Investigating Membership on University Institutional Review Boards: The Case for Social Work*

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Abstract

The mission of institutional review boards at universities is to protect human subjects. Social workers, given their professional obligation to ethical and just research along with their holistic training, are well-suited to address these ethical responsibilities. Additionally, this provides insights into communities from which social workers can promote macro advocacy.

Keywords: ethically responsible research, social work, institutional review boards, higher education, macro advocacy

Introduction

In this article we review the origins of institutional review boards (IRBs), citing their necessity in regulating the production of ethical research. We examine the number of social work researchers that serve on social-behavioral IRBs at all universities in the U.S. designated as "very high research activity (VHRA)" by the Carnegie Foundation. All research with human subjects performed in association with universities must have IRB approval prior to the commencement of

research activities in order to ensure the protection of the physical/mental health, rights, and privacy of participants. Since VHRA universities are by definition the most active research universities and therefore institutions in the U.S. (and a great deal of this research involves human subjects) it is important to understand who serves on the board that determines what responsible, safe, and ethical research is. Furthermore, as researchers have noted, what constitutes risk, harm, and ethical differs depending on whether research falls under biomedical or social-behavioral lines (Labott & Johnson, 2004). By ethics, we mean the rules by which people discern right from wrong, and which govern research behavior (Olen & Barry, 2010). We argue that for several reasons, namely a professional obligation to advancing human rights, a commitment to enhancing social and economic justice, and a profession-wide Code of Ethics (NASW, 2008), social workers are uniquely suited to apply their expertise in producing rigorously ethical scholarship to university research through their involvement in social-behavioral IRBs. At the same time, serving on IRBs can alert social workers to the needs of the community so that they may be better able to serve their communities.

Background

Institutional review boards (IRBs) were created to protect human subjects and to ensure ethical integrity in academic research. Established in reaction to a series of infamous research studies, IRBs were created by the U.S. federal government through the National Research Act (1974) to prevent such abuses in future research. This included instances such as the Nuremberg trials, the Tuskegee experiment, Stanford prison experiment, and the Milgram experiment, which perpetrated gross ethical and harmful violations of human participants. The Nuremberg trials (1947) revealed the atrocious experiments Nazis performed on humans, which resulted in the Nuremberg Code, in which judges codified ethical requirements and human protections for conducting research. This code is regarded as the first international standard for protecting human research subjects. In the Tuskegee experiment (1932-1972), a group of African-American men with syphilis were given free medical exams but not informed of their medical condition, and even when a cure became readily available in the 1950s, they were not treated with it. Several of the men died due to complications associated with the disease (Heintzelman, 2003). In the Stanford prison experiment (1971), a group of Stanford students were assigned to be either guards or inmates in a mock prison that resulted in trauma for all participants created by the brutal treatment of the students-as-guards directed toward the studentsas-prisoners. In the Milgram experiment (1961), which sought to study the obedience of participants, the participants were told to shock another person if that person answered a question incorrectly. Although the experiment was staged and no one was shocked, participants were led to believe they were, in fact, shocking another person, which caused them psychological harm. Taken together, these experiments raised professional, safety, and ethical concerns over the twin needs of protecting human subjects from such abuse and creating a process of informed consent whereby participants understood the nature of the research they were being asked to participate in.

In order to prevent such ethical violations and abuse in future research and to ensure the rights of participants, IRBs were created to maximize the responsibility of the researcher to conduct research with minimal harm to participants. The passage of the National Research Act (1974) created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to study and generate U.S. federal guidelines on performing ethical biomedical and social-behavioral research. This commission established IRBs as the responsible party that provides oversight to ensure protections of human subjects and created extra protections for vulnerable populations (e.g. prisoners, pregnant women, and children). To that end, this commission also sponsored the Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1979), which continues to provide ethical and practical guidance for the protection of human subjects involved in all research that receives federal funding, including universities. Emphasizing the values of justice, beneficence, and respect, it does so through the use of informed consent, assessment of risks and benefits, and subject selection, respectively.

The National Research Act requires all U.S. institutions which receive federal funding and conduct research with human subjects (e.g. universities, hospitals, foundations) to have an IRB. IRBs are comprised of both members from the institution and non-affiliated community members. The community members must include both lay people and professionals to ensure that the full range of views of community residents are being adequately represented and voiced in research decisions. For example, any proposed research being conducted on prisoners must have a prisoner representative from the community (a former prisoner) participate in the decisionmaking. For many academic institutions review boards are typically divided into bio-medical and social-behavioral. Bio-medical review boards tend to oversee research conducted in the medical sciences, while social-behavioral review boards tend to manage participant protections within research conducted in the social sciences. In order to conduct research on human subjects, researchers must obtain IRB approval for their proposed study prior to conducting research activities.

Very high research activity universities (VHRA), formerly referred to as Research-Intensive, or R-I, according to the Carnegie Foundation, were selected as the sample for this study because they generate a great deal of research in the U.S. Further, as members of the social work field and as one author serves on a socio-behavioral IRB at a VHRA university, who reviews applications for ethical considerations, we sought to investigate to what degree members of social-behavioral IRBs come from social work. We focused on this question for three main reasons. First, given social work is governed by its own Code of Ethics (NASW, 2008) that has a professional obligation to conduct research that advances human rights, it stands to reason that there would be many IRB members from social work. This would also seem logical given social work training is holistic at the micro, mezzo, and macro levels, which provides a broad range of experiences with diverse research populations. Second, such training and clinical experiences have obvious benefits in the oversight of such wide-ranging submissions as the IRB receives and the varied ethical considerations these diverse submissions require. Finally, serving on IRBs would give social workers insight into what projects are going on in their communities. Such information could help guide social workers in their advocacy for macro changes in policy and treatment development.

Methods

Of the 108 VHRA research universities in the U.S. listed by the Carnegie Foundation, we have data for 104 universities, or 96% of the total cases. Data was collected in two ways. First, we contacted the Federal Office of Human Research Protections, the regulatory office of the federal government that provides oversight and assistance for research with human subjects, and obtained the current roster of IRB members for every IRB filed with that office (over 79,500). From this data we determined the discipline of members of the social-behavioral IRBs for 103 VHRA universities. For our second means of data collection, we gathered information from the social-behavioral IRB websites of the missing schools and emailed schools for which rosters were not immediately available. One university keeps IRB members confidential. Using these methods, we were able to collect 104 of the 108 VHRA universities. Given every member was listed by what field they were apart of (e.g. Medicine, Psychology, Anthropology, etc.), we found only 51 of 1,946 members of socio-behavioral IRBs at VHRA universities, or 2.6%, come from social work (A note on methodology: in the cases that there was only one IRB, data were analyzed to include social workers in order to demonstrate the maximum amount of social work participation on IRBs at VHRA universities). Given this low percentage, we argue that universities can benefit from having more social work scholars serve on IRBs and social workers can benefit from serving on IRBs for several reasons elaborated below

Discussion: Social Work Offers an Informed Ethical Perspective

Social workers, as social workers, bring an important and unique perspective to IRBs in three main ways; (1) commitment to ethical standards; (2) a focus on social justice; and, (3) a holistic training. Furthermore, serving on IRBs provides social workers an opportunity to learn the needs of communities they serve. Doing so, they are better positioned to create and advocate for meaningful and important macro policies in addressing the needs of the communities they serve. Historically, social work began as a response in the form of evidence-based research and informed policy recommendations, to structural causes of poverty and injustice (Trattner, 1998). Professionally governed by a strict code of ethics (see National Association of Social Workers (NASW) Code of

Ethics, 2008), or a set of values and standards; these guidelines provide ethical standards for the responsibilities that social work professionals have to their clients, profession, and society (Hepworth et al., 2013). Similar to other professions with a code of ethics (e.g. psychology, clinical counseling, family therapy, etc.), such guidelines include engaging in research with careful consideration for the potential consequences of subjects; with informed, voluntary consent (that protects participants from any harm) and that is confidential (NASW, 2008). Given this ethical commitment to the wellbeing of individuals and society (NASW, 2008), universities could benefit from more social workers serving on socialbehavioral IRBs because social workers bring a unique and informed perspective to the protection of human subjects and the conduct of ethical research.

Social Workers and Ethical Responsibility

Social workers have a professional responsibility to justice, beneficence, and respect for clients and research subjects alike (Council on Social Work Education, 2006). These three values are the same principles IRBs are designed to protect. According to this profession-wide code of ethics, social workers have an ethical responsibility not only to advocate on behalf of clients but to evaluate structures and policies of society (i.e. welfare agencies, domestic violence laws, disaster relief policies, etc.). This code informs social workers' professional conduct in two main ways that are unique to social work. First, the NASW code dictates that social workers advocate for legislation and social policies that promote social justice and provide needed resources (Hepworth et al., 2013). Second, social workers have a professional and ethical obligation to advance human rights by studying forms and mechanisms of oppression and discrimination (Hepworth et al., 2013). Taken together, these aspects of the social work profession create a professional and ethical responsibility for social workers in conducting their research. Social work professors who serve on IRBs extend this professional and ethical responsibility, as well as their experience in these matters, to research across their university.

Social Work Ethics' Importance to Accreditation

In addition to the profession-wide code of ethics, the Commission on Accreditation board for the Council of Social Work Education, which is the body that governs accreditation of social work education, mandates high ethical standards in a number of key ways. First, accreditation dictates that practitioners be trained to treat problems across multiple societal levels, such as the individual, community, and macro levels, in order to make social work as a profession more responsive to the needs of oppressed groups (Hepworth et al., 2013:26). Second, social work curriculum requires students to learn the role of NASW Code of Ethics in their practice and research and to utilize four core ethical issues: self-determination, informed consent, professional boundaries, and confidentiality (Hepworth et al., 2013:57; NASW 2008). These four core ethical tenets are also essential in IRBs' protection of human participants. Lastly, social work professionals' first obligation is to the protection of human subjects (Hepworth et al., 2013). Such a professional orientation and obligation bodes well for university IRBs designed to protect human subjects in empirical research from ethical abuses, psychological and physical harm. Since social workers must abide by strict ethical commitments in accordance with their professional values, often termed responsible conduct of research (RCR), they are primed for overseeing ethical guidelines established and promoted by IRBs. This attitude extends not only to research but also to all professional responsibilities (Anastas, 2008).

Social Work and Social Justice

Social work, with its emphasis on social justice (see Gasker and Fischer, 2014; Reamer, 2014), brings an important orientation to IRBs. This focus helps to ensure potential subjects are not only fully protected but also will have just and fair participation experiences. This is especially important given

the high remunerations that researchers may try to offer that often can be construed as coercive. This is also true for vulnerable populations (e.g. pregnant women, children, and prisoners) who require greater protection from possible research abuses. Social work teaching and research not only values culturally sensitive research but also works to discover and cultivate better ways of conducting sensitive research that are more beneficial for individuals (see Jackson, 2010; Bowles & Hopps, 2014). Such an orientation provides both skills and a vantage point with which to assist other members of the academic research community to develop more sensitive and just studies. In recognizing these major concerns in conjunction with social work's core values of beneficence, justice, and respect, the Council on Social Work Education (CSWE), the accrediting body for schools of social work, calls for social work researchers to join university bodies that design and distribute research regulations and policies (CSWE, 2006). Specifically, the CSWE calls on social work professors to join their local IRBs in order to protect the interests of human subjects (CSWE, 2006). Accordingly, social work researchers, through their professional experiences and obligations to beneficence, justice, and respect, have much to offer IRBs.

Importantly, it would be inaccurate to conceptualize these two governing bodies of professional social work, NASW and CSWE, as mutually exclusive. They are inter-related and both contain feedback mechanisms that guide and inform the policies of each body moving forward. For example, as the practice environment changes for NASW social workers in a clinical setting (e.g., changes to reimbursement polices of Medicaid), CSWE revises its educational policies of required material in accredited MSW programs to account for this new information. One of the most important requirements of CSWE, which enhances the benefit of having social workers serve on IRBs, is the CSWE requirement that faculty in accredited MSW programs must have at least two years of professional, post-MSW, practice experience in order to teach MSW practice classes (evidence of policy adherence is most frequently demonstrated in CSWE accreditation reviews by being licensed to practice social work in the state where the faculty member is employed). We argue that this practical experience is essential in identifying subtle nuances of risk in studies that come before IRBs.

For example, in a recent study that came before our socio-behavioral IRB, a Principal Investigator was seeking to evaluate a trauma intervention for children exposed to gun violence by having the Informed Consent form for the study simply appended to the end of the form used by the agency for the trauma counseling service. Having worked many years as a social work practitioner with traumatized children, the social worker on the IRB pointed out: (a) how confusing this might be to parents, particularly those also dealing with trauma themselves; and, (b) that many parents would likely conflate the study with the counseling service, which would make them think they had to participate in both if they wanted their child to receive the counseling service. Had the social worker not been on the board, we believe the IRB would have endorsed the study as it was originally proposed, since it had a technically correct policy for both Informed Consent and Assent procedures and none of the other IRB members had registered any objections to it.

Social Work and Holistic Training

Having training in theories and methods that address individual, family, and macro levels of analysis, social workers are exceptionally situated to have deep insight into a wide-range of research projects and topics. Doing so provides them valuable experience that could be used to address concerns faced by IRBs. For example, IRB submissions cover a wide range of academic, policy, and research concerns that must be adequately addressed for approval. Further, submissions to social-behavioral IRBs come from disciplines as diverse as anthropology and public health, which typically focus on different levels of society (e.g., individual and community) and utilize a wide-range of methodologies (e.g. ethnography and program evaluation). Experiences and insights garnered by social workers from their training at multiple levels of analysis in multiple methodologies, ranging from ethnography to program evaluation to quantitative analysis, uniquely situates them to inform and guide the IRB process.

Social Work and Macro Advocacy

Finally, serving on IRBs will provide social workers insights into needs of the communities they serve. IRB membership helps the university know what types of projects are taking place in a community, which has direct implications for our obligation for macro advocacy. Put another way, social workers are in a better position to advocate and protect community members since they know what kinds of things are happening in their communities and what researchers are asking of them. Creating such macro advocacy also fulfills another aspect of the stated code of social workers, which is to reveal systemic inequalities and develop policy that promotes a more equitable society (see Brueggemann, 2014; Payne, 2014). Developing informed macro social policy has ramifications across society and can improve treatment options for a range of issues many social workers face (e.g. substance abuse, intimate partner violence, family violence, etc.).

Conclusions

We argue that social work academics are uniquely situated to provide ethical rigor to socialbehavioral IRBs at VHRA universities due to their professional obligation to protect human subjects from harm, profession-wide code of ethics, and required educational training in conducting ethical research. Given this conclusion, our finding that only 2.6% of social-behavioral IRBs at VHRA universities are made up of social workers is distressing. With their commitment to high ethical standards, central focus on social justice, and holistic training, social workers are well suited to extend their expertise to university scholarship by participating in socio-behavioral IRBs. Furthermore, serving on IRBs fulfills the ethical obligation put

forth by social work associations, Council on Social Work Education and National Association of Social Workers. Finally, serving on IRBs will provide insights into community needs from which social workers can develop macro policies and treatments. Social workers' leadership and guidance will have significant benefits to research subjects, especially vulnerable populations, and their commitment to social justice will increase the probability that "bad" or "unethical" research practices can be avoided. Lastly, we encourage social workers at VHRA universities, then, to contact their IRBs to figure out how they might be able to serve on these important research regulatory boards. Social workers not attached to VHRA universities may also be able to serve as community members to boards and serve in advisory roles in order to use their professional skills and ethical commitments to bettering academic research and ensuring human participant protections.

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