A re-examination of the relationship between action research and human subjects review processes

Mary Brydon-Miller and Davydd Greenwood

Action Research 2006 4: 117
DOI: 10.1177/1476750306060582

Action Research

Volume 4(1): 117–128

London, Thousand Oaks CA, New Delhi
www.sagepublications.com
DOI: 10.1177/1476750306060582

ARTICLE

A re-examination of the relationship between action research and human subjects review processes

Mary Brydon-Miller
University of Cincinnati

Davydd Greenwood
Cornell University

ABSTRACT

In this brief article, we review the history of the human subjects review process and identify key aspects of that review as they relate to action research. In particular, we examine the issues of coercion, predictability, confidentiality, and risk – concerns central to the criteria used in current review processes but reflecting fundamental differences in the basic conceptualization of ethical practice as this is understood in action research.

KEY WORDS

- action research
- human subjects
- institutional review board (IRB)
- research ethics

As the articles included in this special issue make clear, ethical concerns related to the development, conduct, and dissemination of action research shape the basic nature of our practice regardless of whether we work in settings requiring formal human subjects review, and even for those of us who do, these concerns extend far beyond the point at which the researchers receive approval for their work from the Institutional Review Board (IRB). Notwithstanding this, the way this process influences practice constitutes an important aspect of research ethics for academic action researchers and our community partners. In this brief article, we review the history of the human subjects review process and identify key aspects of that review as they relate to action research. In particular we will examine the issues of coercion, predictability, confidentiality, and risk – concerns central to the criteria used in current review processes, but reflecting fundamental differences in the basic conceptualization of ethical practice as this is understood in action research.[1]

A brief history of institutional review boards[2]

The chain of events leading to the creation of institutional review boards (IRBs) is long and complex. Though there have long been debates about the ethical treatment of human research subjects, probably the most immediate cause of attention to these issues were the genocidal medical practices of the Third Reich that resulted in the Nuremburg Codes (Anderson, 1996). Subsequent international declarations on human rights and informed consent created an environment in which the free play of professional and funded research came to be subject to scrutiny. Beginning with the Helsinki Declaration of the World Medical Association in 1964 and subsequently revised a number of times, these codes came to include consideration of the following issues: substituting laboratory and animal experimentation for experimentation on human subjects; having independent committee reviews of research protocols; having informed consent; insisting on the professional qualifications of the researchers; and making certain that risks were outweighed by benefits. The US Public Health Service weighed in with specific structures for review boards as early as 1966. Subsequently the Belmont Report published in 1979 elaborated these notions (see Sales & Folkman, 2000 for a copy of the text of the report). The first clear statement of federal US policy was the Federal Policy for the Protection of Human Subjects (Federal Register, 18 June 1991, Sections 46.101–124). This policy prohibits the use of Federal funds without prior IRB review and, for the purposes of research universities in the United States, this has meant that all research involving human subjects potentially endangers the federal funding of these institutions, resulting in blanket processes of oversight and approval of researchers and research projects.

In addition to this increased oversight of research on the international and national levels, a number of instances of studies in which human subjects were either knowingly or unwittingly exposed to physical or psychological harm – the Tuskegee syphillis study (Jones, 1993; Thomas & Quinn, 1991), Milgram's work on obedience (Baumrind, 1964; Hock, 2001; Milgram, 1963) and Zimbardo's prison study (Haney, Banks & Zimbardo, 1973; Haney & Zimbardo, 1998), for example – led to concerns regarding the need for increased oversight of research and to the development of both institutional review boards as well as professional codes of ethics (Anderson, 1996; Linders, 2005).

The current role of institutional review boards and their relationship to action research

Ostensibly, the whole focus of the IRB movement has been to avoid or stop abusive behavior and no one could agree with that goal more than action researchers.[3] However, as fears about the loss of federal funding and the use of these various policies to sue university researchers have become prevalent, IRBs have been forced into a difficult regulatory position. In effect, they are required to guarantee that due diligence has been performed to avoid harm to human subjects and that therefore the university is blameless and not legally liable for violations.

The ideal scenario for imposing this kind of screening on social research would seem to be in the case of conventional positivist research where the hypotheses, methodologies, and expected outcomes are fully articulated in advance. These kinds of projects can be reviewed, evaluated, and approved or disapproved in a fairly straightforward manner. However, action research projects appear to present an entirely different kind of problem. Open-ended, collaborative, methodologically eclectic, and without specific methods, processes, or final goals determined in advance, AR seems to be an open invitation to a legal and financial disaster for universities, and some US university IRBs have responded by denying permission for action research to be carried out at all.

This, however, is a completely unacceptable outcome on a number of grounds. In the first place, it is built on an utterly misleading idealization of positivist research. While in the textbooks, positivist research appears to be driven by well-defined hypotheses with pre-determined methods and with predictable outcomes, this is not how most positivist research actually operates. Like any human process, positivist research involves guesses and calculations that often turn out to be wrong or, at the very least, a little off target. Methods are modified during the process and often hypotheses are reformulated. In most cases, IRBs turn a blind eye to these realities because they can neither be predicted or regulated. Given the above, the difference in predictability between AR and conventional research does not loom nearly so large.

Action research, in our view, holds out much more important guarantees for the ethical treatment of human subjects than does conventional research because it: is built on voluntary partnership between a researcher and local stakeholders who form a collaborative team that determines the subject and methods of the work; learns and applies the methods together; analyses the outcomes; designs and implements the actions arising from the process; and together determine representations of that process. Democratic collaboration, co-generation of knowledge, and a commitment to the democratization of human situations are the major guidelines that AR follows and so it stands to reason that the interests of the human subjects involved would be respected with care throughout the process. Indeed, AR is, or should be, far from the evils that IRBs are supposed to combat.

This is an argument that can be made and made successfully. In the case of Cornell University, we were fortunate to have both a well-developed group of action researchers and a superb chair of the University Committee on Human Subjects, Professor Elaine Wethington. After some discussion of the human subjects rules, we in the Cornell Participatory Action Research Network decided to invite Professor Wethington and her administrative colleagues to a meeting to discuss how the committee would review action research projects. We spent a few hours together coming to a common understanding of AR and then talking frankly about the difficulties of matching the IRB processes to the character of AR. The meeting was cordial and constructive.

Subsequently, IRB reviews of AR projects have been both thorough, fair-minded, and thoughtful. In many cases, reviews have gone through with no difficulty and only in those cases involving minors and other at-risk groups has a more thorough review been undertaken. In no case do we feel that AR has been blocked or penalized by this process.

The situation at the University of Cincinnati is similar in that the IRB under the leadership of Dr Margaret Miller has been very open to learning more about action research. A regular meeting of the board was designed to provide training on action research, and Ms Claudia Norman, Program Manager for the board, has even made a point of attending additional presentations to learn more about our practice.

Are these idiosyncratic results or is it the outcome of a good AR process of dialogue among the relevant stakeholders? We would like to believe it is the latter. We offer the following reflections on specific concerns sometimes raised by IRBs in response to action research proposals as possible means of deepening this dialogue with our institutional IRBs and in the hope that we can together develop strategies for addressing our common goal – protecting the welfare, rights, and dignity of those individuals participating in institutionally sanctioned research.

Predictability vs process

As noted earlier, one problem that is often raised in the response of the IRB to AR proposals is in the open-ended nature of the process. In a conventional positivist study, the researcher can predict (or believes she can predict) with reasonable certainty how the research will be carried out and what the possible outcomes might be. In action research, because the articulation of the issues to be addressed, the development of possible interventions, and the processes of group reflection and ensuing actions are all under the control of the participants themselves, rather than the researcher, there is no such control. This lack of any specified procedure, much less a clear sense of potential outcomes, is distinctly, and understandably, unsettling to the IRB. The recommendation from some IRBs has been to suggest that researchers develop an initial proposal describing the first stage of the project and then submit amendments as necessary. This may be problematic, however, because AR can move very quickly and is a fluid process in which the researcher, rather than guiding that process, is often responding to participant recommendations. Waiting, even for a day or two, for permission from the IRB, would make it impossible for groups to act spontaneously or to reach a decision to engage in some immediate action. Under these circumstances, the control of the action research process, rather than being in the hands of the participants themselves, or even of the researcher, is now under the control of the IRB. One way to reconceptualize the problem is to acknowledge that it is not the community action itself which requires IRB approval, but the use of that action within a research context.[4] Reflecting this distinction, the informed consent could simply specify that the researcher would like permission from the participants to describe whatever actions they decide to take (this decision being wholly theirs and not in any way conditional upon IRB approval) as part of the research process. Another strategy might be to appoint an IRB/AR liaison who could be consulted quickly and without the need for forms, signatures, and all the rest of the rather cumbersome protocol, as the action research process develops. Perhaps some combination of these two approaches would help to address the IRB's concerns regarding the problem of unforeseen and potentially dangerous outcomes, while still not undermining the community's ownership of the action research process.

Protection vs participation

This leads to a consideration of the issue of protection, and the role of the IRB in insuring that participants are not harmed by the research processes in which they are taking part. Clearly, in a conventional research process controlled by the researcher, the onus is on that researcher to provide such guarantees. But what of a process in which the participants themselves determine the direction and scope

of the research? When does protection become paternalism, and concern become control?

In those cases in which the project is truly being led by members of the community itself, we do not control what actions the group decides to take to address the issues facing them, and so, we should not need IRB approval of the process itself. But we do need to be cognizant of the possible consequences of making such actions public. Laurie Vasily's research with Nepali Dalit communities provides a compelling example of this dilemma. Vasily's research grew out of her long-term personal and professional commitments to quality education and social justice in Nepal. Given political events in that country, however, she was concerned about her representation of research conducted in partnership with members of these communities. Changing conditions of political repression shifted the ethical implications of representing this research at a time when re-negotiating the terms of such representations with her research partners was made impossible, forcing her to re-examine the ethical implications of conducting and representing research under circumstances of such political repression. Protecting the lives and well-being of research partners in such cases suggests that it is sometimes wiser for the researcher to take the lead, and take the heat, in presenting the results of politically dangerous research findings.

Of course, the other side of this is that these are precisely the circumstances under which action research has the best opportunity of addressing instances of serious social and political oppression and so conducting our research under such circumstances is all the more important. One of our gravest concerns regarding the IRB process as a whole is that simply knowing the hurdles they will face in attempting to gain IRB approval may dissuade many researchers of all kinds from even attempting to address the truly important issues facing us, settling instead for studies that skirt the issues or in some other way 'play it safe' as a strategy for streamlining the approval process and completing their research in a timely manner.

This can be likened to the statistical concept of balancing Type I and Type II error rates, a dilemma faced in quantitative research. A Type I error is, in essence, an error of commission, in which the researcher falsely rejects the null hypothesis, concluding that there is a significant difference between groups, when there is not. Historically, the major focus of concern has been over minimizing such Type I errors. However, setting a very high threshold for Type I errors increases the likelihood of making a Type II error, that is, of failing to find significant differences in a study in which such differences do, in fact, exist. Efforts to minimize the likelihood of harm to human subjects by severely limiting the kinds of research that can be done, the questions that can be asked, and the types of individuals involved in the research, can, while providing protection, at the same time have the effect of making social research largely impotent in terms of addressing issues of real importance.

As one example of the way in which concerns regarding the IRB approval processes can affect the researcher's ability to conduct such critical research, one former student at the University of Cincinnati, Linetta Collins, shifted her initial interest in conducting her dissertation research with HIV positive young people in schools, to concentrate instead on the attitudes of adults within those schools toward these youth as a conscious strategy for avoiding what she feared might be an endless process of IRB review. Her long-term research interests continue to focus on working directly with HIV positive youth, but the short-term effect of potential IRB red-tape was to continue to silence the voices of these young people. Might such research prove difficult for the participants? Yes. But we must balance the urge to protect, with a commitment to empower by giving potential research participant opportunities to make their voices heard. Of particular concern are cases in which researchers, anticipating problems and delays, choose to self-censor the research they submit to the IRB. This both guarantees that challenging and difficult projects will not be undertaken, while simultaneously shutting down dialogue between researchers and board members that might increase the extent to which they both understand and are able to address common concerns.

Lundy and McGovern (49–64) address this concern in their examination of the difficulty some of the participants in their study faced in discussing the lives and deaths of loved ones caught up in the violence in the North of Ireland. The researchers developed specific strategies to provide emotional support during the process, but even given these efforts the process often proved difficult. The participants themselves were keenly aware of the trauma they faced in reliving these events, but willingly accepted the pain involved as the price of having these stories made public.

Another way to look at the issues of protection, informed consent, and IRB approval was suggested by Tom Newkirk (1996) in his article 'Seduction and betrayal in qualitative research'. Newkirk warns us against the possibility that by showing an interest in people's lives and experiences we might be engaging in an act of seduction in our relationship with research participants, only to betray the trust they have placed in us when we then go on to write about these lives, representing the experience of our research subjects in ways that they might not feel reflect well upon them. As part of this process, Newkirk suggests 'the measures devised to protect those being studied often aid the researcher in the seduction' (1996, p. 4). Referring to IRB forms and informed consent procedures specifically, he observes that, 'these forms provide a very brief and often vague description of the project, and then provide a number of assurances', 'the form helps to reinforce the impression of the researcher's solicitousness' (p. 4), and tends to 'heighten the sense of the importance of the study about to be undertaken' (p. 5). If this is true in more conventional forms of inquiry, how much more powerful might such powers of seduction be when, as action researchers, we come in

promising social change and an end to oppression? We need to be honest with research participants about the limitations of protection, the risks of participating in research, the likelihood of achieving substantive social change, and we must make clear the obligation of the researcher to tell the truth, even if that truth might not always be altogether positive or complimentary.

One possible means of addressing these concerns within an action research context, is to make the process of developing the IRB proposal itself and the content and language of the consent forms a collaborative process (see Boser, 9–22). Explaining the genesis of the human subjects review process, and exploring the ethical challenges of research, would provide participants with a sense of the process as a whole and of the possible implications of their participation, allowing for the development of a more genuine informed consent process.

Confidentiality vs credit

Another issue that bears mentioning as an aspect of the IRB approval process is that of confidentiality vs credit. Often we take implied credit for the contributions of our research subjects by masking their identity through the use of pseudonyms or initials. In some cases, such as Vasily's research within Nepali Dalit communities described earlier, to use the actual names of research participants might in a very real way endanger or embarrass them. But don't our research partners have the right to determine if and how they want their names to be used? This is frequently not so much a problem with the IRB approval process itself, as it is a matter of habit among researchers to assume the need to insure confidentiality. Some researchers, such as Michelle Fine (Fine et al., 2004) and M. Brinton Lykes (Lykes in collaboration with the Association of Maya Ixil Women – New Dawn, Chajul, Guatemala, 2001; Women of ADMI & Lykes, 2000), regularly include those taking part in their research as co-authors and are clear and direct about the contributions these individuals make to the research process. We believe that this should become the norm, rather than the exception, in our research (for additional discussion of this issue and its relation to the concept of intellectual property see Greenwood and Brydon-Miller, with Shafer, 81–96).

Coercion vs caring

A final concern frequently raised by the IRB, especially in response to proposals using action research in schools and other institutional settings is that of coercion. At the University of Cincinnati, the majority of students in the action research seminar are educators, working either as classroom teachers or school administrators, and many have been interested in using their AR projects to examine their

own professional practice. But to do so meant using their own students, in the case of teachers, or staff in the case of administrators, as participants in the study. The question raised by the IRB, and it is a very legitimate concern, was how can these researchers provide assurances that the individuals with whom they wish to conduct the study do not feel pressured in any way to participate? Here again the distinction between actions that take place as a function of one's work and the research which can result from these actions is important. All teachers (all good teachers, at any rate) gather information to help guide their practice. They don't need permission from the IRB nor informed consent to do this. What they do need permission for is the use of this information as part of a research presentation or publication. So what is really being asked of research participants in such cases is, 'May I take the material we have generated as part of this class or school activity and use it within a more formal and public research context?' And there are ways of going about soliciting this consent that allow participants to opt out without fear of retribution or other negative consequences. For example, in the case of a classroom action research project, another teacher or school official could distribute and collect the consent and assent forms and hold them until after the end of the school year when students in the class could be assured that the decision regarding whether to participate could not affect final grades or classroom support. The teacher/researcher, who would have collected data from all the students in the class, could then draw solely on data from those students who had agreed to participate in the study as part of the research. Granted this is a bit cumbersome, but it does provide a kind of firewall between the roles of teachers and researcher.

There is, however, an issue of deeper concern here than simply trying to develop strategies for avoiding such potential conflicts of interest, and that is in understanding the nature of coercion itself, and of distinguishing between coercion on the one hand and a shared interest in promoting the generation of knowledge and positive social change on the other. And then there is the possibility of human relationships within the research context, a notion that is anathema to traditional positivist research, but central to our practice as action researchers. We care about the people with whom we work, and they, in turn, care about us. The issues facing their communities concern us, and they, in turn, seek ways to reciprocate our caring and to join us in addressing these issues. How can we distinguish between caring and coercion in the context of close, on-going, collaborative relationships? One key to this is to always be cognizant of the power and privilege we carry with us into our interactions with research participants, and at the same time not allow these concerns to immobilize us in working for social change (Brydon-Miller, 2004). Another is to develop avenues for reflection in which we are challenged to examine these relationships and the potential for coercion in a critical manner.

Implications for revisiting the IRB process

In concluding this brief article, it is important to restate our conviction that the human subjects review process is an important and generally helpful set of guidelines designed to safeguard the interests of those taking part in research. However, based on the considerations raised here, we believe there are strategies we can recommend for improving the process, especially in terms of how it relates to the distinct nature and demands of action research.

First, we suggest making clear the distinction between engaging in action and reporting on that action in some way. Actions or interventions, developed in collaboration with community members, whether this is the gathering of student portfolios or the training of community mental health workers to assist victims of state-sponsored violence, do not in and of themselves constitute research and so should not require IRB approval. What does require review is the process of taking this action and transforming it into research for presentation or publication. The approval process should recognize the difference between these two aspects of the action research process, and the IRB should acknowledge the limitations of their control over the actions of participants in AR projects.

Second, we should develop strategies for incorporating the development of IRB proposals and consent forms into the action research process itself. We should see this as a form of community education and as a means of increasing ownership of the research process, rather than as an impediment to our work. Included in this would be a discussion of any potential hazards involved in participating in the research process; a consideration of the pros and cons of maintaining confidentiality vs giving credit to all participants in the research process; a clear negotiation of the roles and responsibilities of all participants in the process; and an explicit understanding of how decisions regarding the dissemination of the results will be made.

Finally, we must remind ourselves that IRB approval is only the first stage and the minimum ethical standards to which we must hold ourselves. We must guard against the kind of betrayal Newkirk describes, while at the same time finding ways of telling the truth even in the face of bad or damaging news. We must continually challenge ourselves and one another to take responsibility for ensuring that our projects do real good for real people; that the claim to serve as agents of social change is not an empty one. And we must resist complacency and a conviction of our own moral superiority by continually revisiting the issue of research ethics in both our teaching and our practice, to ensure that we hold ourselves, our students, and our colleagues and co-workers to the highest possible standards.

Notes

1 Our thanks to Laurie Vasily, Linetta Collins, and Claudia Norman for their comments on drafts of this article.
2 This historical review and our comments regarding the human subjects review process are based in large part on our experience working in university settings in the United States. While similar processes exist in other places, the US seems to present the most draconian system currently in place, and our experience will, perhaps, serve as a cautionary note to our colleagues in other parts of the world.
3 In our more cynical moments we are inclined to view the process as one designed to avoid lawsuits rather than harm, but we choose here to assume that we do indeed share a common goal of protecting human subjects.
4 We are grateful to our friend and colleague Dr Annulla Linders for making this distinction clear.

References

Anderson, P. V. (1996). Ethics, institutional review boards, and the involvement of human participants in composition research. In P. Mortensen & G. Kirsch (Eds.), *Ethics and representation in qualitative studies of literacy* (pp. 260–285). Urbana, IL: National Council of Teachers of English.

Baumrind, D. (1964). Some thoughts on ethics of research after reading Milgram's 'Behavioral study of obedience'. *American Psychologist*, *19*(6), 421–423.

Brydon-Miller, M. (2004). The terrifying truth: Interrogating systems of power and privilege and choosing to act. In M. Brydon-Miller, P. Maguire & A. McIntyre (Eds.), *Traveling companions: Feminism, teaching, and action research* (pp. 3–19). Westport, CT: Greenwood Press.

Fine, M., Torre, M. E., Boudin, K., Bowen, I., Clark, J., Hylton, D., Martinez, M., Rivea, M., Roberts, R. A., Smart, P., & Upegui, D. (2004). Participatory action research: From within and beyond prison bars. In L. Weis & M. Fine (Eds.), *Working method: Research and social justice* (pp. 95–119). New York: Routledge.

Haney, C., Banks, W., & Zimbardo, P. (1973). Interpersonal dynamics in a simulated prison. *International Journal of Criminology and Penology*, *1*, 69–97.

Haney, C., & Zimbardo, P. (1998). The past and future of U.S. prison policy: Twenty-five years after the Stanford Prison Experiment. *American Psychologist*, *53*(7), 709–727.

Hock, R. (2001). *Forty studies that changed psychology: Explorations into the history of psychological research*. 4th edn. Upper Saddle River, NJ: Prentice Hall.

Jones, J. H. (1993). *Bad blood: The Tuskegee syphilis experiment* (Rev. ed.). New York: Free Press.

Linders, A. (2005, May). The bureaucritization of ethics. Paper presented at the First International Qualitative Inquiry Conference, Urbana, Illinois.

Lykes, M. B. in collaboration with the Association of Maya Ixil Women – New Dawn, Chajul, Guatemala (2001). Creative arts and photography in participatory action research in Guatemala. In P. Reason & H. Bradbury (Eds.), *Handbook of action research: Participative inquiry and practice* (pp. 363–371). London: SAGE.

Milgram, S. (1963). Behavioral study of obedience. *Journal of Abnormal and Social Psychology*, *67*(4), 371–378.
Milgram, S. (1974). *Obedience to authority: An experimental view*. New York: Harper/Collins.
Newkirk, T. (1996). Seduction and betrayal in qualitative research. In P. Mortensen & G. Kirsch (Eds.), *Ethics and representation in qualitative studies of literacy* (pp. 3–16). Urbana, IL: National Council of Teachers of English.
Sales, B. D., & Folkman, S. (2000). *Ethics in research with human subjects*. Washington, DC: American Psychological Association.
Thomas, S. B., & Quinn, S. C. (1991). The Tuskegee Syphilis Study, 1932–1972: Implications for HIV education and AIDS risk programs in the Black community. *American Journal of Public Health*, *81*(11), 1498–1505.
Women of ADMI, & Lykes, M. B. (2000). *Voces e imagenes: Las mujeres Maya Ixiles de Chajul/Voices and images: Mayan Ixil women of Chajul*. Guatemala: Magna Terra.

Mary Brydon-Miller is Associate Professor of Urban Educational Leadership and Educational Foundations at the University of Cincinnati. She is a participatory action researcher who engages in both community-based and educational action research. Her publications include work on participatory action research methods, academic writing in the social sciences, elder advocacy, and disability rights. Her most recent research focuses on the uses of art and photography in the area of family literacy with recently arrived refugee families. She is also on the editorial board of *Action Research*. *Address*: Division of Educational Studies, College of Education, Criminal Justice and Human Services, Mail Location 0002, University of Cincinnati, Cincinnati, Ohio, 45221-0002, USA. [*Email*: mary.brydon-miller@uc.edu]

Davydd J. Greenwood is the Goldwin Smith Professor of Anthropology and Director of the Institute for European Studies at Cornell University. He has been elected a Corresponding Member of the Spanish Royal Academy of Moral and Political Sciences. He served as the John S. Knight Professor and Director of the Mario Einaudi Center for 10 years and was President of the Association of International Education Administrators. He also has served as a program evaluator for many universities and for the National Foreign Language Center. His current work focuses on the impact of corporatization on higher education with a particular emphasis on the social sciences. He is the author of seven books and numerous articles. *Address*: Institute for European Studies, 120 Uris Hall, Cornell University, Ithaca, New York, 14853, USA. [*Email*: djg6@cornell.edu]