Grant and was able to use this funding to employ RAs who were uniquely situated to do this work.

In general, it is challenging to hire someone with a criminal record, and my institution was no different from many. Initially I was told I could not hire individuals with criminal records, and I had to emphasize that part of the job *requirement* was to have been formerly incarcerated, which meant the employee would necessarily have a criminal record. At my institution, every potential employee must go through a background check, and if an individual has a criminal record, they are evaluated on a case-by-case basis. In some situations, the case will go through the general council, which requires an interview before the individual can be approved for employment. Ultimately, I was able to employ both RAs, but it required a significant amount of time (over three months) and both women were required to have an extensive phone conversation with a

university lawyer about their pasts and their criminal records. The lawyers also required that the RAs not have access to money or funding and were not allowed to supervise anyone. These requirements and constraints were problematic and further emphasized the power differential between us. Although it is clear when I hire someone I am their “supervisor,” I actively strive to create relationships where we come together as equals to bring our unique skill sets and expertise to the project.

These requirements took time and energy for everyone involved and were particularly stressful for the RAs because they had to discuss their pasts in detail and then wait to find out if they could be hired. I wanted them to work on the project because of their experience with and expertise about incarceration, and yet having a criminal record was the primary obstacle in their hiring process. I was told the university had not previously hired RAs who had criminal records, and I explained that this is something we would continue to do and therefore needed to figure out the process and decrease the barriers and time required to become employed. This lengthy process made me wonder if the women would have been hired had I not expressed explicitly that having a criminal record was a *requirement* of the position. All of our positionalities make us uniquely situated to create the questions, analyze the transcripts, interview each other, and present the results.

### *Allowing CBPR to Shape and Teach Us*

Banks et al. (2013, p. 274) document many of the challenges CBPR projects encounter with research governance:

Institutional codes of ethics and research governance frameworks generally pay little attention to participatory research. They assume that researchers from research institutions are in control of projects and have complete responsibility for ensuring ethical practice. They assume predictability rather than flexibility in the research process, tend to be “risk averse” and may categorise community researchers in the same way as research participants who are simply informants. Policies, frameworks and forms need to be re-thought to take account of these complexities—both to support CBPR and to take account of other forms of knowledge mobilisation and exchange that do not fit existing categories.

A CBPR project’s methodology and underlying assumptions are different from conventional research, and therefore, I would argue, could not be used, for example, to produce the infamous and unethical Tuskegee study. Tuskegee is particularly atrocious, and I include it because it is difficult, if not impossible, to imagine that Black men, the majority of whom had contracted syphilis, would create a study that examined the long-term effects of untreated syphilis, especially after an effective treatment was found. What we find is that conducting research with the population most affected by and knowledgeable about the research topic can lead to greater consideration about *how* the research process may ethically impact participants, and different, if not even more useful, findings may result. Shore et al. (2011, p. 19) state, “Strengthening

communication and coordination between CRPs [community-based review processes] and I-REBs [institution-based research ethics boards] may lead to improved understanding of each other’s roles and contexts, stronger working relationships, and ultimately more efficient and thorough reviews of CEnR [community-engaged research].”

To respond to these challenges, I call IRBs, researchers, community partners, and communities to work toward more inclusive CBPR practices to ensure community input in research.

### *Recommendations for Researchers, IRBs, and Community Organizations and Partners*

I outline several recommendations that can help ensure a more productive working relationship for CBPR researchers, IRBs, and communities. These recommendations promote more efficient and community-centered practices that can lead to more effective research outcomes and impacts for all groups, specifically marginalized or vulnerable communities.

*For IRBs.* Consider asking researchers to provide the following information to the research community and IRB in order to obtain approval:

- Information about themselves and their relationship to the research topic and/or research communities;
- A description of how the most-impacted communities have been involved in research design, the development of research questions, and ethics applications.

Know that CBPR is not linear or straightforward and consider offering greater flexibility in these projects so that researchers and community members can determine what will work best for the community. In many ways, the researcher may not know the best ways to gather the data, determine next research steps, and move into new areas of research. Work to create flexibility initially to alleviate multiple amendments and delays for approval and read applications with an eye toward flexibility and options.

IRBs and researchers must work together to establish a process that is less bureaucratic and cumbersome. Allow researchers to integrate multiple scenarios from which they can move forward so that if the initial one does not work for the community, they can try a different one without having to create an amendment and return to the approval process (for example, meeting once or several times with key groups of people). Integrate these discussions into the process, findings, and future research steps.

*For researchers.* As I have continued my work with my IRB, I take the time to talk with them about the projects to determine where the potential pitfalls may lie (for instance, paying collaborators cash to participate in interviews) and how we might work around these challenges. Oftentimes they help make me aware of what will and will not be allowed prior to writing and submitting an application. Speaking with the IRB manager and



Chair of the IRB has been invaluable and has saved me a lot of time and energy that I would have spent otherwise revising and updating protocols, amendments, and other required documentation.

Simultaneously, it is also imperative to work with the community to:

- Ensure the central research questions are coming from the community.
- Determine how the information should be gathered and disseminated. For example, determine what format would be most useful for the group and integrate this dissemination into the project. When you publish your results, publish in community-based and academic journals that are directly accessible to the community. Increasingly academic journals are no longer behind paywalls, making research findings accessible to everyone. Also co-author articles with community members.
- Meet with your Quality Assurance/Quality Improvement (QA/QI) Program affiliated with your IRB prior to and during your study design to discuss potential CBPR complexities and how the community will be integrated into the process. Educate them on the importance of CBPR research and adequately fund research participation with cash—not gift cards (see McCracken, 2019 for a detailed explanation of the importance of providing cash rather than gift cards or other incentives that may not be directly useful to the community).

The QA/QI Research Compliance Managers were there to help me document the process for annual continuing reviews (and potential audits) as well as to explore which research tools could best capture the most important data without compromising confidentiality. They were available to talk through ethical issues and are now the first people I approach to change how IRB administrators understand and delineate what constitutes “ethical” research and how community partners and collaborators can be integrated, especially within CBPR models.

*Community review board (CRB).* The Meharry-Vanderbilt Community Engaged Research Core explain (2013, p. 4): “The Community Review Board creates a framework for community experts to review and provide immediate feedback to the investigator on specific areas of concern before the research project is implemented.”

- Try to locate a CRB that has expertise in your research area and then determine how IRBs might collaborate with or co-review the CBPR project. This step will necessarily require additional time and resources, but it will also work toward ensuring that the community (rather than academia, its lawyers, and its reputation) is at the forefront of determining if a research study poses harm to co-researchers.
- Talk with your IRB chair and committee and your institution’s QA/QI Program to educate them about Community Review Boards (CRB) that work to protect and

support the community engaging in the research. As Boilevin et al. (2019) argue, integrating the CRBs perspective, in addition to academic or institutional review boards, allows an application to be considered from a variety of perspectives.

- Budget support for a CRB into grant applications so that the community provides oversight for the project, especially if they work with other researchers and institutions.

The Meharry-Vanderbilt Community Engaged Research Core state this collaboration benefits both the researcher and the community (2013, p. 3):

After participating in a Community Review Board, researchers often remark that they wished they had done so earlier in the development of their research project. The input they received from community members proved invaluable and in retrospect could have saved them a lot of time and effort in the planning of their community based interventions, in building community partnerships, and in recruiting community members into their study. [...] Community members, too value the opportunity not only to learn about research and how it can benefit themselves or their community, but also to contribute to its development and execution in a way that increases the researchers understanding of, and sensitivity to the community.

Community review boards can be instrumental in their review of research plans to determine potential risks for the community members’ and organizations’ perspectives.

*Certificate of confidentiality.* Consider obtaining a Certificate of Confidentiality from the National Institutes of Health (NIH) (if warranted by the research project and especially if you work with marginalized or vulnerable communities). A Certificate of Confidentiality (CoC) can “protect the privacy of research subjects by prohibiting disclosure of identifiable, sensitive research information to anyone not connected to the research except when the subject consents or in a few other specific situations” (NIH, 16 January 2019). Researchers can use this certificate to legally refuse to disclose information that may identify participants in federal, state, or local civil, criminal, administrative, legislative, or other proceedings, such as a court subpoena. The researchers can use the certificate to resist demands for information that would identify participants.<sup>4</sup> Researchers may obtain this certificate after IRB approval has been granted. This certificate legally protects the research group from most requests for information, but also shows that your group is actively working to maintain participants’ privacy. Once IRB approval has been granted, the CoC application and approval process typically takes about two weeks.

*The research process.* Determine if documenting the research process itself is important to your project. If it is not essential to capture that data, work with the community to design and write the IRB application or, at a minimum, to lay out the most

significant steps of the study prior to submitting the IRB application.

- Talk to the chair of the IRB committee about their familiarity with CBPR research protocols and perhaps attend the board meeting when your protocol will be discussed in order to educate and inform the IRB of any issues they may find concerning or problematic.
- Familiarize yourselves with other CBPR protocols that have been approved, preferably within your same institution, if possible. Talking with other researchers and from personal experience, IRBs not only vary by institution, but they vary in how they understand and implement ethical standards, especially regarding CBPR projects.
- Be aware that the research process will most likely take more time than more conventional studies—both in working with the community and obtaining IRB approval—but the knowledge gained throughout and as a result of the research is invaluable.
- Finally, do not give up. Persevere. Your group can make it happen. I became frustrated many times during the research process, and at one point considered giving up and ending the project. If you get discouraged, connect with colleagues, community organizers and researchers to talk about ideas, obstacles, and the research in general. My colleagues were influential and incredibly supportive during challenging times. They assured me the research was important and the obstacles and challenges have ways of teaching us.

If we value CPBR methodologies, we need to educate IRBs and ourselves to determine better frameworks whereby co-researchers and collaborators can work together equitably to design the research process and engage in the research together. This shift *will* require IRBs to reconsider conventional research as the ideal or norm and develop oversight tools that bring community researchers into the process. Research design directly impacts research findings, who has access to those findings, and how they are disseminated. When we shift our perspectives (IRBs, academics, and community partners), we can change how research is conducted in the world, which then has implications for ethical research practices and ultimately lived experience. In order to facilitate this shift, we need to place the communities at the center of the research.

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### Notes

1. See McCracken (2019) for more information on the need to compensate individuals when they participate in research.
2. This process is documented in McCracken (2019).
3. For a more detailed explanation of this process, see McCracken (2019).
4. The certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of federally-funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA). A certificate also does not prevent a participant or a member of a participant's family from voluntarily releasing information about participants or their involvement in this research. If an insurer, employer, or other person obtains written consent from participants to receive research information, then the researchers may not use the certificate to withhold that information. And finally, the certificate cannot be used to prevent disclosure to state or local authorities of child abuse and neglect, or harm to self or others (NIH, 16 January 2019).

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